

**ACTION ON ALBINISM IN AFRICA: TIME FOR IMPLEMENTATION!**  
**19 & 20 February 2017 - Regional Meeting of Civil Society groups representing persons with albinism in Africa**

**Work Plan (2018-2021)**

Name of your organization/group: **STANDING VOICE**

Country: Tanzania, Malawi

Specific region(s) within the country where you work:

**Tanzania:** Mwanza; Mara; Simiyu; Shinyanga; Kagera; Kigoma; Geita; Tabora; Singida, **Dodoma, Mbeya, Dar Es Salaam** (2018)

**Malawi:** Southern Region

**STEP 1**

What are your **current activities/actions** and how they contribute to the Regional Action Plan? (One activity may contribute to several targets)

Activity	Activity description	RAP Measures	RAP Targets
	<b>A. PREVENTATIVE MEASURES</b>		
<b>1</b>	Documentary productions	A.1 Prevention – Public education	A.1.1 / A.1.2
	<i><b>SV Activity description:</b> The Standing Voice team has been behind leading albinism documentaries which continue to be powerful tools for public education. These include ‘In the Shadow of the Sun’ (BBC / PBS Broadcast in 80 countries) and BBC documentary ‘Born Too White’ (co-produced by SV). SV most recently produced a film that documents the process of the Standing Voice Skin Cancer Prevention Programme.</i>	<i><b>RAP Measure justification:</b> These productions exist as consistently relevant and powerful tools for education.</i>	<i><b>RAP Target justification:</b> Film productions have had international impact in 80 countries, as well as direct impact in-country through SV’s community film screenings. In the Shadow of the Sun launched the first recognized International Albinism Awareness Day at the UN in Geneva in June 2015.</i>
<b>2</b>	Music production – The Albinism Collective	A.1 Prevention – Public education	A.1.1 / A.1.2

	<p><b>SV Activity description:</b> We are facilitating the establishment and training of albinism music groups, the first of which was the Tanzania Albinism Collective which was established at SV's Umoja Training Centre and trained by Grammy Award Winning music producer Ian Brennan. Collective have played at their first international music festival in the UK and have received global media recognition for their work.</p> <p>Standing Voice has also brought together international musicians with albinism together to perform in Tanzania such as Peter Ogik (Uganda, Ras Six (Tanzania) and John Chiti (Zambia). Through this project new songs about albinism have been created.</p>	<p><b>RAP Measure justification:</b> The Tanzania Albinism Collective have now released an album which is being sold worldwide. The tracks on the album all relate to the realities of having albinism in Tanzania. Titles include: 'Disability Is Not a Curse' and 'Mistreated'.</p>	<p><b>RAP Target justification:</b> We seek to promote the album within Tanzania and other musicians across the continent.</p>
<b>3</b>	Genetics-based Public Engagement	A.1 Prevention – Public education	A.1.1 / A.1.2
	<p><b>SV Activity description:</b> This project has trained a task force of Tanzanian artists, musicians and performers in the genetic origins of albinism who have then created pop-up theatre performances and songs to debunk myths about albinism in communities across Tanzania. Geographically concentrated in the Lake Zone (where reported attacks have historically been highest).</p>	<p><b>RAP Measure justification:</b> The project has been endorsed by the Prime Minister's Office (Tanzania) as an example of positive public education which should be scaled up nationwide.</p>	<p><b>RAP Target justification:</b> So far the project has reached rural communities directly, and used community members as key participants (target 1.1). With expansion we hope to reach large numbers across Tanzania. The current implementation has focused on Mwanza Region which has the highest number of attacks reported in the country (target 1.2).</p> <p>We view this a model that can be scaled up across other African countries.</p>
<b>4</b>	Youth Media Training	A.1 Prevention – Public education	A.1.1 / A.1.2

