An investigation into the impact of stigma on the education and life opportunities available to children and young people with albinism in Tanzania and Uganda

Funded by
FIRAH (International Foundation of Applied Disability Research)

Lead
Coventry University, UK

UK Partners
Advantage Africa (Uganda) and Standing Voice (Tanzania)

Partner in Uganda
Source of the Nile Union of Persons with Albinism (SNUPA)

Partner in Tanzania
New Light Children Center Organization (NELICO)

Final Report

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1. Foreword written by Stakeholders in the field

Uganda

Jane Betts, Advantage Africa

The Ugandan element of this research was facilitated by the Source of the Nile Union of Persons with Albinism (SNUPA) working in partnership with Advantage Africa. SNUPA is a Ugandan non-governmental organisation formed in 2012, by and for persons with albinism in Busoga sub-region and its neighbouring districts. SNUPA aims to change attitudes and improve life for people with albinism and their families. Advantage Africa is a UK-based non-governmental organisation founded in 2002 which supports people affected by poverty, disability and HIV in East Africa. In 2013, SNUPA and Advantage Africa began working together to help people with albinism to stay safe from cancer, attend school, earn an income and overcome discrimination and lack of opportunity.

SNUPA's team, composed of grassroots outreach workers relatively new to research, undertook intensive training at the start of this project in order to develop effective facilitation and interview techniques. This training and subsequent sessions to monitor the research's progress provided invaluable benefits in confidence and team-building.

Through the focus group discussions, the SNUPA team have worked closely with people with albinism and their families in eight communities in the Busoga region of eastern Uganda. The fact that all but one of the team have albinism themselves, and that they are not professional researchers, has enabled them to establish a comfortable, mutually trusting atmosphere when meeting with participants. SNUPA team leader Peter Ogik in particular has helped participants feel valued and part of a unified, positive process to bring change in the lives of people with albinism.

The people who took part in the discussions told SNUPA how much they appreciated the opportunity to tell their stories and meet with others in similar circumstances. Many had previously felt isolated and marginalised, but discovered a shared sense of purpose and friendship with their peers. The participants across the region shared their experiences with generosity and openness. SNUPA and Advantage Africa will ensure that their contribution continues to be valued and they are fully included in the ongoing dissemination process.

The research's wide regional scope has enabled SNUPA to interact with new people with albinism. Therefore, alongside the research activities, SNUPA has been able to offer practical support as needed, including protection from skin cancer.

All SNUPA and Advantage Africa team members have been highly motivated and committed throughout this project, driven by the goal of developing evidence-based recommendations and tools to improve the lives of people with albinism. The team will harness the enthusiasm and engagement of all stakeholders involved over the course of the project to widely disseminate these results and ensure the recommendations are implemented.

Tanzania

Jon Beale, Standing Voice

This research project has revealed fundamental learnings for achieving social change, learnings which have been illustrated by people with albinism and their communities in response to identified social challenges. It is perhaps with these learnings in the forefront of our minds that we should consider the research findings, in a bid to ensure we achieve tangible impact.

One of pronounced demonstrations of the research is the far-reaching constellation of individuals who define the life experience of people with albinism. This constellation consists of local, national and international stakeholders – ranging from family members and neighbours to key influencers in multi-lateral agencies. Understanding the importance of this social constellation is key to comprehending how we must collectively apply these research findings. The transcript material demonstrates the impact of an individual being surrounded by a supportive network of individuals, with them at the centre. Crucially the research participants emphasize repeatedly how it is the person at the centre of this constellation who has the most impact on how these surrounding people effect the present moment and future social reality of the individual. Both people with and without albinism who participated in FGDs and interviews demonstrated how the sphere of influence of an individual with the condition was far greater than may be assumed.

This learning is of the upmost importance. We have a responsibility to respect that people with albinism have the right to be the centre of influence on their individual social constellation. Participants have spoken of their need to be listened to and have their voice heard. 'Nothing for us without us' is a common expression that has surfaced in the transcripts in numerous different forms. Taking this on board when considering social application of the research findings means that people with albinism are true agents in the social changes we collectively hope to affect.

The second learning of vital importance when reading into the findings is that there is indeed a network of individuals who need to be worked with when implementing the research recommendations. The transcripts reveal how this network is not simply a static matrix of individual entities operating unilaterally, but rather there is a constant process of influence at play within that social fabric.

These key learnings can be considered as navigation aids for us as stakeholders tasked with applying this research. The challenges which surface in the research are associated with proactive solutions which react to and anticipate the experiences of people with albinism, based on evidence-based findings. These solutions feature in the project Recommendations, primarily generated my members of TAS. These recommendations are not end points in our journeys, but rather actions to aim for that will require constant reassessment and evaluation.

In using these findings to continue our journeys towards the goal of true social inclusion for people with albinism in Africa, we should be reminded of our research participants who emphasized the powerful influence different stakeholders can have on their lives whilst keeping in mind the fact that only people with albinism are able to define who these stakeholders should be and how they should act. If we are to truly take this research on board as coalitions and individuals, we will understand that it is only by promoting people with albinism as centres of influence in their own right that we achieve true social change. This research seeks to platform the voice of these individuals, so we may respond accordingly in fellowship and with respect for people with albinism as agents of change.

2. Project summary

Patricia Lund, Coventry University

Individuals with albinism in Africa are visibly different from their dark skinned peers, with their inherited lack of pigmentation in their skin, hair and eyes. This study was conducted at a time of danger as they are targeted for their body parts for use in witchcraft related rituals. Geita and Ukerewe districts in the Lake Zone of Tanzania where security issues for those with albinism are particularly pronounced were chosen as study sites. In Uganda districts within the Busoga sub-Region were chosen; this is one of the poorest regions of the country with a largely rural population leading a hand-to-mouth existence.

Issues of albinism in Africa are steeped in negativity and much has been written about the attacks on people with albinism and the challenges they face. Myths and misconceptions abound. In the context of attacks on those with albinism which have been highlighted in both national and international media reports, this project aimed to document in a positive way the innovative and practical ways in which those with albinism navigate the many challenges they face in accessing appropriate health, education and welfare services. This fills a crucial gap in our understanding and provides the evidence base to inform interventions by both governmental and non-governmental agencies.

The Ugandan focus group discussions and interviews were conducted by Peter Ogik of SNUPA (Source of the Nile Union of Persons with Albinism) and Fazira Kawuma, supported by Jane and Andrew Betts of the UK based charity Advantage Africa. Local researchers, Eddy Kennedy Okoth and William Jonan of NELICO (New Light Children Center Organisation) and a team from the UK based charity Standing Voice led by Jon Beale and Jamie Walling facilitated the research in Tanzania. The Coventry based team comprised Patricia Lund (principal investigator), Anita Franklin who lead the literature review and Simon Goodman, an independent analyst who was not involved in data collection. All members of the team involved in the research contributed to the final analysis.

The project produced a rich vein of narratives from both countries, identifying the multiple agents and facilitators helping to provide a supportive network for families with albinism, with the affected person at the centre as an active agent in promoting their own advocacy. A theme running throughout the narratives is the importance of self acceptance by those with albinism, bolstering self confidence and leading to success. There was evidence of attitudes to those with albinism changing in a positive way as a result of many initiatives to raise awareness and provide information on albinism. From the Tanzanian narratives it was clear that this was a slow process, requiring time, with examples of those with albinism persisting in educating their communities about albinism and engaging with their friends and neighbours to gain acceptance.

A striking point of the research was the importance of single individuals in helping to break the cycle of discrimination and downward cycle of despair. One person can make a key difference in the life of a person with albinism. As may be expected the support of family is crucial, with fathers often rejecting and abandoning the mother and child with albinism. Indications of understanding and support from teachers, pastors, neighbours, friends and, most importantly, potential employers can make a pivotal difference in the transition of a person with albinism as they move through education to gaining appropriate employment and finding a partner and starting a family.

Given the very strong evidence that economic success is crucial to the lives of those with albinism, further exploration of ways in which job prospects can be improved for people with albinism, in terms of equality of opportunity or even positive selection for those with albinism would help inform appropriate interventions. The misperception that the skin of those with albinism is ‘weak’, that they cannot do routine manual chores such as working in a flour mill need to be challenged. The more damaging mistaken belief that they cannot achieve ‘anything’ is being discounted as more and more people with albinism take up jobs and positions in society and provide evidence to the contrary.

This research identified a gender difference in marriage prospects for those with albinism which requires further investigation; one woman with albinism commented *men seduce me but I cannot maintain a relationship*. Men with albinism usually marry women without albinism, because if they have economic stability that will attract a partner. Women with albinism find it harder to find partners because they cannot bring that economic power to a marriage.

There are numerous cases of positive role models among those with albinism and those around them. Some of these have been developed into illustrative case studies, showing how individuals have gained success and recognition, be it through showing initiative in thwarting an attempted abduction or persisting in training as a tailor despite being mocked when they could not see to thread a needle.

In collaboration with participants and other actors, the team have developed a series of recommendations at different tiers, listing specific action points to be taken at different levels from national government, through local government in conjunction with the community and including calls to those with albinism themselves to be more proactive in putting themselves up for positions in the community.

Outputs from this study include a booklet for children developed by Patricia Lund with images by Teresa Robertson is available at

https://pureportal.coventry.ac.uk/en/publications/born-with-albinism-in-africa

This has been translated into Swahili and they also include a series of evidence based comic strips by the Tanzanian artist Theophil Reginald for use on multiple platforms to raise awareness, and a film shot by Hamidu Ramadhan documenting the final dissemination events.

The importance of reporting the findings of the research back to the participants and local communities is paramount, as is the presence of local officials at the final dissemination events in both countries when they could see their voices being considered seriously. The team have used the findings to develop a Call to Action, for all stakeholders to work collaboratively to act on the research findings and improve the lives of those with albinism.

3. Synthesis of the Literature Review

Anita Franklin, Reader in Children and Family Research
Patricia Lund, Principal Lecturer in Genetics
Faculty of Health and Life Sciences, Coventry University

Children in African communities born with oculocutaneous albinism look significantly different to their peers due to the lack of melanin pigment in their hair, skin and eyes – leading to light coloured hair, blue/hazel eyes and pale skin which is very sensitive to the damaging effects of the sun. Albinism also affects eyesight including involuntary nystagmus which causes eyes to move from side to side, photophobia, poor depth perception, strabismus (squint), poor visual acuity and refractive errors. In one study 85% of children with albinism in South Africa had less than 30% vision, even with the best optical correction.

Oculocutaneous albinism is an inherited condition which, if not understood or managed correctly, can have significant health and social impacts on the lives of those affected. These impacts are particularly acute in regions of the world where myths and superstitions surrounding the condition can lead to stigmatisation, discrimination, rejection and misconception, and in some cases violent assault and murder.

The literature review highlights the significant challenges faced by people with albinism living in Africa. These range from physical danger to life through attacks and murders, to inadequate health and educational resources to meet the specific needs resulting from their visual impairment and susceptibility to skin lesions and cancers. Stigma and discrimination permeate all aspects of their lives and limit social integration. The evidence also points to the difficulties faced by families in trying to protect members with albinism, particularly children, from attacks, whilst maintaining their rights to freedom of movement, family life and choice.

Media and NGO reports have been used to follow the nature and impact of attacks on people with albinism in Tanzania, with some recent evidence that these are declining, although under reporting makes the scale of the problem uncertain. Despite efforts by government and other agencies, concern for their security continues to dominate the lives of those with albinism. Poverty and ignorance are key factors driving the traffic in body parts of those with albinism, mistakenly believed to bring wealth and good fortune.

A lack of understanding of albinism, even among professionals, limits the effectiveness of any support offered to families, and reinforces stereotypical beliefs and misconceptions. The importance of education and raising awareness about albinism at all levels is stressed by many authors, as a way to challenge deeply entrenched mistaken beliefs and myths, and lead to better acceptance.

Although evidence on solutions remains limited, the research highlights specific ways in which the lives of adults and children with albinism could be improved with some authors stressing that any intervention strategies that attempt to address health and/or social issues affecting this group need to be holistic and mindful of the cultural, value and belief systems of the local communities (Lund and Gaigher 2002[1]).

The evidence also examines the importance of empowering people with albinism so that they can lead and/or work in partnership with others to bring about change. Both national groups and international agencies such as the United Nations are becoming directly involved in promoting the human rights of those with albinism in Africa.

Overall, the available literature is limited, with significant gaps in the research evidence base including a paucity of studies which give a voice to adults and children with albinism, and to the families of children with albinism.

Note

The editorial, bibliography, reading notes and full literature review of albinism in East and Southern Africa have been submitted as a separate document using the FIRAH template.

Two journal articles have been written and submitted; links will be provided on publication.

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[1] Lund, P. M., and Gaigher, R. (2002) ‘A health intervention programme for children with albinism at a special school in South Africa’. *Health Education Research* 17 (3), 365-372

4. Method of the Project

4 a. Summary of the Method

The overall aims of the study were to examine the impact of stigma and fear surrounding albinism upon the education and life opportunities of children and young people who are directly affected by the condition, and more general perceptions and beliefs held about the condition within Tanzania and Uganda.

This project addressed the following research questions:

How can survival from birth, educational integration and subsequent life opportunities be enhanced through an understanding of the barriers and facilitators that influence successful transition of children with albinism into pre-school, from primary to secondary education and into work?

Objectives for investigation include:

1. Local myths, traditions and positive/negative attitudes that surround people with albinism in Tanzania and Uganda that contribute to the stigma associated with their condition, with particular emphases on survival, where having albinism is life threatening as babies are sometimes killed at birth and young children are targeted for their body parts for use in witchcraft associated rituals
2. The strategies that enable some children with albinism to survive and overcome stigma in order to access education
3. Parents, teachers, community leaders and other opinion-formers' roles in supporting children with albinism and the nature of the support (if any) that they provide to each of the educational transition points and transition into work
4. The strategies of local and national albinism associations and other NGOS in advocacy and influencing educational policy to ensure inclusion and access to educational opportunities

Theoretical context and methodology:

The project adopted a participatory methodology, involving people with albinism (including children and ensuring there was a balance of genders) and other stakeholders from the start, enabling them to influence its direction and scope. It engaged with those who can help break the barriers for young people with albinism, focusing on positive support structures, facilitators and agents. In this way it addresses the aims of the UNCRPD to secure lasting, effective and positive change in the lives of persons with disabilities in sub-Saharan Africa. The results of the project will contribute directly to the implementation of the UNCRPD through greater societal awareness and understanding of albinism, improved survival rates for infants and opportunities to access education, work and other life opportunities; indeed full and effective participation and inclusion in society for children and young people with albinism. The novel and innovative aspect of this project is the focus on positive factors that facilitate 'survival' and how these can be fostered and nurtured.

This qualitative study collected data from focus group discussions, followed by more in depth face-to-face semi-structured interviews in both countries. Ethical approval for the study was obtained formally from the Research Ethics Committee of Coventry University and locally in each country.

Pilot Study:

Two pilot focus groups (FG) were held in each country at the start of the project. Each FG comprised of a representative sample of 7-10 people with albinism, ensuring a gender balance. As for the main study recruitment for the pilot FGs were via the albinism associations in each area and were led by two facilitators from NELICO (in Tanzania) and SNUPA In Uganda). One FG comprised of adults with albinism aged 18-30, and the other of children with albinism below the age of 18. The purpose of these FGs was to identify key questions, prompts, and matters of relevance for each target population. On reviewing the results of the pilot studies further training of the facilitators was put in place, to ensure the discussions were non directional, with less input from the facilitators and more freedom for the participants to discuss their views freely.

Data validity and changes during the project:

In Uganda the researchers included someone with albinism and the range of stakeholders interviewed differed from the home visits in Tanzania where partners, family members, friends and neighbours of those with albinism were interviewed. It was therefore decided to analyse the two data sets separately.

The two researchers from NELICO in the Tanzanian based study are from an NGO that works in the Geita area, they support families with albinism including economic assistance, training in entrepreneurship skills and provision of protective gear and sunscreen. They felt that the participants with albinism feared they would withdraw this support if they mentioned too many positive aspects of their lives; this may have been a limitation of this project which sought to elicit these. Furthermore, the researchers knew all of the participants in Geita personally but none on Ukerewe; the researchers commented that those on Ukerewe were found to be very open in giving their responses, compared to those in Geita, who were more reticent.

The SNUPA team were keen to extend the scope of the project to include more face to face interviews with other stakeholders including journalists and a dermatologist. In Tanzania the team decided to include home visits where family members, neighbours and friends.

Sample recruitment and data gathering:

Focus Groups in Tanzania and Uganda: A total of 8 FGs were conducted in each country, each comprising of 7-10 people, each with two facilitators from NELICO or SNUPA.

The purpose of the FGs was to elicit and discuss perceptions and experiences of albinism as they relate to the research objectives. The FGs were digitally recorded, transcribed and translated by the field researchers.

Through the FGs the research team identified individuals for a follow-up interview, and key questions to ask in those interviews.

Semi-Structured Interviews: Semi-structured interviews were conducted, with individuals selected on the basis of their position in society, experience, or view on albinism, using a theoretical sampling strategy. Interviews were conducted at a mutually convenient location for both participant and interviewer. The purpose of the interviews was to investigate understanding of albinism, its perception and effect on individuals, and to examine the conditions under which the condition restricts education and life opportunities and if/how those barriers can be overcome. Interviews were audio-recorded, translated and transcribed by local transcribers.

Table of Participants of the study in Tanzania (April 2016 to July 2017)

Location	**Method**	**Number without Albinism***		**Number with Albinism**		**TOTAL**
		Male	**Female**	**Male**	**Female**	
Geita	Focus Group	9	5	8	7	29
	Home visit Interviews	3	7	3	2	15
Ukerewe Island	Focus Group	12	8	9	4	33
	Home visit Interview	9	10	2	3	24
	TOTAL	33	30	22	16	**101**

Age range of participants: 15 to >70 years old

*Participants without albinism included partners, parents, guardians, grandparents, siblings, neighbours and friends of people with albinism

Process of the data analysis:

Data will be analysed using thematic analysis (Braun and Clarke 2006) to unpack meanings and experiences surrounding albinism. This method of analysis allows for a detailed understanding of the key issues, concerns and experiences of people with, and those connected to people with, albinism.

Braun, V & Clarke, V. (2006). Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3, 77-10 DOI: 10.1191/1478088706qp063oa

4b. Presentation of the engagement of the researchers and stakeholders in the field

Uganda

Jane Betts, Advantage Africa

The Source of the Nile Union of Persons with Albinism (SNUPA) is a Ugandan non-governmental organisation formed in 2012, by and for persons with albinism in Busoga sub-region and its neighbouring districts. SNUPA aims to change attitudes and improve life for people with albinism and their families.

Advantage Africa is a UK-based non-governmental organisation founded in 2002 which supports people affected by poverty, disability and HIV in East Africa. In 2013, SNUPA and Advantage Africa began a partnership to help people with albinism to stay safe from cancer, attend school, earn an income and overcome discrimination and lack of opportunity.

Children and adults with albinism are amongst the most marginalised and neglected people in Uganda. Discriminatory attitudes and ignorance about their condition means that people with albinism struggle to access appropriate healthcare, education and sustainable livelihoods. Uganda has not experienced the same level of highly publicised violence committed against people with albinism as in Tanzania, but there is widespread fear and awareness of these atrocities and that the search for highly-prized albino body parts may spill across borders. This means that parents of children with albinism are afraid to let them go to school unaccompanied and many are kept hidden. People with albinism regularly report attempts to take clippings of their hair and nails and feel vulnerable and under threat as a result.