	<b>SV Activity description:</b> <i>Standing Voice trains young people with and without albinism in Mwanza in media production and broadcasting, radio and photography. This skills development programme facilitates the production of broadcasts and campaigns to positively platform PWA and counterbalance negative reporting in regional media.</i>	<b>RAP Measure justification:</b> <i>This activity is innovatively educating the wider public on albinism and the lives of PWA, as well as again involving wider community members in generating this public education.</i>	<b>RAP Target justification:</b> <i>This activity directly reaches rural communities in areas where stigma levels and attack reports remain high.</i>
<b>5</b>	<b>Health Data: Skin Cancer Prevention</b>	<b>A.2 Prevention – Data collection</b>	<b>A.2.2</b>
	<b>SV Activity description:</b> <i>The SV Skin Cancer Prevention Programme collects in-depth clinical and social data from over 2600 PWA at 36 locations across 8 regions of Tanzania every 6 month. This regular clinic service is now also active in multiple locations in Malawi. Data captured includes: rates of erythema; cheilitis; solar keratosis; skin cancer (BCC/SCC); treatment methods; treatment outcomes; frequency of prevention methods such as clothing and sunscreen application documented. We have also recently tested a bespoke Electronic Medical Records (EMR) digital database—the first of its kind for PWA in TZ. The EMR database is fully developed and operational, and is soon due for field implementation.</i>	<b>RAP Measure justification:</b> <i>To our knowledge, data collection achieved through this programme is the most advanced and comprehensive of its kind specifically for PWA in Africa.</i>	<b>RAP Target justification:</b> <i>This activity provides a foundational model for state-led data collection relating to skin cancer prevention and treatment for PWA.</i>
<b>6</b>	<b>Health Data: Visual Impairment</b>	<b>A.2 Prevention – Data collection</b>	<b>A.2.2</b>
	<b>SV Activity description:</b> <i>The SV Vision Programme collects data from more than 1600 PWA, so far across 7 regions of TZ. Data includes: visual acuity; prescription data; acquisition of vision aids; educational attainment.</i>	<b>RAP Measure justification:</b> <i>The data collected through this programme is a unique study of visual impairment among people with albinism in Africa, its impact on educational and professional performance, and the positive change that treatment and provision of assistive devices can deliver.</i>	<b>RAP Target justification:</b> <i>This activity provides a foundational model for state-led data collection relating to the visual impairment of PWA.</i>

<b>7</b>	Root causes research	A.3 Prevention – Root causes	A.3.2
	<i><b>SV Activity description:</b> In-depth interview-based research into the root causes of social exclusion and positive influences on the realization of social inclusion. Recent phases of this 11 years of ongoing research involve a 2-year academic study<sup>1</sup> of people with albinism’s access to life opportunities [recommendations soon to be published] and Word Bank-financed national consultations to map priority needs and actions across Tanzania.</i>	<i><b>RAP Measure justification:</b> The research conducted forms an ongoing drive to expose the root causes of human rights violations, which is continuously informing our pursuit of solutions.</i>	<i><b>RAP Target justification:</b> The research conducted has resulted in recommendations aimed at the state to inform government legislature and policy with regards to root causes of human rights violations against PWA.</i>
	<b>B. PROTECTIVE MEASURES</b>		
<b>8</b>	State-focused advocacy	B.1 Protection – Effective law enforcement / B.2. – Review of legislative frameworks	B.1.2 / B.2.1-4
	<i><b>SV Activity description:</b> SV advocates for effective legislature and effective law enforcement by the state through government meetings and media-based advocacy.</i>	<i><b>RAP Measure justification:</b> This activity contributes to pressure on the state to realize effective &amp; comprehensive legislature and law enforcement.</i>	<i><b>RAP Target justification:</b> Broadly SV advocacy in this area is pushing the albinism agenda resulting in pressure on the state to strengthen legislature and law enforcement.</i>
<b>9</b>	SV Skin Cancer Prevention Programme	B.3 Protection – Training of health-care workers and midwives	B.3.1
	<i><b>SV Activity description:</b> The SV Skin Cancer Prevention Programme continues to train networks of Community Dermatologists; Surgeons; and Civil Society Organizations involved in implementing biannual Skin Cancer Prevention clinics reaching 2600 PWA at 36 locations across 8 regions of Tanzania,</i>	<i><b>RAP Measure justification:</b> This model trains in-country healthcare workers and other stakeholders to be the makers of rapid and widespread change in</i>	<i><b>RAP Target justification:</b> Programme training is conducted for and by MoH representatives and employees. We are therefore</i>

<sup>1</sup> Funded by the Foundation for Applied Disability Research, in collaboration with: Coventry University (academic lead); Source of the Nile Union of Persons with Albinism; New Light Children’s Centre Organization; Advantage Africa.

	<i>and 200 PWA at 3 clinic sites in Malawi. Our training of health-care providers has resulted in hundreds life-saving skin cancer operations and a 30% increase in comprehensive self-care by PWA [SV Impact Study]. The Programme has been running for 5 years.</i>	<i>dermatological health for PWA in Africa.</i>	<i>providing a model for state-led change countrywide with regards to healthcare provider training. We have also formed a Programme committee of international dermatology experts who are the leading experts in their field, which ensures healthcare provider training is up to international standards.</i>
<b>10</b>	SV Vision Programme	B.3 Protection – Training of health-care workers and midwives	B.3.1
	<b>SV Activity description:</b> <i>The SV Vision Programme trains a parallel network of optometrists to implement a clinical service reaching over 1600 PWA across 11 sites in 7 regions of Tanzania. The trained network of optometrists has distributed over 800 pairs of prescription glasses and 1000 monoculars. 13 optometrists have been trained to date, resulting in an average of 5% test score improvement of students supported by our trained optometrists.</i>	<b>RAP Measure justification:</b> <i>This programme is unique in its promotion of local capacity development for optometrists in Tanzania. The scale and depth of our optometrists’ clinical exposure to the low vision of PWA in Africa—together with avenues of treatment—is breaking new disciplinary ground and building global knowledge around the complex visual impairment of this hitherto largely inaccessible group.</i>	<b>RAP Target justification:</b> <i>As with the dermatological training delivered through our Skin Cancer Prevention Programme, the Vision Programme offers a foundational model for state-led replication and scale-up.</i>
<b>11</b>	Umoja Training Centre	B.4 Protection – Social welfare schemes that include PWA	B.4.1
	<b>SV Activity description:</b> <i>On Ukerewe Island, where SV has worked for over a decade, we have built a community training facility and</i>	<b>RAP Measure justification:</b> <i>The income-generating activities at</i>	<b>RAP Target justification:</b> <i>The Umoja Training Centre’s</i>

	<p>hub of integration called the Umoja Training Centre. There, we have delivered a range of income-generating projects and skills-development initiatives for people with albinism and their families, friends, and wider community members. Increased economic security and social cohesion for PWA are the twin ambitions of this state-of-the-art project, which has functioned as a blueprint for our community development work elsewhere in Tanzania.</p>	<p>the Umoja Training Centre achieve social welfare through generating economic security and social inclusion. The key to the activity's success is involving the wider community in all actions, so community members view their own empowerment as inseparable from the empowerment of PWA.</p>	<p>focus on economic security and social inclusion as prerequisites of protected welfare offers a model for state adoption and scale-up. The model demonstrates how the state can involve PWA in social welfare schemes whilst at the same time break down negative perceptions towards this group through notions of shared empowerment and wellbeing.</p>
12	Strategic priorities workshops for CSO reps	B.5 Protection – Monitoring and reporting; supporting the work of civil society	B.5.1 / B.5.2
	<p><b>SV Activity description:</b> As part of World Bank / JSDF-funded consultations, SV has coordinated a strategic priorities workshop gathering an array of civil society partners and specialists to map the cross-sectoral needs and priorities of PWA in localities across Tanzania (stratified by Health, Education, Economic Empowerment). This process produced a robust national monitoring system made up of a network of CSOs across the country, trained and tasked with surveying a matrix of social indicators including security of person and perceived or actual vulnerability to violence.</p>	<p><b>RAP Measure justification:</b> This activity provides civil society with the framework and support to be the actual vehicle for monitoring and reporting. Rather than feed civil society information, we are positioning CSOs as the gatherers of this information at the local level and training these actors to record, monitor and evaluate creating a coherent process for monitoring. This will provide a monitoring framework for the RAP.</p>	<p><b>RAP Target justification:</b> This activity empowers civil society stakeholders as front-line actors, and arms them with evidence and know-how for their own fundraising (target B.5.1). This activity also crucially provides the RAP evaluation with structure, legitimacy and reliability in Tanzania through creating a nationwide network of CSOs trained and tasked with surveying a matrix of social indicators relating to the RAP implementation (target</p>