Jane Betts, Andrew Betts, Advantage Africa; Peter Ogik SNUPA

Summary table of key activities in Uganda

No.	Date	Location	Participants	Activity
i.	22nd June 2015	Kampala	Peter Ogik, Chair SNUPA Fazira Kawuma, Executive Secretary, SNUPA Patricia Lund, Coventry University (CU) Andrew Betts, Advantage Africa (AA)	Meetings with Uganda Government representatives in Ministry of Gender, Labour & Social Development and Ministry of Education.
ii.	Between 23-27 June 2015	Jinja and wider Busoga sub-region	SNUPA Executive Committee, including research facilitators Patricia Lund, (CU) Andrew Betts, (AA)	Training in research aims and objectives and facilitation methods.
iii.	Between 23-27 June 2015	Jinja	Peter Ogik, SNUPA Fazira Kawuma, SNUPA Patricia Lund, (CU) Andrew Betts, (AA)	Meetings with local government, district councilors, civil society representatives

iv.	21st September 2015.	Luuka District, Busoga sub-region	Peter Ogik, SNUPA Fazira Kawuma, SNUPA	Luuka District pilot focus group discussion for people with or affected by albinism aged 18+
v.	28th September 2015	Kamuli District, Busoga sub-region	Peter Ogik, SNUPA Fazira Kawuma, SNUPA John Mugangu, SNUPA District representative	Kamuli District focus group discussion for people with albinism aged under 18 and their parents/carers
vi.	13-16 October 2015	By email and phone	SNUPA research team Patricia Lund, (CU) Jane Betts, Rob Aley, Andrew Betts (AA)	Evaluation of pilot focus group discussion process and resultant transcripts.
vii.	November 2015	By email and phone	SNUPA research team Jane Betts, (AA)	Review of facilitators role, FGD process, challenges and successes.
viii.	19th January 2016	Jinja	SNUPA Executive Committee Jane Betts, (AA)	Research training and planning.
ix.	21st January 2016	Kaliro District, Busoga sub-region	Peter Ogik, SNUPA David Gonza, SNUPA District representative Jane Betts, (AA - observer)	Kaliro District Focus Group Discussion for those affected by albinism or their carers
x.	10th March 2016	Advantage Africa, Office, UK	Patricia Lund, (CU) Jane and Andrew Betts, (AA) Jon Beale, Standing Voice (via Skype)	FIRAH research review and planning

Outcomes in Uganda

i. June 2015: SNUPA team leaders, Patricia Lund and Andrew Betts met with Uganda Government representatives in Ministry of Gender, Labour & Social Development and the Ministry of Education. These meetings helped raise awareness amongst ministry staff who knew very little about albinism. They obtained approval for the research and brought its aims to the attention of relevant stakeholders to ensure national level engagement. The project falls under the jurisdiction of the Ministry of Gender, Labour and Social Development and its Department for Disability and Elderly. The Department Commissioner commented that ‘they like the way we have gone about approval because it was in line with their methodology of using community-based structures’.

ii. June 2015: Patricia Lund and Andrew Betts met with SNUPA’s executive committee including the full research team. A start-up workshop was held to ensure the team members’ full engagement with the aims and objectives of the research project. The SNUPA team received training in research techniques and effective facilitation of focus group discussions. The workshop was also a successful team-building exercise which included an exercise called the ‘Game of Life’ which helped participants to frankly explore prejudices and obstacles faced by people with albinism in a positive, supportive environment.

The participants did a focus group discussion and demonstrated what they had learned during the workshop. Observations included:

The facilitators kept quiet to allow the discussion to flow

The participants were at ease

They participants recounted their personal

experiences Nobody gave speeches

The group kept to time

The session was recorded properly but unobtrusively

People listened to each other well

There was respect and appreciation for the contributions made.

Almost everyone contributed but nobody was pressurised to do so.

These were all good indicators of the team’s ability to conduct the focus group discussions going forward.

The SNUPA team tries the ‘Game of Life’

Animated group discussion

Exploring research methods and key community stakeholders

iii. June 2015: Peter, Fazira, Patricia and Andrew met with local government representatives and Jinja district councillors to introduce the project, secure approval and support for the research activities and consolidate regional level engagement. There were strong indications of interest and support for the research at both ministerial and local government level. There was also keen engagement from the National Council for Disability (NCD) which monitors, evaluates and reports to the Ugandan Government, using research-based evidence to influence policy. SNUPA and Advantage Africa have pledged to keep them and other stakeholders informed of the project's progress.

iv. Sept 2015: The first pilot focus group discussion (FGD) for people aged 18+ took place in rural Luuka District about 50 kilometres north-east of Jinja town on 21st September. Five people with or affected by albinism attended.

v. The second pilot FGD, again in a rural setting, took place on 28th September in Kamuli District about 70 kilometres north of Jinja town. This discussion was for people with albinism aged under 18 and their carers and was attended by ten people.

vi. From the end of May/early June 2016 SNUPA undertook the remaining FGDs, approximately one every three weeks, in the remaining districts including Jinja, Buyende, Iganga, Namayingo and Mayuge. These locations will ensure that the research findings are drawn from urban and island/lakeshore as well as rural settings.

vii. It was decided to extend the list of interview to include major stakeholders such as journalists, dermatologists and other groups working with people with disabilities.

Peter and Fazira started each pilot FGD by sharing the aims and objectives of the research and helping people to understand the process of consent. Most participants knew Peter as the Chair of SNUPA based in Jinja town, but he approached them with humility saying that he was just a person with albinism like them, wanting to learn and, with their permission, share their experiences.

The SNUPA facilitators spoke enthusiastically about the level of interaction, laughter and excitement of the participants. While each pilot discussion was evidently positive and dynamic, the SNUPA facilitators were still in the process of gaining confidence in their research techniques and keeping the conversation on track while remaining neutral, observational and objective.

The process of translating and recording the transcripts clearly proved challenging for the SNUPA team. Peter worked with a SNUPA volunteer to transcribe the contents of the recording devices, trying diligently to register all contributions and translate from Lusoga, the local language. Lusoga is a difficult language to work with and providing coherent translation into English clearly demanding. The resultant transcripts were limited and shorter than expected given the level of participant interaction reported, but some gems of information about the experiences of people with albinism did emerge from the contents.

The process of facilitating the pilot FGDs was an invaluable capacity-building exercise for Peter, Fazira and other SNUPA team members involved and their enthusiasm for the research is without question. The SNUPA facilitators' respectful approach of working together to explore issues which would help improve life for people with albinism helped to nurture good rapport and mutual trust between the research team and initial participants.

viii. October and November 2015: The teams at Coventry University, Advantage Africa, Standing Voice and their research partners in Uganda and Tanzania evaluated the process and results of the pilot FGDs in both Uganda and Tanzania and were able to identify gaps and areas for improvement. This resulted in completion of guidelines on facilitation of group discussion to help ensure all future discussions are fully participant-driven and improve the relevance and quality of the information gathered.

ix. For SNUPA, relative newcomers to research processes, it was evident that a clearer facilitation framework, along with more confidence in their abilities to gently and appropriately guide the FGD conversation, should yield improved results in both quality and quantity. Jane Betts and the SNUPA team discussed effective facilitation, accuracy of data collection and translation and transcription methods in depth via phone and email. Preparations were also made for further training during Jane's visit to Uganda in January 2016.

x. January 2016: Jane Betts met with the SNUPA Executive Committee, including all Busoga sub-region representatives, for comprehensive discussions on the research progress and training in the revised facilitators' guidelines. Plans were made for the next focus group discussion to take place in Kaliro District with a provisional timetable for future FGDs to be agreed.

ix. January 2016: The Kaliro District FGD took place in Bwayuya Primary School, in a semi-rural setting three kilometres from Kaliro town and was attended by 8 children and adults affected by albinism. The discussion was facilitated by Peter Ogik, SNUPA Chair and David Gonza, District representative and observed by Jane Betts of Advantage Africa. It was challenging for Peter to take part as he was suffering from malaria, but his determination and commitment are such that he facilitated the discussion with his usual humility, empathy and friendliness. The aims, objectives and consent process of the research were carefully shared with the participants, who reacted with great enthusiasm when informed that their experiences could be helpful in improving life for people with albinism in Uganda and beyond.

The FGD lasted for approximately one hour and the conversation was open and free-flowing. As the FGD was brought to a close, the participants were each given simple refreshments of a drink and small cake. They were keen to linger and talk to each other further and expressed appreciation that their personal experiences and challenges were being listened to for the first time. Before leaving the primary school, each participant with albinism was also provided with high sun protection factor (SPF) sunscreen and lip salve and new beneficiaries were noted on
SNUPA's membership list. For some participants, this was the first interaction with SNUPA. For example, Lydia who brought her son Trevor (a nine-month old baby boy with albinism) was unaware of the dangers of skin cancer and the need to protect him from the sun. Trevor's skin was already showing signs of damage and Peter told Lydia how to apply sunscreen and ensure he was protected from the sun.

x. 10. March 2016: Meeting at Advantage Africa office, Olney, UK with Jane Betts, Patricia Lund and Jon Beale via Skype to discuss the progress of the research and plan next steps.

: The research’s consent process is explained to participants.

The Kaliro District FGD showed how the process of bringing groups of people with albinism together is proving enormously beneficial beyond the boundaries of the research. The participants support and listen attentively to each other and form supportive friendships. SNUPA is also able to register and engage with new beneficiaries for involvement in their wider activities including prevention of skin cancer.

Before leaving Jinja, Jane reviewed how the Kaliro FGD had gone with the SNUPA team. Peter was impressed by the openness and communicativeness of the participants and that they brought up issues he had not previously considered. Overall he thought the discussion was good and all agreed that the new facilitators’ guidelines had been enormously helpful. District representative David participated in the discussion but did not play a significant role as co-facilitator with Peter. He spent a disproportionate amount of time supporting participants with the consent process at the risk of hindering the discussion. Jane and the SNUPA agreed that further support should be made available, as required, to each SNUPA researcher to ensure they felt equipped to co-facilitate their district FGDs and also that the process of explaining and signing consent forms should be completed before the discussion began.

The transcript from the focus group discussion in Kaliro District demonstrated the positive progress of the SNUPA team in their research methods since the evaluation of the pilot FGDs. The transcripts were far more detailed and clear and Peter’s improving facilitation skills had elicited a wealth of valuable information. The transcript was reviewed by Patricia Lund and Jane Betts who then worked with Peter to clarify the finer details.

Final project dissemination event in Kampala, Uganda

On 24th November 2017 a one-day conference to disseminate the results and recommendations from the Ugandan element of the research was held at the Africana Hotel, Kampala. The conference was attended by nearly 100 people including representatives from government, academia, NGOs and media including radio and television stations. After a welcome by the SNUPA and Advantage Africa team, a rousing speech from the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism Ms. Ikponwosa Ero, was read to the delegates by the UN Human Rights Adviser for Uganda, Uchenna Emelonye.

The agenda then continued with an explanation about albinism and an introduction to the work of Advantage Africa and SNUPA among people with albinism before the results of the research were explored. This was first done in the form of an engaging drama which used direct quotes from the FGDs and interviews to powerfully portray the stigma experienced by people with albinism and how it adversely affects their life journey. The research results and recommendations were then outlined in more detail by theme in a formal presentation by SNUPA's Chairperson Peter Ogik. Peter brought in the personal experiences of some of those present as well as his own, to illustrate the findings and how the recommendations could improve the lives of thousands of people living with albinism. An interactive question and answer session then followed during with issues discussed included educational conditions, access to employment for people with albinism and the local production of sunscreen. During this session, the representative from the Equal Opportunities Commission pledged to act on discrimination against people with albinism and the CBR Africa Network offered to publicise the research.

The inclusion of 'edutainment' activities such as drama and music ensured the conference was stimulating and enjoyable for all who came. Comments received included 'people's eyes were opened' and 'this was a special kind of conference'. Disability MP Hellen Asamo described the conference as a 'turning point in the history of albinism' which 'bridged the gap between people with albinism and the general public'. Dr. Sarah Kamya, Senior Lecturer in Social Work at Makerere University said: 'The findings were an eye opener to different issues related to albinism.'

The successful conference and the dissemination document launched on the day built a strong foundation on which further advocacy to advance the rights of people with albinism in Uganda can take place. It also enabled representatives of albinism groups from all over Uganda to meet for the first time and plan a national organisation to represent their interests going forward.

Tanzania

Jon Beale, Standing Voice

Standing Voice is managing the data collection in Geita and Ukerewe (Tanzania). This has involved managing the Tanzania project budget and guiding the focus and approach of the NELICO research team, generating interest in the project across a range of stakeholders and getting the necessary local approvals and endorsements. Particular attention has been paid to ensuring all costs covered are realistic and reflective of the local context.

Standing Voice is an international NGO based in Tanzania (Reg. I-NGO/08536), with its headquarters in the United Kingdom (Reg. 1151250).

Our team designs and delivers Health, Education, Advocacy and Community initiatives, reaching thousands of people with albinism in Tanzania. We exist as a catalyst to amplify the voices of others, enabling individuals to take charge of their own lives and forge their own futures. Crucially, we work alongside the disempowered, not for them, over them, or on their behalf. We give the disempowered vital tools and platforms to speak back to their societies and reassert their presence and equality. We strive to nurture people's understanding of others so that in future marginalised groups will be embraced by society. And in the meantime, we meet essential basic needs wherever they have been denied.

The Tanzania-based facilitating partner is the New Light Children Center Organization (NELICO) www.nelicotz.org.

The New Light Children Center Organization (NELICO) coordinators have facilitated all data collection in Geita and Ukerewe, produced full transcripts, and reported back on progress regularly to Standing Voice.

NELICO is a non-profit, non-governmental organization registered under the Non-Governmental Organizations Act in March 2006 (registration certificate No. OONGO/0739), and based in Geita District. The organisation has been active since 2004. NELICO aims to bring a positive change in the lives of the children and youth with a particular focus on orphans and most vulnerable children, through the promotion of their well-being and creation of an enabling environment where communities promote, respect and protect child rights. NELICO's core programmes are: Prevention of Killings of People with Albinism (promotion of social inclusion of people with albinism); Psychosocial Support; Youth Voice; and Legal Aid and Child Protection.

Study locations in Tanzania

Geita, on the shore of Lake Victoria has 308 people with albinism registered with the Geita Albinism Society. This is a particularly dangerous area for those with albinism, with seven reported murders since 2007 and eight who survived attack. Following the submission of the application to FIRAH to fund this research Yohana Bahati, a one-year-old baby, was kidnapped and killed in Geita Region. His body was found days later in February 2015. Yohana's mother Esther took part in a FGD in Geita in April 2016. A large amount of gold mining is conducted in Geita Region, either by large mining companies or by local communities.

Ukerewe Island is the largest island in Lake Victoria and the largest inland island in Africa, with an area of approximately 530 km². It is part of the Ukerewe District in Tanzania, and situated 45 km (25 nautical miles) north of the city of Mwanza to which it is linked by a 4 hr ferry. The estimated population of Ukerewe district is 300,000. Ukerewe Island is known for having a large population of people with albinism. Local folklore often claims that many of the first people with albinism to live on Ukerewe were taken to and abandoned on the island by their families as children. During the first Island census carried out in 2006 by the Ukerewe Albinism Society 72 people with albinism were recorded.

Activities including data collection in Tanzania

Consent: Prior to conducting all FGDs and interviews the NELICO facilitators explained the research to the participants, and all participants signed consent forms to signal their willing participation in the research.

Interviews were conducted by one or two facilitators and audio recorded. All interviews have been translated and transcribed in full.

Focus group discussion lead by the NELICO researchers.

Summary Table of Activities in Tanzania

Date	Location	Activity	Stakeholders involved
August 2015	Geita town	2 Pilot focus groups: Focus Group 1: People with albinism over 18 years of age N=9; 3 female, 6 male Age range: 22-45 years Focus Group 2: Children with albinism under 18 years of age N=5 female Age range: 15-17	NELICO researchers: Eddy Kennedy and Ludovick Peters at the NELICO offices.
November 2015	Nansio, Ukerewe Island	Focus Group 1: Youth with albinism N=4 male Average age: 21 years Focus Group 2: Mothers and carers of children with albinism N=7 female; 6 with albinism and 1 without Average age: 37 years Focus Group 3: Adults with albinism N=5; 2 female, 3 male Average age: 41 years Pilot home visit Two interviews were conducted, one with the grandchildren of the host, a	NELICO researchers, Jamie Walling of Standing Vice; Patricia Lund, Coventry University; FGDs at the Umoja Training Centre on the periphery of Nansio Town Each interview lasted approximately 10 minutes and was audio recorded, translated and transcribed.

		man with albinism, and one with a neighbour	
April 2016	Geita–Kasamwa Lwezera & Katoro Wards (all rural)	Focus Group 1: Youth with albinism N=5; 2 female, 3 male Age range: 13-17 years Focus Group 2: Adults with albinism N=5; 4 female. 1 male Age range: 18-53 years Focus Group 3: Parents/guardian of people with albinism N=4; 2 female, 2 male Age: above 18 years	FGDs were conducted by the NELICO researchers in local authority premises
April 2016	Geita-Kasamwa ward	Home visits: 4 families were visited with 9 interviews.	Free interviews were conducted individually. Interviewees were informed at the start of the interview that there were no specific questions to answer, but rather the discussion was intended to be an experience-sharing conversation to explore their experiences of albinism,
November 2016	Ukerewe	4 home visits N=15; 9 female and 6 male Age range: 19 to > 70 years These included a neighbour, step brother and landlady of a couple with albinism; neighbour and friends of a female tailor with albinism; neighbours, friends, son and wife of a man with albinism who owns shops; mother of a child with albinism, a neighbour and a friend 4 focus group discussions with and without people with albinism separately N=19; 8 female and 11 male Age range: 12 to 60 years old	NELICO researchers; Eddy Kennedy and William Jonan
February 2017	Geita	3 home visits N=6; 3 female and 3 male	NELICO researchers; Eddy Kennedy and William Jonan

		Age range: 16 to 47 years These included people with albinism and their neighbours, partners and friends; one was the grandfather of a 16 year old boy with albinism whose parents had died 4 focus group discussions including both adults over 18 and youth (12-17 years) with and without albinism in separate groups N=15; 4 female and 11 male Age range: 13 to 42 years old	
April 2017	Ukerewe	3 home visits N=8; 4 female and 4 male Age range: 19 to 47 years These included people with albinism and their parents, and friends of people with albinism; one was a traditional healer with a daughter with albinism 2 focus group discussions including adults with and without albinism all with relatives or friends with albinism, in separate groups N=12; 4 female and 8 male Age range: 13 to 17 years old	
Summer 2017	Coventry, UK	Initial analysis of the data sets, identifying key themes and agents/facilitators providing a supportive network for those with albinism	Initial analysis by Simon Goodman, Coventry University with input from Patricia Lund and the Standing Voice team (Jamie Walling and Jon Beale)
July 2017	Geita	21 July was a one day workshop with 11 key participants from Geita (5 female; 6 male) to share the findings of the project and get feedback on the initial comic strips by local Tanzanian artist Theophil Reginal Mnyavanu, based on evidence from the project	NELICO researchers and Patricia Lund, Coventry University, 11 participants with albinism including members of the Tanzanian Albinism Society TAS at workshop; 2 home visits to women with albinism for developing case studies; one is the mother of a child with albinism who was murdered; she was seriously injured
11 August 2017	London Standing Voice office	Tanzanian research team met to discuss and refine the initial analysis of the data	Jamie Walling and Jon Beale (via Skype) from Sanding Voice with Simon Goodman and Patricia Lund (Coventry university)

November 2017	Geita and Ukerewe Island	Dissemination event including photo exhibition, presentation of key participant quotes in both English and Swahili and the initial comic strips by local Tanzanian artist Theophil Reginal Mnyavanu; dissemination visit in Ukerewe captured by local film maker Hamidu Ramadhan; home visits in each of the two study sites	Sam Clarke from Standing Voice with Mashaka Tugu organiser on Ukerewe; Eddy and William Jonan of NELICO in both sites; joint organisers of the Geita dissemination; Patricia Lund of Coventry University
November 2017	Bukongo Secondary School, Ukerewe Island	Visit to Secondary school to explore the training round albinism in the Biology curriculum in Form 4 by checking the 2005 centralised curriculum	The Tanzanian team visited this local school, near Standing Voice's, Umojo Centre, and spoke with the Deputy Head and Patricia Lund spoke to the Biology teacher who teaches about albinism in the curriculum

Data validity in Tanzania

On assessment, the pilot study was too structured, which resulted in participant contributions which were effectively prompted. These data were not included in the final analysis and provided a focus for the training in November 2015 on a field visit by Jamie Walling of Standing Voice and Patricia Lund of Coventry University, resulting in an additional pilot study on Ukerewe Island in November 2015 alongside training for the facilitators, to refine the methodology for collecting the data.

Efforts were made to ensure gender parity and to separate males and females in focus groups, as it was felt the females would feel more comfortable contributing in an all female group.

The delivery of the refined guidelines, and Jamie Walling and Patricia Lund's visit to Ukerewe in November 2015 to guide the research process, formed the training stage for the facilitators. The team considered triangulating by undertaking more home visits when other protagonists important to a person with albinism would be identified and interviewed, to gain a broader perspective on their lives and social context. The research team found that interviews during home visits provided a more intimate insight into individual participants' day to day lives and situated them in the context of their social fabric (by also interviewing neighbours and relatives).

Comments on refined strategy following the Ukerewe pilot focus groups and interviews:

Some of the FGDs were large and not restricted in number in this pilot. It was decided that it is most conducive for the research to consistently involve 4-5 participants, so that each contributor had the opportunity to have their voice heard.

In the remaining focus group discussion the participants were cooperative and ample time was allocated to the discussion.

A note on cultural context of the two study sites in Tanzania:: Because the rules for interaction differ across cultural contexts with two different predominant indigenous ethnic groups (Sukumas in Geita and Kerewes in Ukerewe); facilitators paid attention to whether or not eye contact was acceptable and what positions they should sit in, to avoid being disrespectful (eg: feet towards interviewees). Facilitators avoided interrupt participants with follow up questions, because this allowed silences to give participants time to think, as well as avoiding giving their own opinions or showing disagreement, but at the same ensured participants' points were properly understood.