			B.5.2). This activity is a workable model for replication across Africa.
	<b>C. ACCOUNTABILITY MEASURES</b>		
<b>13</b>	SV Tailored Support Programme & Women’s Albinism Action Group	C.2 Accountability – Victim support	C.2.1
	<b>SV Activity description:</b> On Ukerewe Island through the Umoja Training Centre, SV has provided tailored support to many vulnerable PWA. This has included counseling, group therapy, and in cases of extreme vulnerability, construction of secure accommodation for PWA. Additionally, SV’s Women’s Albinism Action Group is a community outreach collective providing advocacy for mothers with children who have albinism, or women who have albinism. The Women’s Albinism Action Group ensures those who are most effected by this ongoing crisis take their position as change makers in their community. New developments for the group are planned in 2018.	<b>RAP Measure justification:</b> SV’s Tailored Support Programme ensures victims of human rights violations (including but not limited to attack) are assisted professionally in their recovery and re-assertion of their presence and value in their community. The SV Women’s Albinism Action Group ensures victims have a support network (led by women) in their own community.	<b>RAP Target justification:</b> The support services offered under the Tailored Support Programme and Women’s Albinism Action Group are a model for replication and scale-up. This model ensures PWA and their families are not simply receivers of support but are empowered to take control of their future.
<b>14</b>	Education Scholarship Programme	C.3 Accountability – Reintegration of the displaced	C.3.1
	<b>SV Activity description:</b> Our Education Scholarship Programme reintegrates marginalised and abused children with albinism—often housed in protectorate centres—into mainstream, high-achieving mixed schools.	<b>RAP Measure justification:</b> The Education Scholarship Programme has demonstrated successful results where we have reintegrated displaced children into mainstream schools. We have evidenced improvements in motivation, qualification achievement, independence and self-care.	<b>RAP Target justification:</b> The Education Scholarship Programme safely reintegrates children into mainstream education environments. We are now designing new approaches to promote the state’s role in this reintegration process.
<b>15</b>	Umoja Training Centre activities	C.3 Accountability – Reintegration of the displaced	C.3.1 / C.3.2

	<p><b>SV Activity description:</b> The Umoja Training Centre continues to function as a counterforce to the protectorate centres by promoting shared prosperity and security for PWA and their communities on Ukerewe Island. Crucially this initiative involves the wider community in training and events, as well as any construction or maintenance work associated with the centre. This approach has promoted notions of shared well-being and empowerment. Activities at the Centre include training in business development and crafts, music and advocacy, research and media/journalism.</p>	<p><b>RAP Measure justification:</b> The activities at the Umoja Training Centre have promoted notions of shared well-being and empowerment, resulting in the 'reintegration' of PWA on Ukerewe Island to a level not evidenced previously.</p>	<p><b>RAP Target justification:</b> With the approach demonstrated by the Umoja Training Centre activities, reintegration of the displaced can be achieved safely at the local level rather than returning the displaced into vulnerable situations. This involves preparing communities for that reintegration, by involving the wider community in the re-integration process so they see benefit in it. We have evidenced this working through the reintegration of attack victims on Ukerewe Island, through involving victims in the Centre's community-focused activities whilst promoting the role of the wider community in these individuals' recovery.</p>
	<b>D. EQUALITY AND NON-DISCRIMINATION MEASURES</b>		
<b>16</b>	SV Vision Ambassador Training Scheme	D.2 Equality and non-discrimination – Accommodation in educational settings	D.2.1 / D.2.3 / D.2.5
	<p><b>SV Activity description:</b> As part of our Vision Programme, Standing Voice has established a Vision Ambassador Training Scheme to professionally train school teachers in vision support for students with albinism. So far targeting 52 schools, this</p>	<p><b>RAP Measure justification:</b> The SV Vision Ambassador Training Scheme is setting the standard for accommodation in educational</p>	<p><b>RAP Target justification:</b> This activity directly trains teachers and educators (including Government</p>

	<p><i>initiative has trained a network of over 80 education professionals to espouse and promote inclusive teaching practices, including the accommodation and mitigation of the visual impairment of children with albinism (use and storage of vision devices, adjustments to lighting and seating position, sharing of textbooks, buddying up etc). Students and teachers have responded overwhelmingly positively to this provision, with an average test score improvement of 5% among students. This Scheme has also been expanded to include Government Special Education Officers.</i></p>	<p><i>settings, through training education professionals about albinism and the vision needs of students with albinism. Each Ambassador is then responsible for their school’s approach to accommodating these vision needs, resulting in a network of Ambassadors each having a ripple effect through influencing other teachers and therefore reaching their entire school population.</i></p>	<p><i>Special Education Officers) in providing excellent accommodation for students so they may thrive and become an inspiration to others in society (D.2.3). Additionally, this training provides model content for teacher training curriculum improvements (D.2.1). As part of the Vision Programme more broadly students receive monocular telescopes at no cost (D.2.5). However, SV hopes the government will remove import taxes on all vision devices.</i></p>
17	SV Skin Cancer Prevention Programme	D.3 Equality and non-discrimination – access to health care for those with skin cancer	D.3.1 / D.3.2
	<p><b>SV Activity description:</b> <i>The SV Skin Cancer Prevention Programme currently provides more than 2600 PWA across Tanzania with regular access to dermatological healthcare including Kilisun sunscreen produced at the KSPU at RDTC in Moshi. Through the initiative, knowledge of cancerous presentation among PWA—and effective strategies for its prevention and treatment—has been developed in Tanzania, as well as the first structured sunscreen distribution network to reach large numbers of PWA on a regular basis. Access to care has widened, and the quality of care available (and knowledge of relevant professionals) has increased vastly. SV has recorded a 32% increase in patient selfcare amongst patients. This activity is</i></p>	<p><b>RAP Measure justification:</b> <i>From our extensive research there appears to be no other example in Africa of sunscreen distribution being achieved on such a scale whilst integrating this distribution into a broader service that includes the full range of skin cancer treatment, and whilst involving the government so substantially. All service deliverers are MoH employees.</i></p>	<p><b>RAP Target justification:</b> <i>This activity is a model for how states can realistically distribute sunscreen to thousands of PWA whilst integrating that distribution into a full health care package relating to skin cancer prevention and treatment. This includes health education at the point of distribution. When</i></p>

	<i>fully established in Tanzania and newly established in Malawi, and we look to further replication in other African countries.</i>		<i>presenting this model to states we advocate for sunscreen to be on the national list of essential medicines, and for import taxes to be waived on dermatological healthcare imports.</i>
<b>18</b>	SV's general work taken as a whole	D.4 Equality and non-discrimination – Intersectionality	D.4.1
	<b>SV Activity description:</b> <i>When considering intersectionality in SV's work the entire SV 'package' of support is relevant. We have built our programmes (grouped into Health, Education, Advocacy and Community Programmes) to be intersecting, thus creating a holistic support package tackling intersecting discrimination. This support strengthens both the individual with albinism, and other stakeholders in their society who have influence, to become the makers of positive change with SV's facilitation.</i>	<b>RAP Measure justification:</b> <i>The intersecting discrimination faced by PWA takes multiple forms at both the community, national and regional level. SV's work monitors this intersecting discrimination through its ongoing research and consultation with PWA and partners, then works with those individuals and groups to develop evolving strategies to meet changing demands.</i>	<b>RAP Target justification:</b> <i>SV is meeting this target already by implementing actions which tackle multiple and intersecting forms of discrimination (eg. exclusion from health and education services). We are advocating for states to take similar approaches.</i>