The two researchers from NELICO in the Tanzanian based study are from an NGO that works in the Geita area, they support families with albinism including economic assistance, training in entrepreneurship skills and provision of protective gear and sunscreen. They felt that the participants with albinism feared they would withdraw this support if they mentioned too many positive aspects of their lives; this may have been a limitation of this project which sought to elicit these. Furthermore, the researchers knew all of the participants in Geita personally but none on Ukerewe; the researchers commented that those on Ukerewe were found to be very open in giving their responses, compared to those in Geita, who were more reticent.

Final dissemination events in Geita and Ukerewe

Comments on the dissemination events in Geita and Ukerewe in November 2017 (Sam Clarke, Standing Voice and Patricia Lund, Coventry University):

The final dissemination events in both Geita and on Ukerewe island were a celebration of the contribution of the participants in this project and an opportunity for them to 'see' print outs of their words in both English and Swahili. This provided direct evidence that their words had been noted and considered and was very popular with both the audience and invited guests.

The events included a photo exhibition of photos from Standing Voice's archive. Although not taken as part of this project, many of the subjects were participants and were delighted to see the high quality, large outs of their positive images to share with their families and communities. There were also print outs of the comic strips produced using evidence from the project.

The event in Geita was a single day and included a photo shoot by Sam Clarke of those with albinism as they viewed the exhibition. There were also 2 computers streaming a powerpoint of images of a few families with albinism in the Geita area as they were not included in the printed images.

Honoured external guests included a representative of Geita District council which covers 37 wards, from Geita Town council I (13 wards) and the local chairman for the area here the event was held, the Yohane Memorial Centre. This was a joyous event with speeches, intermingled with song and exercises. Eddy Kennedy of NELICO summarised the finding of the project in Swahili.

A memorable event was a series of drama sketches by a local youth group supported by NELICO, The actors included a girl with albinism at the centre of each sketch.

Of interest was the information that both were collating data on albinism, with 52 identified in Geita District up to June 2016 (24 male and 28 female: in Geita Town there were 32 with albinism, 20 female and 12 male. They were intending to update their local records on a regular basis.

The event in Ukerewe was held at the Umoja Training Centre built and supported by Standing Voice. The first day was to showcase the findings and outputs to the community and participants. The second day included seven officials, headed by the District Commissioner who gave a long speech in Swahili in response to the presentation of the findings. Local musicians with albinism sang a few songs on albinism and local journalist attended to record the second day. A short film will be produced of the Ukerewe event, edited from extensive footage shot by a Tanzanian film maker, Hamidu Ramadan. This is a valuable resource for use by Standing Voice in its advocacy and by the academic team for secondary analysis.

In terms of the recommendations made by TAS, an interesting pattern emerged. At the national level, participants' recommendations seemed to have focused on healthcare, education, and employment. Interestingly, security seems to be something that participants think should be coordinated at the local level, through community vigilance and alertness, and protection systems within households and wards. It's also coming through that security should not be an excuse to hide people with albinism away or isolate them; communities should find ways to protect people with albinism while continuing to promote their integration in wider community processes.

5. Findings and Discussion

The transcripts of the interviews and focus groups were analysed by Simon Goodman of Coventry University, using Thematic Analysis. This approach involves a detailed reading of the transcripts, which are then coded and organised into systematic themes that represent meaning for the participants in the interviews and focus groups. The analysis is as follows

The lives of those with albinism in our Ugandan community

The analysis of the interviews and focus group discussions with 66 participants, including families directly affected by albinism and other stakeholders, have highlighted a range of factors that influence the lives of people with albinism:

Prejudice and discrimination
The prevalence of myths about people with albinism
The role of government and NGOs in supporting families with albinism The role of God
Impact on education at school
Health implications

Each of these factors consists of events and experiences that can be seen to affect the lives of people with albinism in positive and negative ways.

Prejudice and discrimination to persons with albinism (PWA)

A major theme of the lives of PWA is the large amount of prejudice and discrimination that they face. Discrimination comes in the form of abandonment from family members and isolation. Other forms of serious discrimination include violence and attacks for body parts to use in witchcraft-related charms believed to bring good fortune and easy wealth. This is turn leads to fear, which also impairs the quality of life for PWA. On top of this, PWA experience bullying. PWA can be discriminated against because of their poor eyesight, especially at school where they may also be isolated. Discrimination also comes in the form of difficulties in getting jobs and in finding partners.

Rejection from family

A major part of the life experience of PWA is being rejected by those around them, including from very close family members. Despite pressure on partners of PWA to leave their families, they often defy this pressure and stay by their sides.

Fathers often leave their children with albinism and their wives on the birth of a child with albinism

Pressure on partners or parents of PWA to leave their families

Partners often defy prejudice to stay with people with albinism despite any difficulties this may create for them

Fear of people with albinism, which leads to isolation

PWA are feared by the wider community, including fear of physical contact with them. This leads to isolation and perpetuates the cycle of discrimination of PWA.

Much of this isolation is imposed by others, but the fear of attacks means that PWA may choose to isolate themselves or their children with albinism. In addition, others outside the family avoid PWA, so PWA come to be marginalised.

Fear and threat of attacks

As a result of the attacks against PWA because of an interest in their body parts, PWA, and their family members, live in constant fear of being attacked or kidnapped.

Name calling

As part of the wider discrimination that PWA experience, they experience name calling and bullying on a regular basis. This often occurs at school or college, but also in other areas of life.

Discrimination at school

In addition to bullying, PWA often experience problems with their teachers, especially regarding misunderstandings relating to their poor eyesight, which can be interpreted by teachers as being rude. Support from friends, family and teachers helps to overcome this discrimination.

Hard to get jobs

The widespread discrimination towards PWA makes it difficult for them to get jobs.

Hard to find a partner and to marry

This includes discrimination from the family of potential partners, who do not want to accept a PWA.

The prevalence and problems of myths and beliefs about PWA

A major feature of the interviews was the prevalence of myths about PWA in Uganda. These myths are particularly damaging and need to be challenged.

Fear of the witchdoctors and traditional practitioners was often mentioned; they are viewed as instrumental in the trade of the body parts of PWA, and seen as a major threat, especially regarding the risk of being kidnapped or harmed. There was particular interest in the hair of PWA, leading to abuse of young people with albinism as their hair is forcibly cut off. Fear of attack and abuse restricts the movement of PWA, especially at night.

Range of myths about albinism

The myths contribute to the discrimination towards, and isolation of, PWA and demonstrate the general misunderstanding of the genetic cause of albinism.

Laughing at PWA can result in having a baby with albinism yourself

PWA don’t die, but disappear, suggesting they have magical powers

PWA are viewed as a curse, a punishment from god

PWA can be viewed as demons or ghosts, not ‘real’ human

beings They are given derogatory names such as ‘pig’

Having sex with a PWA can cure HIV/AIDS and lead to easy wealth

This appears to affect women more than men, with documented cases of rape of women with albinism.

Role of NGOs and government in supporting families

The important role fulfilled by SNUPA in advocacy was mentioned by participants.

Government support needed

Many participants felt the government could do more to support PWA, particularly financially, with help with start-up capital to develop small businesses to support their families.

The role of faith and belief

For many PWA, God is seen as a major source of support and comfort.

PWA made in God's image

For some, especially religious leaders, the idea that people are made in God's image is used to show that PWA are equal to other people.

At school: overcoming security, social and health problems

Barriers to educational inclusion at school include the discrimination, isolation, bullying and problems with teachers, as well as with short-sightedness. In addition, the fear of the often-long journey to and from school is also a problem.

However, the support of friends and teachers at school can work to overcome these problems.

Fear of the danger of attack on the journey to/from school

Support of friends and teachers at school have a huge impact on the school experience of a learner with albinism

Managing health issues

The threat of the sun, and the associated risk of working outdoors was often mentioned, as well as problems arising from their visual impairment.

Threat of sun exposure leading to sun-induced skin damage including skin cancer limits daily activities including travelling to school and ability to work outdoors

Participants mentioned various strategies to manage their vulnerability to sun induced skin damage.

Their short sightedness may not be recognised by teachers and peers at school, so they are perceived as 'difficult' with no adjustments made to accommodate them in the classroom

The role of poverty

Community leaders and journalists pointed to the role of poverty in the lives of PWA. Difficulties at school and at work can lead to PWA finding themselves in poverty, leading to further hardship.

PWA are normal human beings with the same potential and rights as others

Case study in Uganda: Eunice, Namayingo District, Uganda

Eunice is a 22-year old woman with albinism and vice-chairperson of Source of the Nile Union of Persons with Albinism (SNUPA). She is the single parent of a young boy who doesn't have albinism. Eunice was born and brought up in Namayingo District, by the shores of Lake Victoria, eastern Uganda. People in this district meet their basic needs through subsistence farming or fishing, although the recent discovery of gold deposits has brought miners and buyers to the area. There are many myths and superstitions about albinism, particularly amongst the Lake Region's Samia people.

When Eunice was born, her father disowned her and threw her and her mother out of the house. However, her mother Zabina loved her and brought her up. She said, 'I have passed through a lot; but since its God, who gave me such a child, I decided to struggle with her. God will find a way of repaying me later.'

Zabina has not re-married. 'Since I gave birth to that girl, people propose marriage to me but the moment they realize that I have a child with albinism, they run away. They think I would produce for them albinos…Even my family members, my brothers and sisters; whenever my child touched anything, no body touched it again; even her cup was washed separately…The moment I gave birth to Eunice, they told my husband that a ghost impregnated me…The people who were supporting me ran away when they saw what was coming out of me claiming I was producing an animal. I looked at what was coming out and continued pushing. When they heard the child crying, they came back. But still some people feared to enter the house wondering what I had produced.'

Eunice faced many challenges in trying to attend primary school. One teacher beat her and chased her out of the classroom saying “You’re not supposed to be here!” A neighbour helped Eunice to go back to school and encouraged her to study up to P6 level (penultimate year of primary school). When starting the last year of primary school, further teachers forced her to leave saying she wasn’t supposed to study at that school. This made Eunice believe that people with albinism could only go to special schools and that they weren’t considered to be human like others. On leaving the primary school, Eunice’s mother suggested she visit her father, who lived ten kilometres away, to see if he would support her ongoing education. When Eunice met her father for the first time since her birth, ‘…he told me he doesn’t educate the girls and that’s where I ended my education.’

When Eunice was ill as a child, only one nurse would treat her at the health centre and there was a great reluctance to give her injections. Eunice’s mother said ‘You end up asking yourself the kind of a child you produced. I don’t know why they were behaving like that but again am not surprised because even her father ran away from her.’

Zabina says she stopped blaming her husband for throwing them out because he was young at the time and Eunice was their first born child. As Eunice grew up ‘…he realized that if he got a problem, the child could help him out with some money.’ Eunice agrees that ‘My father has now started to love me; since I started working, He even sometimes invites me to his home.’

Eunice and her mother continue to live difficult lives because of people’s attitudes towards them. Zabina says ‘When albinos join community groups, they are merely members. Eunice can write but no one can accept her to be the secretary...because of her colour. If you’re elected as a treasurer, they say “the ghost will lose our money”.’

Zabina goes on to say ‘The community puts us in a lot of fear due to the demand for the albino hair…One time someone brought one hundred thousand Uganda shillings [about 25 Euros] trying to exchange it with hair; they later started asking for my hair. I also shave at home because they think if they fail to get hair of my child, mine also has blessings as of my child…We refused to receive money in exchange for our child’s hair because we are not sure what would happen afterwards.’

Eunice has occasionally been offered money by traders in order ‘to be the first people to buy from their business. We are so important to them, but they don’t want to produce us, but they want our body parts.’ Equally, ‘some traders think that if you start by selling to a person with albinism, you can’t get customers.’

Even Zabina is superstitious and uncertain about Eunice’s condition: ‘I always hear persons with albinism don’t die but just disappear. I have never seen a grave of an albino nor a dead body of an albino. I gave birth to her but am not sure whether she will just disappear.'

Eunice says the father of her child 'had no problem' with the fact that she has albinism. 'We discussed and loved each other.'

However, when the community realized she was pregnant '…people would wonder how a handsome man like him would love a girl like me. After producing my child, his family members didn't visit me in the hospital yet they were near. They were saying the child isn't theirs claiming that no one can produce an albino. The boy ran just because he feared to be charged for defilement. He came back when the child is grown up [older] and whenever he moves with the child, some people ask him, "Is that Eunice's son? You're so courageous to produce with that ghost!" They tell him, he will be rich but I don't see his richness; I wonder when he will get rich. We are planning to get another child.'

Case study in Uganda: Peter Ogik (National Chairperson for Youth and Disability in Uganda- NUDIPU)

It was a big shock to my parents, giving birth to a pale child. In fact, they feared, but with time they strengthened themselves and also in the community after my birth most of their (parent's) friends distanced themselves; they did not want to come close. People my Dad did business with, they stopped;

stopped fishing with him. Even some relatives of my Mum stopped coming to our family and stopped inviting her (with me) to visit them. They thought it was a curse. But my parents were God fearing people and God helped them and they loved me as I was.

I went to school on the island, aged around 6-7. The pupils didn't want to share with me their seats as their parents were the ones to tell them that I was a curse. So most of them feared to sit with me. Most teachers did not recognise that I am short sighted so they used to put me at the back of the class. Whenever teachers gives work on the blackboard because I couldn't see very well, I ended up missing it and then this results into punishments by canes saying that I am stubborn and don't respect them.

I was always number 1-5 among 150 students around 7 years of age. This started to be my breakthrough as most of the students who feared me (before) they started coming closer as they come to ask for help with their work- 'help me so that I could do it correctly'. Slowly by slowly I started getting friends. Other kids saw that the others are started to be close to me and nothing was happening to them, then they also started coming closer to me.

[A] Pastor from the Pentecostal church came to me and asked why I was alone not playing with fellow children, I explained to him my situation, He said: 'Peter don't worry'. He opened a Bible and read to me - 'You are created in the image of God; God loves you so much'. He read out the book of Genesis chapter 1 vs 26-27. 'You are formed in God's image so don't feel miserable'. He became my best friend. Dad also gave me a positive word- he would say you are going to make it in this world. It gave me also more confidence.

[Peter was elected as head prefect] This gave me courage to start to considering myself not as a curse but as someone who can deliver services to fellow students.

Some Ugandans believe that parents of a children with albinism also have the same powers, so they are also at risk (of attack). One was killed; and those who murdered him faced charges in courts of law. The witchdoctor directly confronted this parent, "sell us your child, we can give us any amount you want". He said, "no I cannot give you my child". After knowing their plan to kidnap her 3year old daughter with albinism, he took his family away from that village for their safety and he came back to protect his home and also to go on with his dairy activities. So within few days the witchdoctor came with some people who helped in killing. The following day community members found him Slaughtered and the blood was in a bucket and it was also spread around his banana plantation beside his house. His head was missing, the reaming body was buried.

I joined the university- became the prime minister- The 2nd head of the student body in the university. Kampala University-I studied social work and social administration. To educate people- course helps to show how to teach people and to advocate for the rights for people. It gave me more skills. Aims and objective was to show people that pwa can also study- to show they can do everything, to change the perception of people towards albinism.

And also to inspire more person with albinism know that can study up to university level and make dream a reality met with Fazira (a woman who is herself blind and advocates for the rights of those with disabilities)- met with other people living with disability in Jinja-through= her power she helped us mobilise pwa in different districts. We came together to form SNUPA- good connection with Fazira as she had all the contacts. Within 3 years of SNUPA the whole country had known the work of SUPA, through social media, conferences. Our work was vibrant so when it came to general election for a new leader for youth of persons with disability I was among the delegates. I thought-Why don't I try; I can do something. I can do this for SNUPA; I think I can do this for the whole youth. I contested to become the Chair.

[Peter has an adopted daughter]. She was abandoned by the father when the wife gave birth; first of all the clan members to this man said you have to chase away this lady. I took her to my Mum to take care of her; she had good experience of taking care of pwa. She grew up, around 5 years I took her to school and she is studying. So I am with her. The mother comes and visit her or calls her- it is her baby.

I live in threat due to the fears and attempts of kidnaps (that) happened to me personally; currently where I live it is surrounded with a built fence brick and at the top glass. With a big padlock on the door; it becomes hard for anyone to enter in. I am also living with my brother and sister and one sister has a daughter, they are living in my home.

Thematic analysis

Tanzania studies - *Overview*

Thematic analysis of the data collected with people with, and parents of, people with albinism (PWA) identified a number of key themes that run through the accounts. Most prominent in the talk is the large amount of *discrimination* that PWA endure. The main form that this discrimination takes is through marginalisation and isolation, where PWA are excluded from partaking in normal activities (such as shared eating and drinking). Discrimination from family members is also an important part of this, with family members and in-laws excluding PWA from family life. The rejection of PWA from fathers (often accusing the mothers of babies with albinism of infidelity) is another serious form of discrimination. Other discrimination comes in the form of bullying at school and in the workplace, and the omnipresent risk of abduction, the taking of body parts and murder. Discrimination is not just limited to PWA but there is also a sense of discrimination by association, where family members and other community members avoid PWA to avoid vicarious stigma.

Findings

The analysis of the interviews and focus group discussions have highlighted a range of factors that influence the lives of people with albinism across their lifespan. These factors have been organised into the following life stages:

1. Birth and young years
2. Education
3. Work and careers
4. Relationships
5. Thanks to God
6. Integration into society.

1. Birth and young years

The first of these life stages is birth and the early years of people with albinism. It has been shown that the support of parents is crucial for a good start in life, but that many fathers and, very rarely, mothers abandon children with albinism when they are born, which means that these children start their lives with additional challenges.

Support of parents and family is crucial

The support of parents (and often grandparents) is often shown to be of extreme importance to people with albinism. In cases where there is good support, people with albinism have stronger and happier starts to their life.

Children with albinism being abandoned

However, despite the importance of family for children with albinism, there are many accounts of children being abandoned by parents either on their birth, or on the news that their mothers have become pregnant. Examples of being ***abandoned on birth,*** usually (but not only) by the father.

Mothers were abandoned on becoming pregnant:

While it is shown that children can be abandoned at birth, it is also the case that women with albinism are often left as soon as they become pregnant, as they are expected to give birth to a child with albinism.

2. Education

Access to education is shown to be key for a successful and safe career, but there are also barriers to successful schooling. Where teachers and friends are supportive, people with albinism are able to succeed in schools.

These barriers to education include:
*Teachers not supporting people with albinism
*Discrimination from other pupils, which can end schooling for some children with albinism
*The distance to school can be too far, which can make the journey risky.

3. Work and careers

Working and having a career is an important life stage. For people with albinism this can be complex. A key concern is that they **cannot safely work outside** because of the dangers of being in direct sunshine. This is why education is presented as important because it can offer a way out of these jobs.

Discrimination in the workplace

People with albinism are also shown to be discriminated against, both in terms of being overlooked for work because their albinism, and then in the workplace, if they are given jobs, often through being avoided by potential customers. Discrimination is therefore a barrier to work and a contributor to economic hardship for people with albinism.

Financial issues are a problem. Many people with albinism live in poverty. This is often caused by the lack of having a job, which is often a direct result of discrimination in school or the workplace.

Economic status. Due to the cycle of deprivation people with albinism face, economic status becomes particularly important. Better economic status can make the lives of people with albinism less difficult. For example, people with albinism with more money are likely to find it easier to marry. Economic and individual empowerment are therefore necessary for people with albinism.

4. Relationships

While there is evidence that people with albinism can form successful relationships, there are also barriers. It will be shown that there can be opposition to marrying someone with albinism from the family of the person without albinism, but that the (potential) partners of people with albinism show courage and strength of character to overcome this opposition, often at great personal expense. Where children with albinism are born, accusations of infidelity on the part of the mother can be made, which are problematic. However, it can be seen that albinism isn't enough to prevent good relationships.

Opposition to marriage from family of partners without albinism yet partners show courage and strong minds to overcome the discrimination that challenges relationships between people with and without albinism

Despite the opposition to people without albinism forming relationships with people with albinism, these partners show courage and determination, often at their own expense, to overcome the discrimination that they face together. This also shows that discrimination towards people who associate with people with albinism also exists.

The role of gender

There is a clear disparity across gender, with women more likely to take the burden for albinism than men. It is often the case that mothers are left to care for children with albinism along, which can mean that these children face financial hardships from birth. It also appears to be the case that men with albinism find it easier to marry than women with albinism do.

Accusations of infidelity on having children with albinism

Mothers who give birth to babies can be falsely accused of infidelity with a person with albinism.

5. Thanks to God

In these examples God can be seen as a source of support and worthy of gratitude for helping PWA through difficulties in their lives.

God’s plan/will

6. Integration into society

There are factors that prevent successful integration, including high levels of discrimination, often taking the form of stigma from others, isolation, the fear of violence, and prejudice to those who associate with people with albinism. However, participants also presented a strong sense of improving attitudes towards people with albinism, which is often attributed to successful awareness campaigns and challenging myths about albinism, where understanding albinism and knowing that people with albinism are just like everybody is used to explain a reduction in prejudice.

Fear of violence

One major barrier to integration for people with albinism is the threat of violence towards them. This threat is made more real through the reports of actual cases of violence against people with albinism.

Discrimination towards people with albinism

There is discrimination to people with albinism more broadly; including by being isolated and avoided by others, prejudice towards those who associate with people with albinism (even if they don’t have albinism themselves).

Isolation

People with albinism often find themselves unable to interact and integrate with people without albinism. In some cases, this isolation is a result of other people avoiding those with albinism, but in other cases this is self (or parent) imposed isolation to avoid the dangers associated with having albinism.

Prejudice to those who associate with people with albinism

The prejudice towards people with albinism can also affect those without albinism, but who have family members or associate with people that do have albinism. This leads to the further isolation of people with albinism.

Sense of improving attitudes towards people with albinism

There is a strong sense of improvement, in terms of better attitudes, and therefore a reducing in violence and discrimination towards people with albinism. Much of this improvement is attributed to the work of the government and NGO.

People with albinism normal people.

This idea works to challenge discrimination against people with albinism and further demonstrate the improving attitudes towards them.

People with albinism need to accept and appreciate themselves

This idea comes from both people with and without albinism and develops from the suggestion that people with albinism are normal and like people without albinism.

The Importance of challenging myths about albinism

Here it is suggested that a lack of awareness and understanding of albinism is a major cause of discrimination and other problems for people with albinism.

The role of Government and NGO awareness campaigns

Government and NGO campaigns are praised because they are viewed as the main reason for the improvement in attitudes that are so important for people with albinism.

The Importance of support groups

In addition to their successful campaigning roles, both Standing Voice and NELICO are praised for their work supporting people with albinism to integrate into society. This shows that their work is appreciated and is deemed to be effective.

Case study in Tanzania: sixteen year old male.

The story of a sixteen year old male with albinism

"I am 16 years old and studying in Geita Secondary school. I was the only child and unfortunately, I lost my parents when I was still young at the age of 12 in a car accident. When I came home I had TZS. 100,000 in my pocket and despite contributed some little amount to support us at home I spared TZS. 70,000 which I used to buy 20 small chicks from within the village and decided to keep them for commercial purposes; Four months later, in December (festive season); I sold each chicken at 15,000. I raised TZS. 300,000 from selling and co incidentally the results were released the same month and passed my exams. At my friend's place, where I was staying immediately after my father's death, they were doing the same business and I loved the idea and decided to replicate it.

I am still running the same business to date. During my school holidays, I buy so many chicks I vaccinate them and sell the big ones. You can't believe, I raised up to TZS. 700,000 last December and I can provide for my grandfather and pay all my academic expenses including pocket money. I did not like the fact that raising me would be expensive enough for my parents to decline giving birth to another child and that is why I was motivated to be self-reliant. Had it not been for the TZS. 100,000 I received from friends as condolence in my parents' burial, I doubt if I would have been this way. Exposure is very important because by staying at my friends place I was exposed to the outside world where I learnt how to generate funds I would like to urge everyone to treat persons with Albinism with all the due dignity and respect. Give them jobs in places of work which will make them interactive. I Urge all the parents with children born with Albinism to allow them play, interact with the rest of the children be in school."

Case study in Tanzania: Martha's story– 49 year old woman with albinism living in Geita District

When asked for her consent to tell her story Martha replied:
'*it should be loud and clear in your transcripts*'.

Martha is a leader, she belongs to two women's group in her locality; she is Chair of one and Secretary of another. Leads a group of more than 30 women and she is the only one with albinism. It is to do with recognition of her skills and leadership potential. She can speak for herself and for others.

NELCO Researcher on this project.

Photo credit: Carrie Bradbury-Jones

Attempted abduction

Martha gave an account of an attempted abduction in 2011.

She usually went out to the collect firewood with her neighbours but on this day they were not available to go, so she went on alone. She was in a remote area when she heard motorbikes and people calling ‘*we have found her’*. At this time motorbikes were very rare, so seeing two men with a motorbike alerted her to the possibility of danger. The men were wearing black hats, one had a long raincoat, and they were carrying a big bag, which made her scared.

The men with the motorbike started with a normal greeting, then one approached her and tried to ‘*seduce*’ her while the other went to the side to make a phone call, She heard him asking someone ‘*to hurry up, come quickly’,* giving directions to their location. When she heard the phone conversation she realised it was not safe and started to move; when they asked her where she was going she said she was going to collect some fire wood she had cut on the other side, and that she would be back soon.

She *‘played a trick on them to escape’* – she left her machete, headscarf and pieces of firewood and went off –they said “*I can help you*” – she said no, and went far, so they could not see her. She ran to the tarmac, going through the bush rather than along the path. There she met two cattle herders, one adult and one young boy, who knew her. Before she met them she heard several motorbikes – perhaps searching the surrounding area. The cattle herder said if he had more men he would attack the men on motorbikes, but he did not, so would help by going to get her things and leaving the child with the cattle. Martha had wounds on her legs from running through the bush. At the tarmac she saw the two men and the motorbike and recognised them.

After that she was too afraid to go to collect firewood or work in the fields.

Community response to the attempted abduction

Martha reported this incident to local leaders and had a meeting with them, when she was told to stay within her residential area, to make sure she was not out of her homestead after 6 pm, to prepare dinner before 7 pm and stay indoors thereafter. After meeting the Ward Executive Officer, they convened meetings in the evening to educate the community to ensure the safety of people with albinism.

She felt the efforts made by the Ward Executive Officer and community after her attempted abduction were done with the best intentions to protect her, but they included blocking the windows of her house with bricks and leaving only a small hole for the air to come in. She has a chest problem and had difficulty sleeping in the airless house and had to keep going outside at night to get air. So in the end she removed the bricks and continued as before, removing the bricks from the window spaces (which would then be left open).

While acknowledging that the community had positive intentions in helping her, she felt that that was not the route to good security. The community should instead have been watchful and ready to question strangers, and be alert, rather than placing the onus on her. The community response to people with albinism was that they should be protected through isolation, remaining in their homesteads; but in Martha’s view this was not a truly progressive community response.

Martha thought initiatives must be developed that enable people with albinism to continue interacting with their community while remaining safe and secure but free and non-restricted.

Earning a living: farming, mining, milling?

The place where Martha farms is far away; after the attempted abduction she was told by the Ward Executive Officer never to go far from her home, so she cannot do farming to get income; the type of work she can do is restricted. Martha feels she needs to be close to others when doing any activities.

At the moment (2017) she is not employed; she has a new house in the compound where she lives. The bricks were made by her children (three children aged 16, 14 and 9) and the iron sheets for the roof were provided by a local well wisher, a relative from the paternal side, who has herds of cattle. For the construction of the house Martha used funds paid as expenses when she attended a workshop at NELICO and received an allowance. She used this to pay a *fundi* to build the house. The children work during school holidays – one of the children is running a small business selling groundnuts, selling locally in the area.

So her question was: '*how can they (people with albinism) win their daily living?"*'

Martha recounted a story of one attempt to get a job in a rice mill, which would have provided a regular, indoor occupation for her:

When a friend asked Martha what she was doing for employment, she replied 'nothing'. Martha's friend was working in a rice milling machine and knew there was a vacancy. Martha went with her friend to ask the boss of the rice mill about this opportunity. He responded that she could not be employed because part of the role was to take the harvested rice and place it in the milling machine; they thought that with the nature of her skin she could not perform such work although Martha was confident that she was perfectly capable of doing this simple task. The perception in this case was not linked to physical strength. It resulted from a general misperception that a person with albinism is not capable of anything. It would have been an advantageous position for her but she was denied it because of her albinism.

Due to the security fears those with albinism have to move around every day and find jobs within their residential areas (though there are few such opportunities) rather than going further afield, and plead a lot with the people to access those jobs. This is a very hard process, which is why they keep on '*crying day after day to the government to see how they can find a lasting solution*'. She said now (November) is the farming season, so she has to move around and look for piece work.

Mining is the most important economic activity in this area, but people with albinism cannot go mining- '*they will be presenting themselves as a gift'*, i.e. it would be dangerous for them to work there. Martha has not seen one person with albinism working in the small mines; when asked if she would be willing to work in the small mines if she could, she replied no. What about the big Geita Gold mine? She was not sure about that because she had never experienced it.

Many people work in these small mines. But they are in very remote areas, which is a security risk and they are exposed to the sun when working. Men go to Geita Gold Mine to pick the remains of the rocks that have been blasted. The women do the further processing of these rocks in the hills, in the open mines. This involves breaking the rocks into smaller pieces which can then be put into a crusher. There are possibilities there for women to find work, but none of them are available to those with albinism.

She felt the need to build capacity to explore alternative ways of income; in the past she did farming and she also had a poultry business, but that was destroyed by disease. So now she feels like a beggar – she has to ask her family for help when she has no food.

In November 2017 she said the situation was:

1.) they still live in fear, scared of moving too far from residential areas which restricts their freedom of movement;

2.) employers are scared to give employment because they will be held responsible if anything happens to a person with albinism-so they are not giving them small jobs like going to help in the *Shamba* (cultivated field), or any job at all – on small gold mines, helping construct buildings by making bricks and carrying materials etc .

Despite this, Martha was positive about recent changes in this gold mining area – the number of killings were down and things have improved but they (people with albinism) still live in fear.

Local policing in rural Tanzania (information from NELICO researchers): There is a local militia (called the *Sungusungu*) who are local vigilante groups who respond to any calls from the community about a stranger or anything suspicious in their area and investigate. Anyone can call or go in person to report to the Ward Executive Officer. Martha would like these groups to step up security for those with albinism. She believes security should be a local responsibility.

In some ways the data from Geita was less negative than the previous set, especially with regards to the '*no problems'* theme, but the level of fear was extremely high and the case of the women who was attacked as her child with albinism was kidnapped, and then murdered, represents the worst case of discrimination in the data.

Challenges

The SNUPA team have experienced a steep learning curve in developing effective research techniques. Peter and Fazira's understanding and skills in facilitating the activities have grown significantly over the first few months of the project, as demonstrated by the contrast between the information generated by the pilot FGDs and the FGD in Kaliro. It is important that Peter and/or Fazira are involved in all the remaining FGDs and that these opportunities are used to continue building the capacity and confidence of the SNUPA district representatives involved.

Translation and transcription is a time-consuming process and can be particularly arduous for people with albinism, and accompanying visual impairment. The translation and transcription activities had a faltering start, but steps have been taken which has vastly improved the process. The SNUPA team have a trusted, knowledgeable translator to support them in this.

Successes

The SNUPA leaders and research team are highly motivated and committed to this project. The fact that they are all affected by albinism or disability (Fazira does not have albinism but is blind) and are not professional researchers has enabled them to establish a comfortable atmosphere of mutual trust when meeting with FGD participants and other stakeholders. Peter, a man with albinism who has experienced many challenges in his life and is passionate about the potential this research has to change people's lives for the better, is able to help participants feel they are united in a positive process with potential to bring change and hope.

The research activities are enabling SNUPA to become known and to interact with new people with albinism, which in turn means they are able to offer support as needed, including protection from skin cancer. People with albinism who were marginalised and isolated are now feeling that they are valued and having their voices heard as a result of participation in this research. They have a new sense of solidarity and friendship with their peers. It is vital that the project continues to have similar tangible outcomes for those taking part in the research.

Conclusion

This project has been highly successful in building the confidence and capacity of both research team and producing the initial research material. It has also helped to unify people with albinism as they freely communicate their experiences in the hope of improving life opportunities for those who share their condition, both nationally and internationally.

Peter Ogik sums up the prevailing attitude in his response to Simon's thematic analysis of the Kaliro FGD:

'*Many thanks for this good work! I am so pleased with the analysis you have made in that focus group discussion. I strongly believe the final findings will make a big impact in influence good policies, help PWAs feel safe, accepted and included with in their communities and in the whole region. More thanks to all the team in this research'*.

The SNUPA Committee and FIRAH Research Team. Fazira Kawuma and Peter Ogik are far right.

6. Recommendations
What we can do about the impact of stigma on the lives of people with albinism

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_ Implementing the Research Recommendations

Research participants were open and generous in sharing their experiences with the SNUPA team and hope that the research will lead to practical and tangible outcomes to improve their lives. The recommendations were launched at the conference 'We are Human Too!' on 24th November 2017 at the Africana Hotel, Kampala, during which stakeholders had the opportunity to reflect on their roles in implementing them. The quotes featured in this report are from the research respondents.

Hadiija, grandmother of a young child with albinism told us: I would request to help us implement our views. I request what we have shared be worked on and implemented.

Recommendations 1. Birth & Family

Stakeholders including Ministry of Health to:

1.1 Include albinism in the curriculum for training midwives and other healthcare professionals with responsibility for childbirth and early childhood care.

1.2 Equip traditional birth attendants and village health teams with knowledge about albinism.

1.3 Provide counselling and simple information to families with new-borns with albinism about how to care for their child.

Amina (mother of child with albinism): When I was producing that child, the nurse saw the child coming out and shouted, "What's this lady producing!" I almost ran off the bed but decided to be strong.

Lydia (mother of child with albinism): …the father of the child has never surfaced ever since I delivered, I look after the child myself.

Sharik (teenage boy with albinism): *I faced many challenges since my day one, I am told that when my mother gave birth to me like this, they told my daddy that your wife has produced an albino so he also told the grandfather, he was so annoyed. He called the community members...then said "I have called you here to witness when am sending this son of mine with his curse away from my home," while referring to me being a curse in a family.*

Hasifa (woman with albinism): *I started doing some small business to support my children since the husband had abandoned me and had stopped supporting my children. My brothers and sisters couldn't interact with me in family matters, they distanced themselves from me and I remained alone.*

Isa (father of children with albinism): *On giving birth to my first born with albinism, people who came to see me scared me a lot; asking me why I gave birth to such a child…Some people encouraged me while others advised me to chase the wife but I kept on refusing since I love my wife. My wife later gave birth to the second child without albinism, so I continued being strong. After a year she gave birth to twins and both with albinism, so people again were shocked and stressed I should chase my wife.*

Sherry (woman without albinism): *A mother gives birth to a child with albinism and the parents separate because the father of this child keeps saying the woman has the genes to produce albinism but the truth is both parents must be carriers so that they can produce a person with albinism.*

Wilberforce (man with albinism*): Giving birth to a person with albinism is hereditary; the mother and the father must have the gene of albinism. It's not as a result of laughing at a person with albinism.*

Amina (mother of child with albinism): *Many people misunderstand albinism; they always tell us after giving birth to children with albinism, "You have to do some ritual ceremonies to be cleaned from that curse."*

Elizabeth (woman with albinism, a mother of a child without albinism): Said her mother was too scared because of the words people used to talk that "she has given birth to a ghost", "she's a misfortune", "a pig", so she really never felt well about that.

Moses (father of boy with albinism): After getting that child, I got shocked because by then, there was no other child like that on the entire village…community members always said I gave birth to lubaale [a ghost]. After getting him, I took him to hospital, the doctors told me the child has no problem but his genes brought that colour.

Peter (man with albinism): *My parents were God fearing people and God helped them and they loved me as I was.*

Julius (Equal Opportunities Commission): You might see the person [with albinism] isolated or on other occasions students surrounding this one, because, they see he or she is very different. Surrounding them all the time because, it's like a sport. So that really affects them; but save for those who have been born and bred in home that give them space, gives them opportunity to exercise their potential, those families where father, mother and siblings who tell them that they are not different from them. You will find a few like that who have grown and they are very assertive; you find a few of those.

Recommendations 2. Education

Stakeholders including Ministry of Education to:

2.1 Train teachers in the educational, health and social needs of children with albinism.

2.2 Include albinism in school science syllabus to help children understand the condition.

2.3 Promote existing booklets and information on albinism to inform and raise awareness of the condition.

2.4 Allow pupils with albinism to wear sun protective clothing including long-sleeved uniform, sunglasses and wide-brimmed hats as part of their national school policy.

2.5 Allow extra time for learners with visual impairment (including children with albinism) to undertake tests and examinations as part of their national school policy.

2.6 Produce educational materials including text books and exam papers in larger print, to benefit pupils with visual impairment.

2.7 Liaise with parents and the entire community to protect the safety of children with albinism walking to school through security measures including 'walk to school peer groups'.

Paul (man with albinism talking about his experience at school): *Then some students were fearing me. They could fear sitting with me on the same seat, sharing things with me but there was one teacher...He could tell them "he is like you regardless of the colour" and he helped me well to study…I still remember that guy though he died. He encouraged me that though you're different in the colour, we shall be with you.*

Betty (teenage girl with albinism): *Now when I could drink water in a cup my fellow pupils couldn't use the same cup again, if I eat food they could restrict them from using the same plate.*

Sharik (teenager with albinism): The Headmaster strongly told my daddy that they will not allow me in school, rather he should look for albino school or any other schools. My daddy was stranded and one of the teachers felt sorry for us and told the Headmaster "Mr. Headmaster, why don't you allow this boy to study, he is also a human like us?"

John (man with albinism) When I was at school, many children used to run away from me and they feared me a lot. They couldn't eat with me, they could just throw me food or eat and leave for me the remains.

Eunice (woman with albinism): *We had a teacher who used to chase me out of class whenever I entered; saying "you're not supposed to be here", one day she beat me and chased me out of class.*

Fred (Religious leader, without albinism): *[People with albinism] face a number of challenges, one, most of them are short sighted, so they…can't clearly see on the blackboard. Two, they are discriminated; some children tease them. Some of the children with albinism feel out of place while at* *school, they lose self-confidence because their fellow children don't involve them in their activities.*

Joel (father of two children with albinism): *The teacher also called the boy weird names like a ghost.*

Paul (teenage boy with albinism): *In our communities, most the of schools are primary and the secondary schools are few…This forced us to look for those schools where they are of long distance from our homes, yet I fear to move alone early in the morning because of much threat attached to albinism condition - and at the end of the day you reach late and you are punished.*

Betty (teenage girl with albinism): *I am a day scholar, ever since my Daddy lost his job...Long distance from school to home… I was walking one day going to school then I heard a whispering sound saying "She is there, catch her, I will trap her this side". I started to run away but in the process of running away, I knocked myself and fell down, this was due to short sightedness. With God's mercy they did not see where I had fallen...I reported to my Dad but he was like "what can we do now my daughter? There is no way. God must just help us with such situations".*

Recommendations 3. Health

Stakeholders including Ministry of Health to:

3.1 Include albinism in the training of all health care professionals.

3.2 Include the specific needs of people with albinism within the national Minimum Health Care Package (MHCP), with national budget allocation for high SPF sunscreen and low vision aids.

3.3 Include the needs of people with albinism in the state cancer policy. This should include making cryotherapy available across the country to treat early stage cancers and ensuring that hospital equipment is working and increasing the number of dermatologists nationally.

3.4 Co-operate with the Uganda Revenue Authority to continue tax and duty waiver on sunscreen imports for people with albinism and ensure this agreement is long-term.

3.5 Endorse and support in-country production of high SPF sunscreen.

Emma (woman with albinism) The biggest challenge we face in our lives; the sun affects us, it affects our eyes, the skin.

Latifu (teenage boy with albinism): With hot sunshine my skin went bad with many wounds.

Paul (man with albinism): If it's farming, I cannot over stay in sunshine the way other people do, actually it can cause skin cancer to me. Actually if I go to dig at 7am, I take 2 hours, I make sure at 9:00 am, I'm leaving the garden.

Julius (Equal Opportunities Commission, without albinism): *they have continuous challenges of the skin, and not wanting to be under the hot sun and then wanting the sun glasses of course, and the lotions that are supposed to protect their bodies against the sun.*

Joseph (Country Director ADD International-Uganda , without albinism): So the government I think needs to do some more, maybe providing tax waivers and incentives to organisations that make cosmetic products in Uganda to begin to manufacture those protective gear that people with albinism need (such as sunscreen).

Sherry (woman without albinism): *Their skin is not good when they live under the sunshine. So I learnt that persons with albinism all the time must be under the shade so that their skin is protected well and they must put on long sleeved clothes so that the sun doesn't heat them hard especially the skins. They must put on wide brimmed hats such that their skins around the neck, the ears are protected.*

Paul (teenage boy with albinism): I had a problem of short sight. … I think short sightedness has caused a lot of deterioration towards my education. Sometimes teachers can draw on a chalk board to show an experiment, but due to short sightedness, this made (me) to perform poorly in such subjects.'

Ngobi Manson(Dermatology officer and medical school lecturer: They [the Medical School] never had that in the syllabus….I gave them some tips on albinism and am spreading it to some other medical students. Otherwise it's not in their syllabus.

Councillor representing persons with disabilities in local government: In the hospitals, once, the nurse feared to inject one of the boys with albinism. About three nurses kept on asking each other how they would inject the boy. His father called me and told me the whole story. When I reached them I told them that the only difference with the albinos is that their skins are somewhat hard. But if you're a real nurse, just go on injecting them.

Recommendations 4. Justice, Security & Public Awareness

Stakeholders including relevant Ugandan Government Ministries to:

4.1 Issue an immediate, high-profile statement expressing determination to ensure that the perpetrators of acts of violence against persons with albinism are brought to justice.

4.2 Review legal and regulatory frameworks to ensure they encompass all aspects of attacks against persons with albinism, including in relation to witchcraft and traditional medicine.