## STEP 2

**New activities/actions** you plan to undertake and how they each contribute to the targets of the Regional Action Plan? (One action may contribute to several targets)

*Note: Across the entire spectrum of SV's work, we are seeking to sustain and scale up our 'current activities' stated above. We therefore just include new project developments in the below table (i.e. either completely new projects, or developments to existing projects which demonstrate an entirely new direction or phase markedly different from what is provided above).*

*As will be obvious, new developments and plans are funding permitting.*

Activity description	RAP Measures	RAP Targets	Support needed for implementation
<b>A. PREVENTATIVE MEASURES</b>			
Genetics-based Public Engagement – new developments	A.1 Prevention – Public education	A.1.1 / A.1.2	
<i><b>SV Activity description:</b> We seek to transform this public engagement project, and to develop its reach. We aim to target Mwanza and Kigoma regions over the next 4 years and involve border enforcement officers in Kigoma region to promote awareness where there is a cross border threat. We also aim to establish a rotating taskforce of creative artists who will be deployed in multiple locations in both regions</i>	<i><b>RAP Measure justification:</b> The project has been endorsed by the Prime Minister's Office (Tanzania) as an example of positive public education which</i>	<i><b>RAP Target justification:</b> This development will see us continue our reach in rural communities and engagement of community members as key participants (target</i>	<i>Funding (application pending) Stakeholder partnership.</i>

reaching 42,000 people over 4 years.	should be scaled up nationwide.	1.1). The new developments to the project will maintain the focus on areas where attack reports are high (A.1.2)	
Health Data: Skin Cancer Prevention	A.2 Prevention – Data collection	A.2.2	
<b>SV Activity description:</b> The SV Skin Cancer Prevention Programme collects in-depth clinical and social data from over 2600 PWA at 36 locations across 8 regions of Tanzania every 6 months. We are now planning the introduction of an Electronic Medical Records (EMR) database, which has already been piloted in specific project locations in Tanzania. The EMR allows for immediate and reliable patient data management and gives health professionals and patients far more control over health management.	<b>RAP Measure justification:</b> The data collection achieved through this programme is the most advanced and comprehensive of its kind specifically for PWA in Africa.	<b>RAP Target justification:</b> This activity provides a foundational model for state-led health data developments relating to PWA.	We have funding secured for this activity until June 2020. We require strong partner engagement and cooperation to continue this work successfully.
Health Data: Visual Impairment	A.2 Prevention – Data collection	A.2.2	
<b>SV Activity description:</b> The SV Vision Programme collects data from more than 1600 PWA. The EMR will also become a key feature of vision data management.	<b>RAP Measure justification:</b> The data collection achieved through this programme is the most advanced and comprehensive of its kind specifically for PWA in Africa.	<b>RAP Target justification:</b> This activity provides a foundational model for state-led health data developments relating to PWA.	We require additional funds to continue this work.  We also require continued partner engagement.
B. PROTECTIVE MEASURES			
SV Skin Cancer Prevention Programme	B.3 Protection – Training of health-care workers and midwives	B.3.1	