4.3 Enable victims of attack to access justice. This should include educating persons with albinism on their rights, provision of legal aid, educating law enforcement and judicial professionals on albinism and publicising prosecution to deter offenders.

4.4 Work with organisations of persons with albinism to raise awareness of albinism nationwide, through public information and media campaigns.

4.5 Promote rights of people with albinism through existing provision in the UN's 2013 Resolution on the Rights of Persons with Albinism, the Uganda Constitution, Children's Act and Local Government Act which calls for 'affirmative action in favour of marginalized groups'.

Jamal (father of child with albinism): *On the side of witchdoctors, they surely hunt these people so we must take serious note on this.*

Paul (local councillor): Previously there were accusations that children with albinism are witch hunted, most of the families keep their children with albinism at home. The insecurity around children with albinism is the major problem.

Fred (religious leader): *People just suspect and want to use body parts of persons with albinism for traditional practices but…those people are the same as I am.*

Julius (Equal Opportunities Commission): *We came up with communicational manual which we gave a title, "No magic, no witchcraft, just albinism"… People think that their condition is contagious, others (that it) involves witchcraft…some think that their body portions have magic in them that they can possibly bring more wealth and that is appalling.*

Gertrude (journalist*): I learnt from a family of five children (with albinism)…that they were having sleepless nights because bad people wanted to steal these children and sacrifice them and get body parts. They are lied to that these body parts have magical powers to give wealth, to help you become important in society and all these things.*

Peter (man with albinism): *They are also at risk [*family members of people with albinism]*…The witchdoctor directly confronted this parent, "sell us your child, we can give any amount you want". He said, "No I cannot give you my child". After knowing their plan to kidnap his 3 year old daughter with albinism, he took his family away from that village for their safety and he came back to protect his home and also to go on with his activities. So within few days the witchdoctor came with some people who helped in killing. The following day community members found him slaughtered and the blood was in a bucket and it was also spread around his banana plantation beside his house. His head was missing, the remaining body was buried.*

Joel (father of children with albinism): A traditional practitioner came to my home...My wife came and told me someone wants the hair of my children…He was giving me 30,000 Uganda shillings in return for the hair. I reported the issue to police and he escaped as the police tried to chase him...I was willing to invest anything to see justice prevail…It's a pity some policemen don't *intervene in such issues. I didn’t get annoyed because he [the traditional practitioner] wanted my child’s hair but because he instilled fear in my child.*

Sherry (woman without albinism): *These men would just use them and leave them there with a myth that when you have sex with an albino person, you get rid of HIV…this has caused the young girls to get HIV and have unwanted pregnancies.*

Gertrude (journalist): I met girls who had been raped and defiled. Young girls living with albinism because their tormenters think they have magical powers, if they sleep with them, they would probably get cured of HIV, they will get rich.

Fred (religious leader): *I urge the community to love these people, we produce them, we marry them and produce children with them, we keep them, so they need to be cared for. We need to love them as we love the rest of the people because if we don’t stop the isolation, we have cases to answer before God…Some people segregate and we really want to tell people in our country that God created everyone in his own image and all people created no matter how he/she looks, is an image of God.*

Adam (religious leader): *I started understanding the cause. I realised they lack melanin but I knew in my understanding that they are normal people, only lacking that pigment. So it’s only the colour of the skin that differs. … . In Islam, one with albinism is not different from other people.*

Sherry (woman without albinism): The difference is the skin, not anything else. They have an upright mind, they have feelings like any other person…Secondly, parents of children with albinism please treat the children the way they are because these children are like any other children in the community, love them.

Recommendations 5. Employment

Stakeholders including relevant Ugandan Government Ministries to:

5.1 Promote access to employment for people with albinism, including accommodating their need for indoor work and access to disability grants, in line with the Government’s goal ‘To ensure that all Ugandans enjoy better standards of living, especially the disadvantaged and vulnerable groups’.

5.2 Take legal action under the Persons with Disabilities Act when employers discriminate against persons with albinism.

5.3 Ensure that persons with albinism have equal access to economic empowerment and social protection programmes such as the Uganda Women Entrepreneurship Programme, the Uganda Youth Livelihood Programme, the Disability Special Grant, and the national health insurance scheme. This should include disseminating information through organisations of persons with albinism, training employers and

officials on the rights of persons with albinism and monitoring representation of persons with albinism.

Gertrude (journalist without albinism): *People living with albinism live in so much poverty. People don't give them jobs because they think you (PWA) cannot work. It's not true.*

Elizabeth (woman with albinism): The biggest challenge I have faced is most albinos never got the chance to go to school and it means they don't have good jobs or white collar jobs.

Peter (man with albinism): People with albinism often lack opportunities to take part in economic activities on an equal basis with other Ugandans, because of frequent discrimination from employers and others in the local economy. Many live in poverty.

Emma (friend of person with albinism): *Discrimination at work place, like once there was a school we went with John [who has albinism] seeking for a job. I told one of trustees of the school about my friend with all qualifications needed for teaching and I was allowed to come along with him. On reaching we found her and she asked "Is this the person you have been telling us that you have? Do you want to scare our children? We won't accept him, rather look for someone else."*

RECOMMENDATIONS FROM TANZANIA

Drawn up by Standing Voice with input from the NELICO team and support in the field from Dr Patricia Lund of Coventry University. These recommendations were contributed by members of the Tanzania Albinism Society (TAS), with local government input.

Below we have compiled key recommendations presented to the research team by research participants present at the dissemination events in November 2017. These participants primarily consist of TAS members in Geita and Ukerewe, our two research locations, as well as local government.

Recommendations are categorised by recurrent theme for clarity and practical application. Namely:

- **Implementing progressive polices and laws Promoting access to education**
- **Promoting access to health services**
- **Promoting financial stability and employment Promoting security**
- **Building awareness**
- **Promoting political inclusion and legal capacity**
- **Improving sustainability and future planning**

In addition, as suggested by TAS members present, we have stratified the intended responders to these recommendations as follows:

- **National government [TIER 1]**

Local government in coalition or collaboration with the community [TIER 2]

People with albinism and their families [TIER 3]

Non-Governmental Organisations (NGOs) [TIER 4]

THEME: Implementing progressive polices and laws:

[TIER 1] National government

Ensure meeting the challenges faced by people with albinism is maintained as a government priority, despite inevitable competing demands on the state. Specifically: policies, laws, and services should be proportionate to the extent of the challenges encountered by citizens who have albinism.

People with albinism should by law obtain free healthcare in Tanzania, and this should translate into properly implemented free healthcare for specific health challenges related to albinism.

THEME: Promoting access to education:

[TIER 1] National government

The Ministry of Education should incorporate albinism awareness programmes into primary and secondary syllabuses.

National government should implement measures to address reported poor rates of school enrolment among children with albinism.

Ministry of Education should promote access to vocational college for people with albinism.

THEME: Promoting access to health services:

[TIER 1] National government

The national government should allocate budget for sun lotion.

Efforts should be made by national government to ensure people with albinism have equal access to mainstream health training and awareness services.

[TIER 2] Local government in coalition or collaboration with the community

Special units for people with albinism should be established in hospitals under the authority of local leaders.

THEME: Promoting financial stability and employment:

[TIER 1] National government

Cash support made available to poor households, such as support administered by the Tanzania Social Action Fund (TASAF), should prioritise people with albinism within these schemes. This prioritisation should not be impeded upon based on the assumption that complimentary NGO support exists for people with albinism.

Consideration at the national level should be given to financial assistance for people with albinism, which may take the form of tax credits or a disability allowance.

[TIER 2] Local government in coalition or collaboration with the community

Local councils should promote access to council loans for people with albinism.

[TIER 3] People with albinism and their families

Communities should assist people with albinism to be visible and active members of their society.

People with albinism should actively seek employment and related ways to achieve and maintain financial stability. It is recommended that people with albinism keep pursuing opportunities even if people attempt to isolate them. Testimony reveals the result is commonly that the individual becomes valued and community acceptance follows.

[ALL TIERS]

People with albinism's access to start-up funds should be promoted, along-side training in financial management.

THEME: Promoting security:

[TIER 2] Local government in coalition or collaboration with the community

Local Government Authorities should promote effective security measures which do not infringe upon the health or wellbeing of people with albinism in their area. Local government initiatives must be developed that enable people with albinism to continue interacting with their community while remaining safe; secure but free and non-restricted.

Local Government Authority security measures should be based upon consultation with people with albinism.

[TIER 3] People with albinism and their families

Community should promote effective security measures which do not infringe upon the health or wellbeing of people with albinism in their area. Community initiatives must be developed that enable people with albinism to continue interacting with their community while remaining safe; secure but free and non-restricted.

THEME: Building awareness:

[TIER 2] Local government in coalition or collaboration with the community

Local government should contribute to awareness-raising ensuring the younger generation are better informed, and that this momentum is built upon over time.

[TIER 3] People with albinism and their families

People with albinism and their families should seek to understand and accept albinism, as a catalyst for shifts in wider community perspectives.

Family members of people with albinism should be educated about albinism when a child with the condition is born, to enhance their own ability to pass this knowledge on to their children and wider community.

It has been effective in some cases for people with albinism to join community groups, which provide entrance points for inclusion in the community.

[ALL TIERS]

All stakeholders should tackle misconceptions, such as that people with albinism have weak skin and therefore cannot do manual tasks.

THEME: Promoting political inclusion and legal capacity: [TIER 2] Local government in coalition or collaboration with the community

- **Ward Councils and Village Councils should ensure there is a committee place reserved for a disabled person, to ensure adequate representation of persons with disabilities in decision-making.**

[TIER 3] People with albinism and their families

- **By people with albinism seeking to be part of regular committee groups, they can be contributing to any issues that are relevant to their lives and therefore achieving social inclusion.**

THEME: Improving sustainability and future planning:

[TIER 1] National government

The government should avoid dependence on NGOs whose future presence cannot be guaranteed.

National government should work progressively with NGOs.

The government should develop its data collection on the population distribution of people with albinism.

[TIER 2] Local government in coalition or collaboration with the community

An accurate record of people with albinism (stratified by gender and location) should be recorded at District and Town levels, with district and town councils responsible for collecting this data on an annual basis. This compliments less regular census data collection.

[TIER 4] Non-Governmental Organisations (NGOs)

Programmes that NGOs implement should be incorporated into national-level government systems.

NGOs should focus their efforts on linking people with albinism to the government, providing people with albinism with direct channels and platforms to address the government.

NGOs should give project feedback to the government, so the government can benefit from findings.

Recommendations on data collection and education

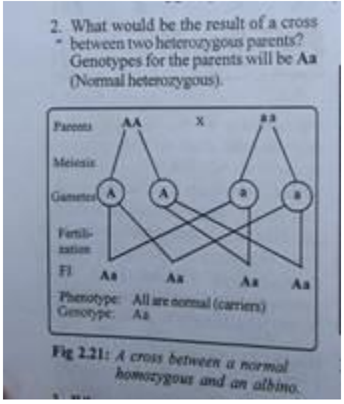
On a visit to a secondary school on Ukerewe Island with the Standing Voice team, with prior approval from the local educational authorities, Lund spoke with the Biology teacher and viewed the Biology syllabus for secondary school (Forms I to IV) of 2005 produced by the Ministry of Education and Culture, The United Republic of Tanzania as well as that for Advanced Secondary Education (Form V-VI) dated 2010. Among the teaching/learning Strategies were a plenary discussion on the various types of genetic disorders which lead to a specific objective that students should be able to explain their causes and effects. An assessment criterion for this objective was *How accurately can the student explain the causes and effects of genetic disorders?*

The worked examples in the supporting handbook included albinism as an example of an inherited, recessive condition, with worked examples showing the possible genotypes of progeny from parents with or without albinism. While largely accurate, these would benefit from revision to present genetic information a more easily accessible fashion and to update the information. For example, this document states '*1/20 000 can be an albino'* which is not true for Tanzania where the census in 2012 data indicate the frequency is about ten fold higher than this.

The explanation about albinism is clear and concise, with minor inaccuracies as shown from the quote below. It is good to indicate this is a condition that occurs in all animals the phenotype presented with light skin, hair and pink eyes is the appearance of someone with another type of albinism and is not the classic phenotype common in east African populations which is usually characterised by some residual pigment, with hazel or blue (not pink) eyes : *Albinism is the absence of pigmentation in animals and plants. In* (sic) *human albinos are characterised by lack of melanin which is responsible for the dark colour of the skin, hair and iris of the eye. As a result the person (albino) has light skin, white hair and pink eyes. Albinism in an inherited disorder and is cause by a recessive gene.....*

The Tanzanian Ministry of Education and Culture is be applauded for including albinism as a study topic at secondary school. There is evidence from our study that education and awareness about albinism has improved in recent years; this training at secondary school is one of the educational initiatives supporting this change.

Below is an example:



2. What would be the result of a cross between two heterozygous parents? Genotypes for the parents will be **Aa** (Normal heterozygous).

Fig 2.21: *A cross between a normal homozygous and an albino.*

The following recommendations are made to support the learning of albinism in Tanzania:

- To include a simplified version of albinism for younger children so they are introduced to the idea of albinism as an inherited condition early in life
- To introduce suitable teaching aids to support the Children's booklet which has been translated into Swahili and other materials developed as part of this project would provide suitable teaching aid
- To revise the section on albinism on the next revision of these booklets
- To continue to include data gathering on the frequency and distribution of albinism to update the 2012 census data; there is evidence that this is being done at local district and town level in Geita

The project team did not investigate the teaching in schools in Uganda; ideally this topic, of such importance to the region, should be integrated into the biology syllabus of all countries in east Africa.

7. Interventions and outputs

Patricia Lund, Coventry University

A booklet has been produced, containing useful advice for people with albinism. It is called 'Born with Albinism In Africa' and can be accessed here: https://pureportal.coventry.ac.uk/en/publications/born-with-albinism-in-africa Additional drawings were commissioned on this project and added to those available from previous albinism projects at Coventry University. These used images rather than words to get key messages across e.g.

Acceptance by the father of a child with albinism

That babies with albinism can be breast fed in the same way as other babies;

Encouraging the use of visual aids

What is your dream?

Encouraging dreams and aspirations

Interventions initiated as a Result of the Research in Uganda

Jane Betts, Advantage Africa

The ultimate purpose behind this project is to inform the work of government, including health, education, and justice, civil society organisations, media and other stakeholders so that their support to people with albinism is based on sound evidence, is of good quality, offers value for money and achieves high impact. It is also hoped that the research will prompt action from stakeholders who are currently doing little or nothing to address the stigma and exclusion it exposes and so result in new services in currently neglected areas of Uganda.

Recommendations from the research in Uganda will be distributed to 100 key stakeholders at the dissemination event co-hosted by SNUPA and Advantage Africa in Kampala on 24th November 2017. These recommendations, underpinned by evidence from study participants, directly relate to the education and life opportunities available to children and young people with albinism, addressing challenges relating to birth & family, education, health, justice & security and employment. The event will enable stakeholders to reflect on their own role in promoting change, as well as opportunities to start and improve vital services.

During the event, different stakeholder groups (for example health, education, media, NGOs) will have breakout meetings to discuss the recommendations particularly relevant to their sphere of influence and how to achieve them. For example, nurses, dermatologists and Ministry of Health representatives attending might reflect on their respective roles in promoting inclusion of the specific needs of people with albinism within the National Minimum Health Care Package and State Cancer Policy.

Some delegates, such as media, NGO and faith representatives, will have cross-cutting responsibility for promoting all the recommendations. Following the breakout meetings, each delegate will complete an individual pledge form detailing the actions they propose to take and how they intend to develop their engagement and co-operation with other relevant stakeholders. Feedback and pledges from event delegates will enable SNUPA and Advantage Africa to work with representatives of the Ugandan Government to develop a national albinism strategy to realise the research recommendations and other resultant interventions.

ALBINISM ACTIONS for CHANGE

HEALTH

Ministry of Health to include needs of people with albinism within the **national minimum health care package** and **train health workers**

Uganda Revenue Authority to make permanent the **sunscreen tax and duty waiver**

Include the needs of people with albinism in the **State Cancer Policy**

Ministry of Health to endorse local production of **high protection sunscreen**

BIRTH

Provide **simple information and support for families** of new-borns with albinism

Train **midwives** and **other health workers** in albinism awareness

Equip **traditional birth attendants** and **village health teams** with albinism knowledge

EDUCATION

Ministry of Education to train **teachers** in education, health and social issues concerning albinism

Include albinism in school **science syllabus**

Allow learners with albinism to **wear sun protective uniforms**

Safeguard learners with albinism when **walking to / from school**

Provide **visually impaired learners** (inc. those with albinism) with large print materials and more time in examinations

EMPLOYMENT

Promote **employment** for people with albinism, accommodating their visual impairments and need for indoor work

Take action against **employers** who discriminate against people with albinism

Ensure people with albinism have equal access to **economic empowerment** and **social protection programmes**

CAMPAIGNS AND PUBLIC AWARENESS

Work with people with albinism to **raise awareness** of albinism nationwide through public information and media campaigns

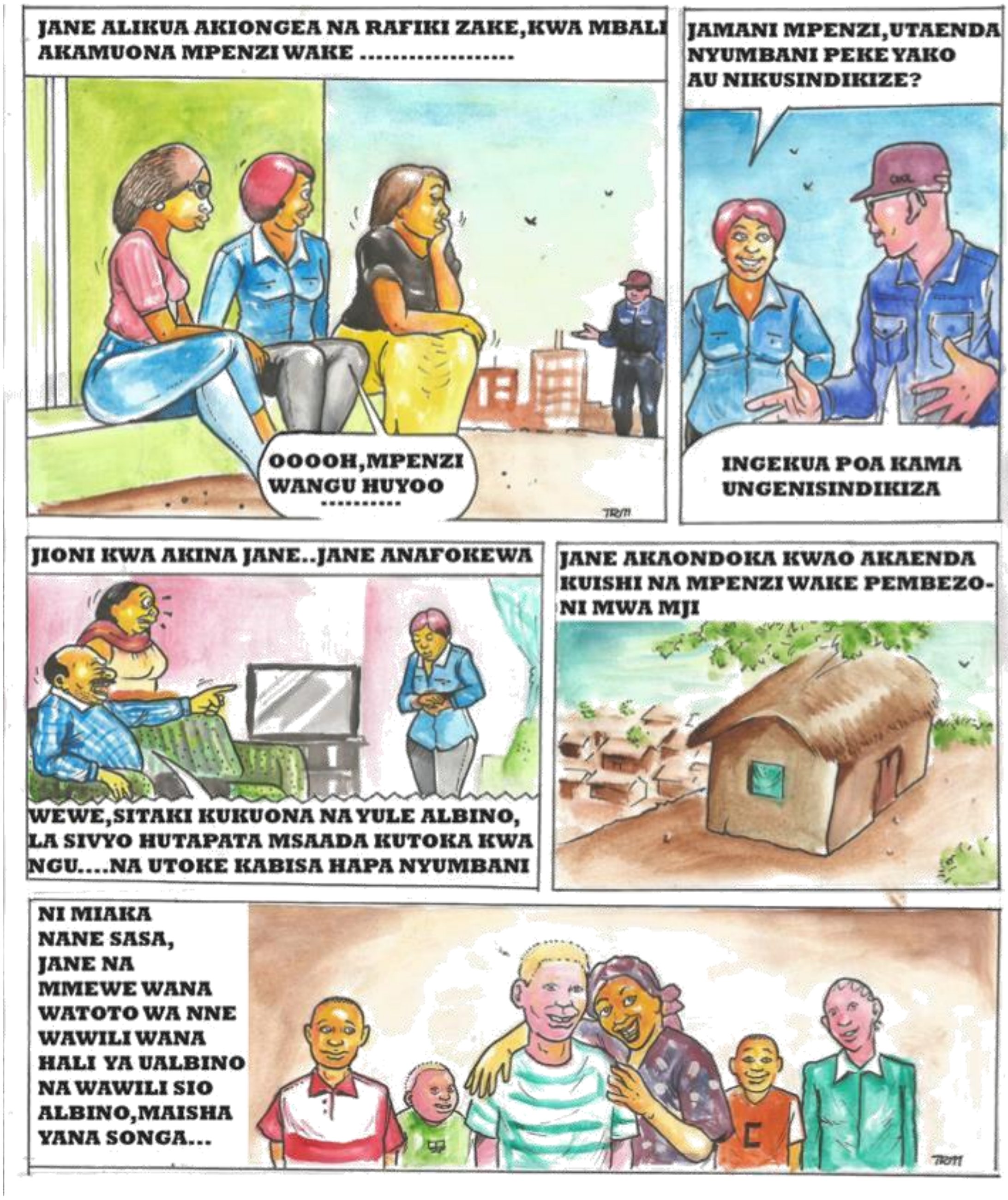
Promote the **rights** of people with albinism with reference to national and international laws and resolutions

SECURITY & JUSTICE

Ugandan Government to state publicly that **perpetrators of violence** against people with albinism will be **brought to justice**

Implement **laws and regulations** relating to violence against people with albinism including in relation to witchcraft and traditional medicine

Enable people with albinism to access justice by provision of **legal aid, training police / judiciary** and **publicising prosecutions**


JANE ALIKUA AKIONGEA NA RAFIKI ZAKE,KWA MBALI AKAMUONA MPENZI WAKE ....
OOOOH,MPENZI WANGU HUYOO ....
TRM
JAMANI MPENZI,UTAENDA NYUMBANI PEKE YAKO AU NIKUSINDIKIZE?
INGEKUA POA KAMA UNGENISINDIKIZA
JIONI KWA AKINA JANE..JANE ANAFOKEWA
WEWE,SITAKI KUKUONA NA YULE ALBINO, LA SIVYO HUTAPATA MSAADA KUTOKA KWA NGU....NA UTOKE KABISA HAPA NYUMBANI
JANE AKAONDOKA KWAO AKAENDA KUISHI NA MPENZI WAKE PEMBEZONI MWA MJI
NI MIAKA NANE SASA, JANE NA MMEWE WANA WATOTO WA NNE WAWILI WANA HALI YA UALBINO NA WAWILI SIO ALBINO,MAISHA YANA SONGA...
TRM


JOHN HAS ALBINISM CONDITION,HE IS WATCHIN- HIS FELLOW STUDENT PLAYING.........
IWISH ICOULD BE LIKE THEM... MAY BE ICAN JOIN THEM..........
HE APROACHED THEM,ASKING IF HE CAN JOIN THEM...
I ALSO CAN PLAY FOOTBALL WELL....CAN I JOIN YOU?
GO AWAY!
THEY ARE REJECTING HIM........
LEAVE US ALONE YOU ALIEN.......
YOU OLD MORON
!
GO AWAY LOSER
THEIR TEACHER SAW EVERYTHING FROM HER OFFICE......................
OH! THAT'S NOT FAIR......... THERE IS GREAT NEED OF TEACHNG THEM ABOUT ALBINISM......... I HOPE THEY WILL CHANGE .. ..
BACK IN THE CLASSROOM.....................
TODAY'S LESSON IS ABOUT ALBINISM....ALBINISM IS NOT CONTAGIOUS DESEASE,THAT IS GENETIC.THE BODY IS LESS ABLE TO PRODUCE MELANIN......
Science.
XY
OOOH, NOW I UNDERSTAND, ITS NOT A CURSE.... ....
AFTER CLASS HOURS,ALL STUDE- ARE NOW INTERESTED TO BEFRIEND JOHN.....................
WE ALL LOVE YOU JOHN....
IAM HAPPY BECAUSE YOU UNDERSTAND MY CONDITION
HEY,WE SHOULD GO INTO THE SHADE TO PLAY......


IT IS MORNING,PEOPLE ARE GOING TO CULTIVATE THEIR FARMS....................
I WANT TO GO OUT TO WORK BUT IAM SCARED TO LEAVE THE CHILD ALONE,MY NEIGHBOURS AND SOME OF MY FAMILY MEMBERS ARE UNTRUSTHWORTHY
ONE DAY SHE GOT A CHANCE TO GO TO HER FARM.....ALL CROPS DIED BECAUSE THERE WERE UNATTENDED FOR A LONG TIME
MY GOD!!!
SHE BROKE DOWN IN TEARS..........
SHE DIDN'T BELIEVE WHAT SHE SAW
THIS IS BECAUSE I WASN'T ABLE TO LEAVE MY DAUGHTER ALONE.... OOOH MY GOD WE WILL BOTH DIE OF HUNGER..............


JEFFY HAS ALBINISM,AND HE WORKS A S ASHOP KEEPER..................
HOW IS HE ALLOWED TO WORK HERE ?....... I CANT BUY FROM HIM..
ITS BAD LUC-KY TO BUY FOOD FROM THAT STALL.
THE OWNER OF THE SHOP TALKS TO JEFFY
JEFFY,YOUR DETERRING CUSTOMERS TO THE STALL................
JEFFY ENDED UP WORKING ON THE FIELD OUTSIDE,AND THE SUN IS BLAZIN OVER-HEAD
THE STALL OWNER FIRED JEFFY
IAM NOT A BAD LUC-K..THIS IS MYTH...... WHAT AM I GOING TO DO?..MY FAMILY DE-PENDS ON ME,...BUT NOW IAM JOBLESS.. THE SUN WILL KILL ME................

Community members at the dissemination event in Ukerewe, discussing the comic strips. Photo credit: Lund, Coventry University

The evidence based comic strips (examples above) generated intense interest and comment; the teams intend to purpose these in several languages for use in multiple media platforms. These will be freely available online for re-use and printing.

Both the Ugandan and Tanzanian team have a vast repository of positive images of people with albinism and their families and friends, which will be loaded on an online site..

A few examples are presented below (Photos, Lund, Coventry University):

A man on Ukerewe enjoying the company of his baby, the latest addition to his family.

There are also images that can be used to give example of simple, practical and low costs means of sun protection, as shown in the images below of a young girl with a locally made wide brimmed hat and a home made cloth flap protecting the neck of a young boy on rural Ukerewe.

8. Appendices

Uganda’s first national conference on albinism

‘We Are Human Too!’

A conference exploring what we can do about the impact of stigma on the lives of people with albinism

Agenda

09:00 Registration

09:30 Welcome and introductions

09:50 Message from Ms. Ikponwosa Ero, UN Independent Expert on Albinism

09:55 Explaining albinism - a genetic condition inherited by chance

10:10 SNUPA and Advantage Africa - improving the lives of people with albinism

10:35 Drama – ‘The Game of Life’ followed by song – ‘Mutuwe Chance’

11:00 Tea break accompanied by entertainment

11:25 Research findings and recommendations

12:25 Responses and pledges from conference participants

13:10 Response from the Guest of Honour

13:30 Lunch and networking

---------------------- *Optional afternoon sessions* ----------------------

14:30 Q & A panel discussion

15:00 ‘Equal Under God’ film

The Game of Life

Four volunteers, ideally two men and two women, representing the following groups:

- women with albinism;
- women without albinism;
- men with albinism;
- men without albinism.

Each volunteer has a role which will be telling a life story, taking the characters on a journey from birth to old age. On reaching each significant life event, they respond according to how their character (or their family) would react. For this version of the Game of Life, we are including direct quotations from the research participants.

The volunteers will need to take:

- two steps forward for a very positive or very successful experience;
- one step forward for a positive or successful experience;
- one step back for a not-so-positive or not-so-successful experience;
- two steps back for a negative or unsuccessful experience.

Set the scene for the story.

Since you want to emphasise links between albinism and stigma, lack of opportunity and poverty, consider placing the story in a typical village. Describe it in as much detail as you can, explaining that many families are quite poor but most have access to land and safe water. For entrepreneurs, opportunities exist in the neighbouring town where there are also health and educational facilities.

To many, this session will dramatically reveal things about their communities which they may never have considered before. It can be fun. Humour can take the edge off the hard facts exposed by the game. But some participants can find it distressing, because it makes plain some painful, personal truths.

Detailed Analysis of Ugandan interviews

Prejudice/discrimination to PWA

Fear of people with albinism (can lead to **isolation**)

Rejection (in-laws, family, parents, forced out of home)
Abandoned by husband/father
    Pressure on husbands and family members to leave PWA
    Partners defying prejudice to stay with people with albinism
Isolation
Fear and threat of attacks (especially kidnapping)
Name calling
Discrimination because of poor eyesight
Including at school – (**problems with teachers and other pupil**s, **isolation**)
Hard to get jobs
Hard to marry
Prevalence of myths (which need ending)
Threat/fear of witchdoctors/traditional practitioners Attempted kidnap
Interest in the hair of PWA, threat of taking it
Including a risk to family members, danger through association
Myths include:
    Sex with PWA can cure HIV
    Laughing at PWA causes others to get it
    Punishment
    PWA don't die, but disappear
    Curse
    PWA a demon
    Ghost
Role of SNUPA (and NGOs)
Gov. support needed
Faith and religious beliefs
PWA made in God's image
PWA normal
School:
    Fear of journey to/from school
    Difficulties from teachers
    Short-sightedness (school difficult)
    Support of friends
Managing health issues (Threat of sun, outdoor work leads to sunburn, threat of skin cancer short-sightedness)

<u>Additional theme from community leaders and journalists</u> The role of poverty

Findings

The analysis of the interviews and focus group discussions have highlighted a range of factors that influence the lives of people with albinism. These factors have been organised into the following areas:

- Prejudice and discrimination
  - The prevalence of myths about people with albinism The role of NGOs
  - The role of god
  - School
- Health

Each of these factors consists of events and experiences that can be seen to affect the lives of people with albinism in positive and negative ways. Throughout this report, examples from the research participants will be presented to illustrate the important experiences that occur for people with albinism.

Prejudice/discrimination to PWA

A major theme of the lives of PWA is the large amount of prejudice and discrimination that they face. Discrimination comes in the form of abandonment from family members and isolation. Other forms of serious discrimination include violence and attacks for body parts to use in witchcraft-related charms believed to bring good fortune and easy wealth. This is turn leads to fear, which also impairs the quality of life for PWA. On top of this, PWA experience bullying. PWA can be discriminated against because of their poor eyesight, especially at school where they may also be isolated. Discrimination also comes in the form of difficulties in getting jobs and in finding partners.

These will be addressed in turn, beginning with discrimination and abandonment from family members.

Rejection from family

A major part of the life experience of PWA is being rejected by those around them, including from very close family members. As a result, PWA come to be abandoned. There is also pressure on partners or parents of PWA to leave their families, all of which can lead to isolation. However, partners of PWA often defy the pressure on them to leave PWA and instead stay by their sides.

Aliba Amwenze Zuraika (mother of two children with albinism): *A miracle happened and I delivered at home; there were many people at home, my brothers and father in-law. My husband’s father asked “what’s that”? The next morning he told his son to chase me. “We have never seen what she has brought to our family. We can’t be with that child; those are problems to our family already.”*

Getrude Tumusiime Uwitware (journalist without albinism): *First of all she [PWA] is a woman that has been rejected by her own husband, the woman who has been rejected by her community because it looks like this is not normal, you cannot have four children who are not 'normal'. … So what I* *found out when I went to the field, from the stories on albinos , they were telling me, "we are being rejected", I knew one, there is rejection and lot of rejection.*

Abandonment from family

One major way this rejection manifests is through the abandonment of PWA by family members. Fathers are seen to leave their children with albinism and their wives on the birth of a child with albinism.

Getrude Tumusiime Uwitware (journalist without albinism): *While as in some areas I found that some children had been abandoned by their own parents, some others have been abandoned by their husbands, some women had been used by men for sexual purposes of thinking they would get wealthy and even just for satisfaction but had dumped them in the end. They tried to get into marriages with them and in the end dumped them because their families refused them or they felt like I cannot be with such a thing, they call them "a thing".*

Nabuba Sherry (coordinator EFPA, albinism foundation, albinism foundation): *A mother gives birth to a child with albinism and the parents separate because the father of this child keeps saying the woman has the genes to produce albinism but the truth is both parents must be carriers so that they can produce a person with albinism. … This man has sex with this girl, the girl gets pregnant, he tells her it's not me. The reason is he is ashamed of relating to be the father of this child from a mother who is an albino. So these children are at a risk or at the hands of the bad people who are the men.*

Pressure on partners or parents of PWA to leave their families

It has now been shown how PWA come to be abandoned. This may be explained by the pressure that is put on partners and parents of PWA to leave their family members who have albinism. However, partners also defy this prejudice.

Isa Matende (parent of child with albinism): *on giving birth to my first born with albinism, people who came to see me scared me a lot; asking me why I gave birth to such a child; but I kept on telling them that it's only God who knows why she gave me such a child. Some people encouraged me while others advised me to chase the wife but I kept on refusing since I love my wife. My wife later gave birth to the second child without albinism, so I continued being strong. After a year she gave birth to twins and both with albinism, so people again were shocked and stressed I should chase my wife.*

Councillor for persons with disabilities (p94): *They always say people produce albinos when they are trying to get riches. A real Samya [people who live around lake] runs away from that lady. Men usually say that if you remain with the lady after producing a child with albinism, she could sacrifice you; you no longer have money; all the riches would shift to the woman's home; you end up being a servant of the woman; men are advised to run from the family. That's why women after producing persons with albinism are suffering a lot. Clan members usually influence the men to run away. Even if the man really* *wants to remain with his family, when the family members tell him "we shall all die if you remain with that woman", they run away.*

Partners defying prejudice to stay with people with albinism

Despite the pressure on partners of people with albinism to leave family with albinism, many partners nevertheless defy this pressure and stay with their loved ones with albinism, despite any difficulties this may create for them. Examples of this can be seen in the following extracts.

Kawala Aminah (a parent of a PWA): *Friends to my husband told him "how dare do you stay with such a woman?, why don't you send her away?", but he would say "why to send her away and for what reason ?, "she is my wife who produced my child"*

Kaggwa Hajira (has albinism, children do not): *we have 4 children 2 girls and 2 boys. We thought we would produce an albino, but so far, all are black. I treasure my husband because he treasures me. I found him with some friends and had money. His friends, told him, is that the kind of wife you got? My husband told me he was willing to leave any friend just to be with me. For sure he left some of his friends.*

Fear of people with albinism, which leads to isolation

One aspect of the prejudice towards PWA is that they are feared by the wider community. This fear takes the form of fear of physical contact Examples of this can be seen in the following quotes. The fear leads to isolation, and therefore the further discrimination of PWA.

Sezibwa Paul (with albinism, treasurer of SNUPA, Primary School Teacher): *Then some students were fearing me. They could fear sitting with me on the same seat, sharing things with me*

Lilian (with albinism): *recently I was looking for a job in a boutique; they directed me to some lady; she looked at me and said she would call us. I knew she only feared to tell us I would scare the clients. When we followed up, she rudely replied to us, "I will call you".*

Isolation

The fear of PWA, coupled with the abandonment, and pressure to abandon them from family members, can contribute to the further isolation of PWA, leading to a cycle of discrimination. Much of this isolation is imposed by others, but the fear of attacks also means that people with albinism may choose to isolate themselves or children with albinism. In addition, others from outside the family avoid PWA, so PWA come to be marginalised, in a serious form of discrimination, as can be seen in the following examples.

Mukasa Emma (Chairperson Albinism Association of greater Masaka): *… Some of our parent's relatives isolate our parents after giving birth to us. … When people see that your colour is different, they isolate you but now, some people have started understanding it. In the past about 10 years back, I would say isolation was 85% but now, it's like 35%.it has reduced.*

Bankyaye Paul (local councillor): *Some friends isolate the children with albinism, they call them offensive names like ghost.*

Fear and threat of attacks

As a result of the attacks against PWA because of an interest in their body parts, PWA, and their family members, live in constant fear of being attacked or kidnapped.

Paul Sezibwa (Treasurer of SNUPA and Primary School Teacher): *someone tried to kidnap me, in 2001 in my primary five, … Good enough there were farmers around who helped me when I shouted. …. And I fear to, …., when somebody over asks me questions* (asks too many questions), *I think he has some goals beyond what he's asking. I fear too much questions because that person who wanted to kidnap me first came to our home and asked my dad a lot of questions.*

Jamal (father of child with albinism): *My wife used to fear to move with the baby, that the human traffickers would snatch from her the baby. Many times we could move together or sometimes I take kid alone for health service.*

Name calling

As part of the wider discrimination that PWA experience, they can also be bullied. This often occurs at school or college, but also in other areas of life.

John (chairman of SNUPA, Kamuli district): *When I joined college, it was worse, they nick named, mistreated me, at night they could come with torch and light on my eyes to see how they twinkle.*

Lugudho Latifu (15-year-old boy with albinism*): In my primary I used to behave very well even though my friends could mock on me. Sometimes advised me to aspire for disciplinary prefect and when I just tried the votes came as if they were just waiting for me. I started leading while I was in primary six up to now where I am the academic prefect in our school.*

Discrimination at school

PWA also experience discrimination and difficulties at school. As can be seen from the previous examples, bullying can be a problem at school. In addition to bullying, PWA often experience problems with their teachers, especially regarding misunderstandings relating to their poor eyesight, which can be interpreted by teachers as being rude. Support from friends, family and teachers can help to overcome this discrimination.

Namwase Betty (17-year-old girl with albinism): *Now when I could drink water in a cup my fellow pupils couldn't use the same cup again, if I eat food they could restrict them from using the same plate, I was ever the 1st or 2nd and could not exceed that.*
The teachers couldn't matter about my sight, they just go with majority I could only consult from friends who can help. Now when it comes to secondary, the teacher don't even bother, worse of it is that now I am a day scholar, ever

since my daddy lost job, money decrease, so I was forced to join day scholars.

Kaggwa Hajira (has albinism, children do not): *At school, teachers were refusing my child to sit in front of the class. I also tried to give the child a long sleeved uniform but the teachers insisted.*

Hard to get jobs

Discrimination towards PWA also means that it is difficult for them to get jobs.

Elizabeth Negesa (Chairperson EFPA): *The biggest challenge I have faced is, most albinos never got the chance to go to school and it means they don't have good jobs or white collar jobs*

Wekulya Samuel (man with albinism): *My situation was not all that bad, there is no job I can't do but some people on looking at our bodies, think we (persons with albinism) are too weak to work.*

Hard to find a partner and to marry

On top of finding it hard to get jobs due to discrimination, PWA also find it difficult to find a partner and therefore to marry. This has already been seen in the rejections PWA find from family members, but also comes in the form of discrimination from potential partners too.

Nabuba Sherry (coordinator EFPA, albinism foundation): *persons with albinism couldn't get married to black people. These men would just use them and leave them there with a myth that when you have sex with an albino person, you get rid of HIV and this has caused a lot of HIV among persons with albinism.*

Agnes (25-year-old with albinism): *In marriage issues, men don't take us albinos seriously, we don't have stable marriages. When a man get you, his family members start the bad feelings on why you were married. Eventually the man abandons you.*

The prevalence and problems of myths and beliefs about PWA

A major feature of the interviews was the prevalence of myths about PWA in Uganda. These myths are viewed as particularly damaging and so need to be challenged. A major feature of the talk about myths is the threat and fear of the witchdoctors and traditional practitioners, and the attempted kidnapping that this can cause. There is also a lot of interest in the hair of PWA, which leads to additional threats for PWA. There are a number of myths related to PWA, which are all discriminatory, including, laughing at PWA causes others to get it, punishment, PWA don't die, but disappear, PWA are viewed as a curse, a demon or a ghost.

Threat/fear of witchdoctors/traditional practitioners

Witchdoctors and traditional practitioners are viewed as instrumental in the trade of the body parts of PWA, and are therefore seen as a major threat, and source of fear, especially regarding the risk of being kidnapped or harmed. This can be seen in the following examples.

Gertrude Tumusiime Uwitware (journalist without albinism): *I learnt from a family of five children living in Buyende that they were having sleepless nights because bad people wanted to steal these children and sacrifice them and get body parts. They are lied to that these body parts have magical powers to give wealth, to help you become important in society and all these things. I learnt also from the field and from what I did with people living with albinism, that so many of people living with albinism live a life in threat, these traditional workers, traditional healers or traditional practitioners have misled people. They tell you go and bring for me body parts, go and bring for me an ear of an albino. And they want to sacrifice for riches. And people have been duped because you know these are very special people and you feel like when we get this part, surely we going to get rich. So people living with albinism, I found out that they are living in a life of threat.*

Agnes (25-year-old with albinism): *One time I was going for church and met a group of people in the corridor. I suspected they were not good people. They asked me to escort them somewhere but I refused telling them I was going to the church. In the end, some person told me they were traditional practitioners.*

Interest in the hair of PWA, threat of taking it

One main aspect of the fear of witchdoctors and traditional practitioners is the specific interest in the hair of PWA, as this is sought after by the witchdoctors. This fear restricts the movement of PWA, especially at night. Isa Matende, who was talking about the fear of witchdoctors in the previous example continues to talk about the risk to hair in the follow example.

Ntambi Joel (father of two children with albinism): *...... a traditional practitioner came to my home. I was busy with my works. My wife came and told me someone wants the hair of my children. My children freely move in town and they don't get any problems. He was giving me 30,000 Uganda shillings in return of the hair. I reported the issue to police and he escaped as the police tried to chase him ... I didn't get annoyed because he wanted my child's hair but because he instilled fear in my child. He no longer wants to go to the saloon alone because of the fear. Some of the children with albinism end up fearing other people because they know people want their hair or to kill them*

Waako Francis (without albinism, parent of child with albinism): *On addition to the lady's words, we are afraid they could cut off our children's hair. We keep in tension always even when our child goes to school. We keep asking ourselves whether the child will come back or not due to the long distance to school.*

Range of myths about albinism

The predominant myth that is of concern to PWA and their family is that their body parts and hair have value to witchdoctors, for use in their charms and rituals. There are additional myths about PWA that were discussed by participants. These myths contribute to the discrimination towards, and isolation of, PWA and demonstrate the general misunderstanding of the genetic cause of albinism.