<p><b>SV Activity description:</b> Following initial replication in Malawi of the SV Skin Cancer Prevention Programme, SV is now planning further international replication in Africa. Plans are being developed for SV's expertise in dermatological healthcare to be exported to other countries. So far, this replication has been demonstrated successfully in Malawi at 3 clinic sites (200 patients). The training component of the Programme forms a key element of sharing expertise and developing health provider capacity across Africa.</p>	<p><b>RAP Measure justification:</b> The training aspect of the Skin Cancer Prevention Programme is setting the standard across Africa for health-care worker skill development with regards to albinism and health services for PWA.</p>	<p><b>RAP Target justification:</b> Programme training is conducted for and by MoH representatives and employees. We are therefore providing a model for state-led change country-wide with regards to health provider training. We have also formed a Programme committee of international dermatology experts who are the leading experts in their field, which ensures health provider training is up to international standards.</p>	<p>We have funding committed for this action until June 2020.</p> <p>Continued partner engagement is vital.</p>
<p>CSO participatory M&amp;E and strategy development</p>	<p>B.5 Protection – Monitoring and reporting; supporting the work of civil society</p>	<p>B.5.1 / B.5.2</p>	
<p><b>SV Activity description:</b> Consultations financed by a World Bank Seed Fund revealed an enduring need to develop the M&amp;E capacity of CSOs in Tanzania, in order for civil society to track impact of interventions and coordinate accordingly. SV is planning to develop the progress already made to create a nationwide network of CSOs tasked with developing strategy and monitoring/evaluating implementations. Over the coming 4 years we plan to hold regular CSO workshops in Tanzania to achieve this objective. The result will be a mechanism through which the Regional Action Plan</p>	<p><b>RAP Measure justification:</b> This activity provides civil society with the framework and support to be the actual vehicle for monitoring and reporting.</p>	<p><b>RAP Target justification:</b> This activity empowers civil society stakeholders as front-line actors, and arms them with evidence and know-how for their own fundraising (target B.5.1). This activity also crucially provides the RAP evaluation with structure,</p>	<p>Partner engagement is crucial to this action.</p> <p>We have a funding application pending to fund this action.</p>

<p><i>implementation by all stakeholders can be monitored and evaluated, and findings can then be reported on. Crucially, CSOs will provide the only realistic method to gauge this impact from the local level across the country.</i></p>		<p><i>legitimacy and reliability in Tanzania through creating a nationwide network of CSOs trained and tasked with surveying a matrix of social indicators relating to the RAP implementation (target B.5.2). This activity is a workable model for replication across Africa.</i></p>	
<p>SV Women’s Albinism Action Group</p>	<p>B.5 Protection – Monitoring and reporting; supporting the work of civil society</p>	<p>B.5.1 / B.5.2</p>	
<p><b>SV Activity description:</b> <i>Beginning in 2018 SV is planning for the Women’s Albinism Action Group (WAAG) to enter a new phase of its development. The group – based on Ukerewe Island in Tanzania – will be appropriately trained and tasked with identifying, documenting and interrupting cases of discrimination and violence against PWA in Tanzania. Though the WAAG will document and respond to any abuse relating to albinism, it is an informed assumption that the majority of abusive incidents will have a direct impact on the rights of women and girls. The WAAG will furthermore be a vehicle for women to become the leading agents of systemic social change when it comes to the ostracization of PWA in their communities. This approach recognizes that the expertise and experience required to tackle this issue lies within society and more specifically among women who have felt the brunt of society’s rejection of albinism. Participants will therefore include women with albinism and</i></p>	<p><b>RAP Measure justification:</b> <i>The SV Women’s Albinism Action Group provides a mechanism for a situational analysis at the local level, and often with relation to specific circumstances which may otherwise go unreported (e.g. abandonment of mothers).</i></p>	<p><b>RAP Target justification:</b> <i>The Women’s Albinism Action Group is a model for community documentation and reporting. This model ensures PWA and their families are not simply receivers of support but are empowered to take control of their future.</i></p>	<p><i>We require funding to implement this action.</i></p>