Having sex with a PWA can cure HIV/AIDS and lead to wealth

There is a myth that sleeping with someone with albinism can heal HIV and provide an easy route to wealth. This appears to affect women more than men, with documented cases of rape of women with albinism.

Sezibwa Paul (treasurer of SNUPA, Primary School Teacher): *others (majority men and some few percentage of females) say that unprotected sex with an albino cures AIDS.*

Laughing at PWA causes others to get it

One of these myths is that albinism can be 'caught' by a parent laughing at someone with albinism earlier in their life. The birth of a baby with albinism is seen as a punishment from God.

Kawnanguza Wilberforce (40-year-old with albinism): *It's good you understood. Giving birth to a person with albinism is hereditary; the mother and the father must have the gene of albinism. It's not as a result of laughing at a person with albinism. Thanks a lot, and we think people will continue to learn and those with negative perceptions will continue to learn and get a different perception.*

PWA don't die, but disappear

Another myth is that rather than dying, PWA disappear. This suggests that they have magical properties.

Charles Kakamwa (Journalist, the head of Vision Group): *Even here in Uganda, those misperceptions (about albinism) are there, we hear people coming up with stories like people with albinism don't die, they just disappear.*

Kawala Aminah (a parent of a PWA): *Again they asked "we are told that albinos don't die but they just disappear, is it true?" I only answered "God is the creator so He knows whatever happens with everyone, I don't know."*

PWA are a curse

PWA can be seen as a curse and a punishment from God. PWA comment on how they cope with this belief.

Obbo Shafik (Bupanga –Luuka, with albinism): *He called the community members, made a party but he told the community members then said "I have called you here to witness when am sending this son of my mine with his curse away from my home," while referring to me being a curse in a family.*

Eunice's mother (Eunice has albinism): *Some people think persons with albinism are a curse; I consider Eunice my daughter.*

PWA can be viewed as demons

PWA are sometimes viewed as demons, not ‘real’ human beings.

Kawanguzi Wilberforce (man with albinism): *The parents gave birth to two of us. My elder sister also had albinism. Previously they considered us demons and on giving birth to my sister, they went to traditional practitioners when she got sick.*

Kigundu Robert (the father to Betty Namwase who has albinism): *when I produced her, many people started to talk about my family that I have produced demon (mujjini) and they hated my home. I wondered and got scared, asking God what should I do? And then later I said God knows what he does, let us don’t over cry.*

PWA as ghosts

PWA are perceived as ghosts by some and called derogatory names such as ‘pig’.

Elizabeth Negesa (Chairperson EFPA): *She was too scared because of the words people used to talk that “she has given birth to a ghost”, “she’s a misfortune”, a pig, so she really never felt well about that.*

Ntambi Joel (father of two children with albinism): *The teacher also called the boy weird names like a ghost.*

Role of SNUPA (and NGOs)

The important role fulfilled by SNUPA in advocacy was mentioned by participants.

Aliba Amwenze Zuraika (mother of two children with albinism): *That’s why I say am proud of SNUPA because what they have done to me, only God will pay back.*

Wekulya Samuel (24-year-old with albinism): *We are now grown up and SNUPA started giving us support when we were in a better situation as compared to other persons with albinism because some persons have poor skins compared to us.*

Government support needed

Many speakers talked about the role of the government, stating that the government could do more to support PWA, particularly financially.

Sezibwa Paul (treasurer of SNUPA, Primary School Teacher): *The government should also make sure find a way of supporting our finance, the way we survive.*

Nabuba Sherry (coordinator EFPA, albinism foundation): *So thanks to the government of Uganda, that they brought the disability grant.*

The role of faith and belief

For many PWA, God is seen as a major source of support and comfort. This is illustrated in the following examples.

Aliba Amwenze Zuraika (mother of two children with albinism): *We were in Kiloba and God made a miracle and I produced Fagir, our second child with albinism.*

Mukasa Emma (Chairperson Albinism Association of greater Masaka, with albinism): *That's the child that God just gives you and he is a person like any other.*

PWA made in God's image

For some, especially religious leaders, the idea that people are made in God's image is used to show that PWA are a positive thing, and are equal to other people.

Peter Ogik (Chairperson of SNUPA, with albinism): *He* (the pastor) *said: 'Peter don't worry'. He opened a Bible and read to me - 'You are created in the image of God; God loves you so much'. He read out the book of Genesis chapter 1 vs 26-27. 'You are formed in God's image so don't feel miserable'. He became my best friend and whenever I met him in the community- he would speak to me positive words such as 'God has a good plan for me'-he read from Jeremiah 29:11.*

Reverend Fred Nabeta (Religious leader, without albinism): *Some people segregate and we really want to tell people in our country that God created everyone in his own image and all people created no matter how he/she looks, is an image of God. … as a spiritual leader, I'll keep telling people that we are all equal , all in the image of God, we must respect each other, help each other, we must work with each other, so that we all move at the same pace and to give glory to God who created us. Remember it's even biblically written that we are images of God. No one should discriminate another.*

PWA are normal human beings with the same potential as others

One challenge to the discrimination that PWA face is the idea that they are not perceived as normal, just like everyone else. This can be seen in the following examples.

Adam Balijja (Religious leader): *I started understanding the cause. I realized they lack melanin but I knew in my understanding that they are normal people, only lacking that pigment. So it's only the colour of the skin that differs. … . In Islam, one with albinism is not different from other people.*

Julius Kamya (Commissioner at Equal Opportunities Commission, without albinism): *I think the myths seriously affect their being, and as you say in your study topic, their ability to access life opportunity. Because with all these myths, these myths do not go, any passing the persons with albinism sees them, hears them. So they grow up knowing they are different and not different for positive reasons but negatively. They grow up knowing they are negatively different and they actually see society rejecting them, or running* *away from them. So that becomes very difficult for them. They cannot associate and play with other children, or retaining in school. Most of the time, two things happen; you might see the person isolated or on other occasions students surrounding this one, because, they see he or she is very different. Surrounding them all the time because, it's like a sport. So that really affects them; but save for those who have been born and bred in home that give them space, gives them opportunity to exercise their potential, those families where father, mother and siblings who tell them that they are not different from them. You will find a few like that who have grown and they are very assertive; you find a few of those.*

At school: overcoming security, social and health problems

School is an important issue for PWA. However, there are barriers, as well as sources of support, to attending school. These include the discrimination, isolation, bullying and problems with teachers, and with short-sightedness, all described above. In addition to this, the fear of the often-long journey to and from school can also be a problem. However, the support of friends at school can work to overcome these problems. Each of these will now be addressed.

Fear of the journey to/from school

One of the main barriers to attending school is the dangers, or the fear of dangers, that may be awaiting PWA on the long journeys to school. This can be seen in the following examples.

Paul Kalili (19-year-old male with albinism): *In our communities, most of schools are primary and the secondary schools are few, the most you can find secondary schools in a sub county is like 2 or 3 schools in a whole sub county. This forced us to look for those schools where they are of long distant from our homes, yet I fear to move alone early in the morning because of much threat attached to albinism condition- and at the end of the day you reach late and* (are) *punished.*

Waako Francis (without albinism, parent of child with albinism): *..... we are afraid they could cut off our children's hair. We keep in tension always even when our child goes to school. We keep asking ourselves whether the child will come back or not due to the long distance to school.*

Support of friends and teachers at school

A key way that the problems with school can be overcome is through the support of friends and teachers at school. Alongside the discrimination and isolation that PWA face, there is also a good amount of support, as illustrated here.

Sezibwa Paul (treasurer of SNUPA, Primary School Teacher): *I cannot remember well but when I went there I remember that teachers had many questions to me. Then some students were fearing me. They could fear sitting with me on the same seat, sharing things with me but there was one teacher called Sajjabi Stanley, he is now deceased. He could tell them "he is like you regardless of the colour" and he helped me well to study, only that the sight was hindering my study because I wasn't seeing well on the board. But that* *teacher helped me in the learning. I still remember that guy though he died. He encouraged me that though you're different in the colour, we shall be with you.*

Nakisozi Daisy (23-year-old with albinism): *Students loved me and I was free to them at school. I had very many friends. I used to sit in front in class and luckily I have never used sun glasses since my childhood. I can at least see on the black board but whenever I failed, my friends helped me out*.

Managing health issues

Health is an important issue for PWA, as reflected in the interviews. In particular, the threat of the sun, and the associated risk of working outdoors was spoken about. Problems of being short sighted were also evident.

Threat of sun and of outdoor work

One major health risk for PWA is the danger of being in the sun, especially in the middle of the day. This is shown to impact on travel to school and the ability to work, so it can have a major impact on the lives of PWA who report various strategies to manage their vulnerability to sun induced skin damage.

Sezibwa Paul (treasurer of SNUPA, Primary School Teacher):*.... if it's farming, I cannot over stay in sunshine the way other people do, actually it can cause skin cancer to me. Actually if I go to dig at 7:00 am, I take 2 hours, I make sure at 9:00 am, am leaving the garden.*

Lugudho Latifu (15-year-old boy with albinism): *With hot sunshine my skin went bad with many wounds.*

Short-sightedness

This has already been shown to be a problem with regards to schooling, where children with albinism are often not supported, but are also often viewed as being difficult, because of their inability to see the blackboard properly. Eye sight problems impact on activities outside of the school setting too, as can be seen in the examples below. The visual impairment associated with albinism is sometimes not recognised.

Nabuba Sherry (coordinator EFPA, albinism foundation): *it seems like persons with albinism apart from the sight, they had more problems than you would think the sighted has. … I also learnt that people with albinism have problems with their sight.*

Paul Kalili (19-year-old male with albinism): *I had a problem of short sight. … I think short sightedness has caused a lot of deterioration towards my education. Sometimes teachers can draw on a chalk board to show an experiment, but due to short sightedness, this made* (me) *to perform poorly in such subjects.*

Additional theme from community leaders and journalists: The role of poverty

The community leaders and journalists pointed to the role of poverty in the lives of PWA. The difficulties with school and work (identified throughout the analysis) can lead to PWA finding themselves in poverty, leading to further hardship.

Gertrude Tumusiime Uwitware (journalist without albinism): *then I realized they live in so much poverty. People living with albinism live in so much poverty down there and these are the people who need good life because they need sunscreen which is not affordable. These are kids who go to the bushes and get pricked by sticks and so on and then their skins are so sensitive. You know, probably they need that too much attention that they need not to go to bushes, they should be in places where there are limited to harm like things that would affect their skins. So for me the poverty and someone actually told me that, "man, why it that people with albinism live in so much poverty", I was like because everyone else has rejected them. People don't give them jobs because they think you (PWA) cannot work. It's not true. I have seen an albino working as a secretary and working really well.*

Abubaker Kirunda (Journalist with Daily Monitor Newspaper): *Now, as far as this is concerned that is fighting poverty as I may sum it, for us, our role as the media; one, we are going to say, people living with albinism have got a deal to begin sensitizing other people living with disability on how they can get out of poverty. And this is going to be some by continuous stories that we shall publish in the newspapers.*

Detailed Analysis of Tanzanian data

The analysis is organised into different stages of life for people with albinism, covering birth and early years, education, work, relationships and integration into society. The analysis demonstrates that life for people with albinism includes many challenges, including abandonment and isolation, discrimination and fear of violence, all on top of the health problems associated with albinism. However, it is also shown that there are major sources of support that can help overcome these challenges. These include the support of family, friends, teachers and partners. There is also a strong sense of improving attitudes towards people with albinism, which is attributed to the work of the government, NELICO and Standing Voice.

Birth and young years: Support of **family** is crucial – many fathers **abandon** children with albinism (men abandon women with albinism on conception, fathers leave partners when a baby with albinism is born)

Education: Access to **education** is key, however there are barriers to education for people with albinism:

- there are problems with **teachers** not supporting PWA and their needs
- There are cases of **discrimination** from other pupils. This discrimination seems to be a key factor in ending schooling, so it's particularly serious
- School can be too far away and **the journey can be risky**

Education is necessary for success and a safe career (i.e. an indoor job, out of the sun)

Work/career: People with albinism cannot safely **work** outside, so a good level of education is needed to avoid these types of job).

- Issues around **health** (need for sunblock etc) and how
- **Discrimination** in the workplace is another potential barrier to work for people with albinism

Financial issues a problem (often because of limited schooling and the resulting inability to work outside)

Economic status

Relationship: There is **opposition to marriage from family of partners without albinism**

- Partners of people with albinism show courage and strong minds to overcome this

The role of gender

- Accusations of infidelity on having children with albinism

Thanks to God

- God as a source of support
- Albinism is part of God's

plan **Integration into society:**

- **Fear of violence** (including actual reports of violence) remains
- There is still much **discrimination**
  - This takes the form of **isolating** people with albinism
  - There is prejudice to people *without* albinism who **associate** with people with albinism
- There is a strong sense of **improving attitudes** towards people with albinism
  - **People with albinism are ‘normal’** people (this is common in the talk of people without albinism in the data)
  - **People with albinism need to accept/appreciate themselves** (not feel inferior) and do more to integrate. This idea comes from both people with and without albinism
- The Importance of challenging myths about albinism is often mentioned
  - Government and NGO **awareness** campaigns are praised and are viewed as the main reason for the improvement in attitudes.
- The importance of **support groups**: Standing Voice and NELICO is described

Findings

The analysis of the interviews and focus group discussions have highlighted a range of factors that influence the lives of people with albinism across their lifespan. These factors have been organised into the following life stages:

1. Birth and young years
2. Education
3. Work and careers
4. Relationships
5. Thanks to God
6. Integration into society.

Each of these stages consists of events and experiences that can be seen to affect the lives of people with albinism in positive and negative ways. Throughout this report, examples from the research participants will be presented to illustrate the important experiences that occur at the different life stages.

Birth and young years

The first of these life stages is birth and the early years of people with albinism. It has been shown that the support of parents is crucial for a good start in life, but that many fathers and, very rarely, mothers abandon children with albinism when they are born, which means that these children start their lives with additional challenges.

Support of parents and family is crucial

The support of parents (and often grandparents) is often shown to be of extreme importance to people with albinism. In cases where there is good support, people with albinism have stronger and happier starts to their life. Examples of this include:

(29-year-old man with albinism and the father of the family; he is also the newly elected chairman to TAS Geita District): *First I would like to thank God for instilling confidence in me throughout my school life without forgetting my lovely parents who constantly encouraged me to keep going in spite of the challenges*.

Children with albinism being abandoned

However, despite the importance of family for children with albinism, there are many accounts of children being abandoned by parents either on their birth, or on the news that their mothers have become pregnant. Examples of being ***abandoned on birth,*** usually (but not only) by the father, include:

(29-year-old mother without albinism): *The problem is that her husband decided to abandon her with the baby because of albinism*.

Mothers were abandoned on becoming pregnant:

While it is shown that children can be abandoned at birth, it is also the case that women with albinism are often left as soon as they become pregnant, as they are expected to give birth to a child with albinism.

(53-year-old, with albinism, has three children all without albinism): *My husband abandoned me immediately I told him that I was pregnant with his baby.*

Education

The next key life stage for children is education. Access to education is shown to be key for a successful and safe career, but there are also barriers to successful schooling. Where teachers and friends are supportive, people with albinism are able to succeed in schools.

The importance of access to education is described first.

(15-year-old with albinism)*: without education in Tanzania you cannot be employed*

Barriers to education

However, there are many barriers to education which can prevent people with albinism from succeeding in education and therefore from gaining the opportunity to work indoors, which is so important for the safety and prosperity of people with albinism.

These barriers to education include:
*Teachers not supporting people with albinism

*Discrimination from other pupils, which can end schooling for some children with albinism
*The distance to school can be too far, which can make the journey risky.

These barriers will now be addressed in turn

Teachers not supporting people with albinism

(17-year-old with albinism)*: I am not schooling and to be open with you it is the teachers who made me feel fed up with school. They are not cooperative at all, they see me as a burden and without education in our country you cannot be employed.*

Discrimination from other pupils

As well as facing discrimination from teachers, children with albinism also face further discrimination from other pupils at school. This often comes in the form of isolation and bullying from the other children.

(13-year-old with albinism)*: I am 13 years old and I am a class 7 drop out. My experience is quite different from[another participants']. I grew up in a rural Ward and people used to call me names like zeru zeru (abusive name to mean albino) and I was not pleased with that even at school, my fellow pupils would call me names would not interact with me since they feared contacting albinism … for me it was different because I had neighbors all over, I was living in a small center in fact and as you know center are always highly populated. So, I had both strange and familiar faces around me, and to be honest I found myself out of school because of this hostility.*

The journey to school is too far

Whilst discrimination from teachers and other pupils is a major barrier for children with albinism, so too is the journey to school, where there is the dual risk of being in direct sunshine for a long time and the threat of violence and abduction:

(53-year-old, with albinism, has three children all without albinism): *As a matter of fact, school was very far from home. I could not just afford to go because it involved a lot of walking on the scorching sun.*

Education as key to success and safe career

Despite these serious barriers to education, it is nevertheless viewed as a very important way to assure that people with albinism can have a successful career, and importantly as a way to avoid outdoor work, which brings with it the risks of being in the sun.

(47-year-old with albinism): *I have a dream of having my own business that will enable me to generate income that I will use so as to ensure my child is raised well, without facing any kind of discrimination, by ensuring he is eating* *well, dressing well, sleeping well, having good health, having good education and heaven living peacefully without any threats or becoming a beggar*.

Work and careers

Working and having a career is an important life stage. For people with albinism this can be complex. A key concern is that they **cannot safely work outside** because of the dangers of being in direct sunshine. This is why, in the previous section, education is presented as important because it can offer a way out of these jobs. In addition to this, discrimination in the workplace represents a further barrier to working. Because of this, financial problems are a major concern for people with albinism. Loans are presented as a solution to this problem, and are shown to be successful. These issues are presented in detail below.

Work and health

(48-year-old with albinism): *Cannot deeply get involved in the commercial agriculture because of the dangers of skin cancer those results from harmful sun rays.*

Discrimination in the workplace

People with albinism are also shown to be discriminated against, both in terms of being overlooked for work because their albinism, and then in the workplace, if they are given jobs, often through being avoided by potential customers. Discrimination is therefore a barrier to work and a contributor to economic hardship for people with albinism.

(20-year-old without albinism, step brother to someone who has albinism): *[stepbrother] used to look for job, sometimes we used to look for a job together, but the issue was that we were always unsuccessful because of his albinism and most employers claimed that he is weak and cannot deliver.*

Financial issues are a problem. Many people with albinism live in poverty. This is often caused by the lack of having a job, which is often a direct result of discrimination in school or the workplace. This can be seen in the previous quote and in the following example:

(38-year-old without albinism): *[people with albinism have a] poor education level that may cause them not to have knowledge and skills so as to get employment, hence affecting the person from right to an adequate living standard hence poverty*

Economic status: Like anyone, economic status is of importance to people with albinism. However, due to the cycle of deprivation that they face, as a result of the pattern of repeat rejections they experience, economic status becomes particularly important. Better economic status can make the lives of people with albinism less difficult. For example, people with albinism with more money are likely to find it easier to marry. Economic and individual empowerment are therefore necessary for people with albinism. Increased finances can therefore offer an end to the cycle of deprivation and a safer lifestyle (including not having to work in the sun). For this reason, loans are shown to be desired by people with albinism:

(48-year-old with albinism): *What I want to ask is for the government to help us in the area of reducing segregation, but above all is the issue of economic empowerment. Cannot deeply get involved in the commercial agriculture because of the dangers of skin cancer those results from harmful sun rays. The government should start giving us small loans so that we can start running our own businesses.*

Relationships

As well as education and careers, developing successful relationships and marriages are an important life stage for people with albinism. However, while there is evidence that people with albinism can form successful relationships, there are also barriers. It will be shown that there can be opposition to marrying someone with albinism from the family of the person without albinism, but that the (potential) partners of people with albinism show courage and strength of character to overcome this opposition, often at great personal expense. Where children with albinism are born, accusations of infidelity on the part of the mother can be made, which are problematic. However, it can be seen that albinism isn't enough to prevent good relationships.

Opposition to marriage from family of partners without albinism

(23-year-old without albinism, married to someone who has albinism): *When I was in the process of being married for example, some people were blaming me for my decision to get married to [husband] because he is living with albinism, some would even advise me to change my decision.*

Partners show courage and strong minds to overcome the discrimination that challenges relationships between people with and without albinism

Despite the opposition to people without albinism forming relationships with people with albinism, these partners show courage and determination, often at their own expense, to overcome the discrimination that they face together. This also shows that discrimination towards people who associate with people with albinism also exists.