<p>mothers of children with albinism, all of whom have experienced marginalization relating to their association with the genetic condition. The WAAG will undergo a program of training, research, stakeholder consultation, and interventions in the field to protect PWA from violence and circumvent barriers to their enjoyment of full equality. The project will be geographically concentrated in the Lake Zone of Tanzania where the majority of recorded attacks against PWA have occurred, and where SV has compiled a large body of evidence documenting women’s unique experience of abuse relating to the social exclusion of PWA.</p>			
<b>C. ACCOUNTABILITY MEASURES</b>			
<b>SV Women’s Albinism Action Group</b>	<b>C.2 Accountability – Victim support</b>	<b>C.2.1</b>	
<p><b>SV Activity description:</b> (Please see above) A key function of the Women’s Albinism Action Group will be victim support for women who have endured trauma and abuse as a result of their association with albinism. This will include women with albinism and mothers of babies with albinism.</p>	<p><b>RAP Measure justification:</b> The SV Women’s Albinism Action Group ensures victims have a support network (led by women) in their own community.</p>	<p><b>RAP Target justification:</b> The support services offered by the Women’s Albinism Action Group are a model for replication and scale-up. This model ensures PWA and their families are not simply receivers of support but are empowered to take control of their future.</p>	<p>We require funding to implement this action.</p>
<b>Child support for displaced and traumatized children</b>	<b>C.3 Accountability – Reintegration of the displaced</b>	<b>C.3.1</b>	
<p><b>SV Activity description:</b> During 2019, SV is planning a new project that focuses on specialized support and reintegration for traumatized and displaced children. This plan is in response to the continued segregation of children in</p>	<p><b>RAP Measure justification:</b> This project development will demonstrate a</p>	<p><b>RAP Target justification:</b> This project aims to safely reintegrate children into mainstream life. We are</p>	<p>We have an application pending to fund this action.  Partner cooperation will be</p>

<p><i>inadequately resourced protectorate centres. This project will involve a specialized support hub offering therapy and rehabilitation services and structured avenues of community reconciliation and interaction. This action will build on the progress already made toward the decongestion and closure of protectorate centres for children with albinism.</i></p>	<p><i>specialist approach to reintegrating children who have endured years of abuse and trauma.</i></p>	<p><i>currently in the design phase of this project.</i></p>	<p><i>vital for this action. In addition, we require political will to make this action a success.</i></p>
<p><b>D. EQUALITY AND NON-DISCRIMINATION MEASURES</b></p>			
<p>SV Skin Cancer Prevention Programme</p>	<p>D.3 Equality and non-discrimination – access to health care for those with skin cancer</p>	<p>D.3.1 / D.3.2</p>	
<p><b>SV Activity description:</b> <i>The SV Skin Cancer Prevention Programme currently provides more than 2600 PWA across Tanzania with regular access to dermatological healthcare including Kilisun sunscreen produced at the KSPU at RDTC in Moshi. Over the coming 2 years we aim to initiate further replication of this sunscreen distribution model in other African countries. We are currently assessing the viability and methodology of replicating our sunscreen distribution services in multiple African countries. This has already been achieved in the Southern Region of Malawi.</i></p>	<p><b>RAP Measure justification:</b> <i>From our extensive research there appears to be no other example in Africa of sunscreen distribution being achieved on such a scale whilst integrating this distribution into a broader service that includes the full range of skin cancer treatment, and whilst involving the government so</i></p>	<p><b>RAP Target justification:</b> <i>This activity is a model for how states can realistically distribute sunscreen to thousands of PWA whilst integrating that distribution into a full health care package relating to skin cancer prevention and treatment. This includes health education at the point of distribution. When presenting this model to states we advocate for sunscreen to</i></p>	<p><i>Funding is committed for this action until June 2020.</i></p> <p><i>We require partner collaboration. In particular CSO contacts in replication countries are key to successful information sharing leading to viable replication.</i></p>

	<i>substantially.</i>	<i>be on the national list of essential medicines, and for import taxes to be waived on dermatological healthcare imports.</i>	
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**STEP 3**

What type of **support** do you need to undertake your activities and action? (support can be financial, political, technical, or others)

*Please see the furthest right column of the above table.*