(23-year-old without albinism, married to someone who has albinism): *But for me I considered him as a normal human being; honestly, I love my husband and I have realized that I do care about all people with disability… it didn't cost me too much time or energy to resist the external pressure because honestly from my heart, I loved [husband] and they were telling me nothing new that I have never heard people say. I could not just afford to turn his marriage proposal down just because he is living with albinism.*

The role of gender

There is a clear disparity across gender. It can be seen that women are more likely to take the burden for albinism than men. As shown above, it is overwhelmingly fathers that abandon wives (or women with albinism) on their becoming pregnant or giving birth to a child with albinism. It is therefore often the case that mothers are left to care for children with albinism along, which can mean that these children face financial hardships from birth. It also appears to be the case that men with albinism find it easier to marry than women with albinism do. This can be seen in the following examples. The first, shows how a man with albinism is married to a woman without albinism, whereas the second shows a woman with albinism who is unable to find a man to marry her because her albinism.

(31-year-old with albinism): *Honestly the situation has changed. In the past, we people with albinism could not find a wife/ husband to marry, but now the situation is different; you can see people with albinism marrying/getting married to people without. For example, I am married to a woman without albinism with two children.*

Accusations of infidelity on having children with albinism

Because of misunderstandings surrounding how children come to be born with albinism, mothers who give birth to babies can be falsely accused of infidelity with a person with albinism. These accusations work to remove any responsibility from the father for the child’s albinism.

(32-year-old without albinism, neighbour to people with albinism): *On my side it was a normal thing, but there were a lot of words that people were talking about this family that were not good at all especially when they were saying that the woman was dating a person with albinism because she gave birth to a child with albinism.*

Thanks to God

In these examples God can be seen as a source of support and worthy of gratitude for helping PWA through difficulties in their lives.

(29-year-old man with albinism and the father of the family; a member in the TAS Geita District): *First of all I would thank God that I have a family which am proud of, the community be honest did not expect this type marriage to happen but I thank God it happened, since every journey must start from a single step, I am happy that the community can now see that such kind of marriages do work. … honestly speaking as an individual, I did not notice anything but my wife kept telling me that her friends would question her decision to get married to me but thank God I have a strong woman who can defend me and her decision in my presence or absence. … I would like to thank God for the continued for this golden opportunity, I have been able to air out my views and I believe that together with other people’s with we will one* *day yield fruits of this research, secondly I want to very much thank the sponsors of this research because I believe they might have decided to invest their money in other areas but they opted for this research especially in Geita may God bless them.*

God’s plan/will

(16-year-old with albinism): *It is by the Grace of our Almighty God that has granted us the breath of life that’s why we are still alive other factors are upon us we human being such as understanding the situation that I have knowing how to take care of myself including eating well and dressing properly.*

Integration into society

Another important aspect of the life experiences of people with albinism is the extent to which they are able to fully integrate into society. There are factors that prevent successful integration, including high levels of discrimination, often taking the form of stigma from others, isolation, the fear of violence, and prejudice to those who associate with people with albinism. However, participants also presented a strong sense of improving attitudes towards people with albinism, which is often attributed to successful awareness campaigns and challenging myths about albinism, where understanding albinism and knowing that people with albinism are just like everybody is used to explain a reduction in prejudice. It is shown that to aid integration, people with albinism need to accept themselves. Each of these issues is now addressed in turn.

Fear of violence

One major barrier to integration for people with albinism is the threat of violence towards them. This threat is made more real through the reports of actual cases of violence against people with albinism. This impacts people with albinism widely, as it can prevent them from travelling, which can make going to school or work very difficult. This fear is addressed next.

(32-year-old, with albinism): *To this extent that I have reached it’s by the God’s Grace that I have attained this age. Because of the life threats and the reports that we have been hearing concerning the killing of our fellow people with albinism, some being chopped their body parts being discriminated. Actually, I have been staying without having peace. For instance, I used to work on other people’s farms as a cheap laborer but currently I cannot go any more to the farms fearing to be invaded by the people who are hunting us so now days I just stay as a house wife just looking after the family while my husband is the one who keeps going out to job so that we can at least afford to have our meals. The only issue that makes my life to be difficult is the discrimination that people are showing me especially when I visit a different place away from our village actually we are treated differently as if we are not human being.*

Discrimination towards people with albinism

In addition to the threat of violence, there is a large amount of further discrimination directed towards people with albinism. This can be seen in the previous sections on schooling, where children experience discrimination from both teachers and pupils, on relationships, where people are opposed to marriages involving people with albinism and the section on work, where people with albinism are also discriminated against. In the following section, it will be shown that there is also discrimination to people with albinism more broadly; including by being isolated and avoided by others, prejudice towards those who associate with people with albinism (even if they don't have albinism themselves).

(32-year-old without albinism): *it is true discrimination in our community to people with albinism still exists whereby they are impeded from accessing adequate services such as in getting health care, social services, legal services and redressing rights abuses.*

Isolation

Isolation remains a major part of the discrimination faced by people with albinism, who often find themselves unable to interact and integrate with people without albinism. In some cases, this isolation is a result of other people avoiding those with albinism, but in other cases this is self (or parent) imposed isolation to avoid the dangers associated with having albinism.

(53-year-old, with albinism, has three children all without albinism): *Yeah sure, I have a lot of experience but unfortunately its predominantly negative; to start with my childhood, I was born the only child in our family with albinism and it was the best times for me. At first, I was asking myself why I was different from others I did not get any answers until I got content with myself. Things were not that smooth on my side because people did not want to associate themselves with me. Some would call me names like zeruzeru (an abusive Swahili word which means albino). During those times school was not an option like these days so I did not go to school. In the recent past the main challenge has been killings of people with albinism. We are being hunted like animals and this has instilled fear in us (people with albinism).*

Prejudice to those who associate with people with albinism

The prejudice towards people with albinism can also affect those without albinism, but who have family members or associate with people that do have albinism. This vicarious discrimination leads to the further isolation of people with albinism and means that people without albinism also face discrimination simply by interacting or being related to people with albinism.

(without albinism): *I have no child with albinism but two years back I stayed with a housemaid with albinism. But despite that I am a parent that means I feel responsible for all children irrespective of their conditions and back grounds. About this house maid (with albinism) I witnessed a lot of awkward behaviors from my friends' visitors and neighbors during the time I was* *staying with this lady. My friends could not even drink a glass of water at my place leave alone eating.*

Sense of improving attitudes towards people with albinism

While there is clearly a high level of discrimination towards people with albinism, it is also the case that there is a strong sense of improvement, in terms of better attitudes, and therefore a reducing in violence and discrimination towards people with albinism. Much of this improvement is attributed to the work of the government and NGOs, especially Standing Voice and NELICO.

(60-year-old without albinism, grandmother to child with albinism): *In the past, I used to hear about people with albinism. I was also told that my family background, we had people with albinism but they disappeared I did not stay close with them, for now I have not heard anything bad or good about my granddaughter Mariam. I think things are okay with the way she is growing up or may be because she is still young but generally I am happy with my family and my neighbors. I don't see any kind of discrimination from my friends or neighbors.*

People with albinism normal people.

The idea that people with albinism are no different from people without albinism is commonly referred to, especially (but not only) by people without albinism. This idea works to challenge discrimination against people with albinism and further demonstrate the improving attitudes towards them.

(21-year-old, with two children, one with and another without albinism): *I just saw it as a normal thing because so they are the same like us without albinism. Since it is my parents who taught me that people with albinism are similar to us, despite their skin difference, so we should not be afraid of them and stigmatize them. I have three children the eldest is 16, the second is seven and the youngest is four years old. They don't stay with us they are staying with their grandmother in Mwanza.*

People with albinism need to accept and appreciate themselves

Following on from the suggestion that people with albinism are normal people, and in the context of improving attitudes towards them, it is suggested that people with albinism need to do more themselves to integrate. This idea comes from both people with and without albinism and develops from the suggestion that people with albinism are normal and like people without albinism. However, this does deny the imposed isolation that people with albinism face.

(30-year-old with albinism): *Self-acceptance is also very important. We people with albinism have the tendency of isolating ourselves from other people and this can also be a contributing factor in terms of the community's* *perception towards people with albinism. It takes self-acceptance to gain community acceptance.*

The Importance of challenging myths about albinism

Here it is suggested that a lack of awareness and understanding of albinism is a major cause of discrimination and other problems for people with albinism. However, improving understanding of issues surrounding albinism, and how it is simply a lack of skin pigment, is shown to reduce problems for people with albinism. It will be shown later that government awareness schemes are praised for increasing awareness, but that also some people feel that still more needs to be done to increase this.

(32-year-old without albinism from a village): *Among the factors for sustainability is that the community is educated and at least they are aware of albinism situation. The deadly Myths on killing of people with albinism is slowly perishing. This has led to the decrease in discrimination level towards people with albinism. This is a good signal that humanity has been restored since people with albinism can now interact and collaborate together with people not having albinism such as in work places, sports even eating together and this makes them to feel as part of the community and making them to sustain in life.*

The role of Government and NGO awareness campaigns

Government and NGO campaigns are praised because they are viewed as the main reason for the improvement in attitudes that are so important for people with albinism. It is therefore shown that this strategy is considered to be very effective, and that more of these are needed to improve their success.

Esther Peter (28-year-old without albinism): *The other issue is that, due to the government intervention it has enabled people with albinism to be respected, such as in our District people with albinism have their association and they have gone into an extent of having a very beautiful centre here in Nansio. This makes them to be respected because they usually organize events and invite all people, and through this is when we get the knowledge on sopping all myths and discrimination to people with albinism.*

The Importance of support groups

In addition to their successful campaigning roles, both Standing Voice and NELICO are praised for their work supporting people with albinism to integrate into society. This shows that their work is appreciated and is deemed to be effective.

These first example shows praise for ***Standing Voice***

(57-year-old with albinism): *The presence of standing voice in Ukerewe has added value to all the Tanzania Albino Society (TAS) members. The community tends to respect people with albinism in Ukerewe because through*

Standing Voice organization people from Europe and many others from big institutions visit them.

This final example shows praise for ***NELICO***

(16-year-old with albinism): *I would like to urge everyone to treat persons with Albinism with all the due dignity and respect. Give them jobs in places of work which will make them interactive. I urge all the parents with children born with Albinism to allow them play, interact with the rest of the children be in school. I would also like to use this platform in sensitizing people with disabilities and especially persons living with Albinism on what, how they can use their skills and talents so as to bring change and total transformation in our society and the whole world at large. Thank you to NELICO on behalf the project funders for coming up with such a reproductive research that I very much anticipate will bring some change in the life of people with albinism.*

Scientific Summary
An investigation into the impact of stigma on the education and life opportunities available to children and young people with albinism in Tanzania and Uganda

Patricia Lund and Simon Goodman, Coventry University

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Albinism in Africa

Children in African communities born with oculocutaneous albinism look significantly different to their peers due to the lack of melanin pigment in their hair, skin and eyes – leading to light coloured hair, blue/hazel eyes and pale skin which is very sensitive to the damaging effects of the sun. Albinism also affects eyesight including involuntary nystagmus, photophobia, poor depth perception, strabismus (squint), poor visual acuity and refractive errors.

Oculocutaneous albinism is an inherited condition which, if not understood or managed correctly, can have significant health and social impacts on the lives of those affected. These impacts are particularly acute in regions of the world where myths and superstitions surrounding the condition can lead to stigmatisation, discrimination, rejection, misconception, and, in some cases, violent assault and murder.

This study was conducted at a time of danger as those with albinism in parts of Africa are targeted for their body parts, from hair to whole limbs, for use in witchcraft-related rituals and charms. These are mistakenly believed to bring easy wealth and good fortune. Issues of albinism in Africa are steeped in negativity and much has been written in both national and international media reports about the attacks on people with albinism and the challenges they face in Africa, both in terms of their personal security and health, with a significant risk of developing skin cancer. In the context of these attacks on those with albinism, this project aimed to document, in a positive way, the innovative and practical ways in which those with albinism navigate the many challenges they face in accessing appropriate health, education and welfare services. This fills a crucial gap in our understanding and provides the evidence base to inform interventions by both governmental and non-governmental agencies.

Foreword from stakeholders
Uganda
Jane Betts, Advantage Africa

The Ugandan element of this research was facilitated by the Source of the Nile Union of Persons with Albinism (SNUPA) working in partnership with Advantage Africa. SNUPA is a Ugandan non-governmental organisation formed in 2012, by and for persons with albinism in Busoga sub-region and its neighbouring districts. SNUPA aims to change attitudes and improve life for people with albinism and their families. Advantage Africa is a UK-based non-governmental organisation founded in 2002 which supports people affected by poverty, disability and HIV in East Africa. In 2013, SNUPA and Advantage Africa began working together to help people with albinism to stay safe from cancer, attend school, earn an income and overcome discrimination and lack of opportunity.

SNUPA's team, composed of grassroots outreach workers relatively new to research, undertook intensive training at the start of this project in order to develop effective facilitation and interview techniques. This training and subsequent sessions to monitor the research's progress provided invaluable benefits in confidence and team-building. Through the focus group discussions, the SNUPA team have worked closely with people with albinism and their families in eight communities in the Busoga region of eastern Uganda. The fact that all but one of the team have albinism themselves, and that they are not professional researchers, has enabled them to establish a comfortable, mutually trusting atmosphere when meeting with participants. SNUPA team leader Peter Ogik in particular has helped participants feel valued and part of a unified, positive process to bring change in the lives of people with albinism.

The people who took part in the discussions told SNUPA how much they appreciated the opportunity to tell their stories and meet with others in similar circumstances. Many had previously felt isolated and marginalised, but discovered a shared sense of purpose and friendship with their peers. The participants across the region shared their experiences with generosity and openness. SNUPA and Advantage Africa will ensure that their contribution continues to be valued and they are fully included in the ongoing dissemination process.

The research's wide regional scope has enabled SNUPA to interact with new people with albinism. Therefore, alongside the research activities, SNUPA has been able to offer practical support as needed, including protection from skin cancer. All SNUPA and Advantage Africa team members have been highly motivated and committed throughout this project, driven by the goal of developing evidence-based recommendations and tools to improve the lives of people with albinism. The team will harness the enthusiasm and engagement of all stakeholders involved over the course of the project to widely disseminate these results and ensure the recommendations are implemented.

Tanzania
Jon Beale, Standing Voice

This research project has revealed fundamental learnings for achieving social change, learnings which have been illustrated by people with albinism and their communities in response to identified social challenges. It is perhaps with these learnings in the forefront of our minds that we should consider the research findings, in a bid to ensure we achieve tangible impact.
One of pronounced demonstrations of the research is the far-reaching constellation of individuals who define the life experience of people with albinism. This constellation consists of local, national and international

stakeholders – ranging from family members and neighbours to key influencers in multi-lateral agencies. Understanding the importance of this social constellation is key to comprehending how we must collectively apply these research findings. The transcript material demonstrates the impact of an individual being surrounded by a supportive network of individuals, with them at the centre. Crucially the research participants emphasize repeatedly how it is the person at the centre of this constellation who has the most impact on how these surrounding people effect the present moment and future social reality of the individual. Both people with and without albinism who participated in FGDs and interviews demonstrated how the sphere of influence of an individual with the condition was far greater than may be assumed.

This learning is of the upmost importance. We have a responsibility to respect that people with albinism have the right to be the centre of influence on their individual social constellation. Participants have spoken of their need to be listened to and have their voice heard. ‘Nothing for us without us’ is a common expression that has surfaced in the transcripts in numerous different forms. Taking this on board when considering social application of the research findings means that people with albinism are true agents in the social changes we collectively hope to affect.

The second learning of vital importance when reading into the findings is that there is indeed a network of individuals who need to be worked with when implementing the research recommendations. The transcripts reveal how this network is not simply a static matrix of individual entities operating unilaterally, but rather there is a constant process of influence at play within that social fabric.

These key learnings can be considered as navigation aids for us as stakeholders tasked with applying this research. The challenges which surface in the research are associated with proactive solutions which react to and anticipate the experiences of people with albinism, based on evidence-based findings. These solutions feature in the project Recommendations, primarily generated my members of TAS. These recommendations are not end points in our journeys, but rather actions to aim for that will require constant reassessment and evaluation.

In using these findings to continue our journeys towards the goal of true social inclusion for people with albinism in Africa, we should be reminded of our research participants who emphasized the powerful influence different stakeholders can have on their lives whilst keeping in mind the fact that only people with albinism are able to define who these stakeholders should be and how they should act. If we are to truly take this research on board as coalitions and individuals, we will understand that it is only by promoting people with albinism as centres of influence in their own right that we achieve true social change. This research seeks to platform the voice of these individuals, so we may respond accordingly in fellowship and with respect for people with albinism as agents of change.

Methodology

This participant-led study used qualitative methods including focus group discussions and in–depth interviews in the vernacular languages to answer the research question:

How can survival from birth, educational integration and subsequent life opportunities be enhanced through an understanding of the barriers and facilitators that influence successful transition of children with albinism into education, from primary to secondary level, and into work?

The transcripts were audio recoded, translated and transcribed, and analysed using thematic techniques to unpack meanings and experiences surrounding albinism. This allows for a detailed understanding of the key issues, concerns and experiences of those with albinism, their families and their communities.

Study sites

In Uganda the study took place in districts within the Busoga sub-Region; this is one of the poorest regions of the country with a largely rural population leading a hand-to-mouth existence. In Tanzania the study sites were in the Geita and Ukerewe districts in the Lake Zone where security issues for those with albinism are particularly pronounced.

The Ugandan focus group discussions and interviews were conducted by Peter Ogik of SNUPA (Source of the Nile Union of Persons with Albinism) and Fazira Kawuma, supported by Jane and Andrew Betts of the UK based charity Advantage Africa. Local researchers, Eddy Kennedy and William Jonan of NELICO (New Light Children Center Organisation) and a team from the UK based charity Standing Voice led by Jon Beale and Jamie Walling facilitated the research in Tanzania. The Coventry based team comprised Patricia Lund (principal investigator), Anita Franklin who lead the literature review and Simon Goodman, an independent analyst who was not directly involved in data collection. All members of the team involved in the research contributed to the final analysis.

Study populations

A total of 66 participants in Uganda and 101 in Tanzania expressed their views on albinism. These included those with albinism, family members, friends, neighbours as well as (in Uganda) stakeholders such as journalists, a dermatologist, and organisations supporting the human rights of those with albinism.

Summary of the findings and outputs

The project produced rich narratives from both countries, identifying the multiple agents and facilitators helping to provide a supportive network for families with albinism, with the affected person at the centre as an active agent in promoting their own advocacy. A theme running throughout the narratives is the importance of self acceptance by those with albinism, bolstering self confidence and leading to success. There was evidence of attitudes to those with albinism changing in a positive way as a result of many initiates to raise awareness and provide information on albinism. From the Tanzanian narratives it was clear that this was a slow process, requiring time, with examples of those with albinism persisting in educating their communities about albinism and engaging with their friends and neighbours to gain acceptance.

A striking point of the research was the importance of single individuals in helping to break the cycle of discrimination and downward cycle of despair. One person can make a key difference in the life of a person with albinism. As may be expected, the support of family is crucial, with fathers often rejecting and abandoning the mother and child with albinism. Indications of understanding and support from teachers, pastors, neighbours, friends and, most importantly, potential employers can make a pivotal difference in the transition of a person with albinism as they move through education to gaining appropriate employment and finding a partner and starting a family. Given the very strong evidence that economic success is crucial to the lives of those with albinism, further exploration of ways in which job prospects can be improved for people with albinism, in terms of equality of opportunity or even positive selection for those with albinism would help inform appropriate interventions. The misperception that the skin of those with albinism is 'weak ', meaning that they cannot do routine manual chores such as working in a flour mill, need to be challenged. The more damaging mistaken belief that they cannot achieve 'anything' is being discounted as more and more people with albinism take up jobs and positions in society and provide evidence to the contrary.

This research identified a gender difference in marriage prospects for those with albinism which requires further investigation; one woman with albinism commented *men seduce me but I cannot maintain a relationship*. Men with albinism usually marry women without albinism, because if they have economic stability that will attract a partner. Women with albinism find it harder to find partners because they cannot bring that economic power to a marriage.

There are numerous cases of positive role models among those with albinism and those round them. These illustrative case studies, show how individuals have gained success and recognition, be it through showing initiative in thwarting an attempted abduction, or persisting in training as a tailor despite being mocked when they could not see to thread a needle.

In collaboration with participants and other actors, the team have developed a series of recommendations at different tiers, listing specific action points to be taken at different levels from national government, through local government in conjunction with the community and encouraging those with albinism to put themselves up for positions in the community

Outputs from this study include a booklet for children developed by Patricia Lund with images by Teresa Robertson which has been translated into Swahili and is available here. They also include a series of evidence based comic strips by the Tanzanian artist Theophil Reginald Mnyavanu for use on multiple platforms to raise awareness, and a film shot by Hamidu Ramadhan documenting the final dissemination event in Tanzania.

The importance of reporting the findings of the research back to the participants and local communities is paramount, as is the presence of local officials at the final dissemination events in both countries when they could see their voices being considered seriously. The team have used the findings to develop a *Call to Action*, for all stakeholders to work collaboratively to act on the research findings and improve the lives of those with albinism.

The impact of this study was felt particularly in Uganda, where the participants reported how much they appreciated the opportunity to tell their stories and meet with others in similar circumstances. Many had previously felt isolated and marginalised, but discovered a shared sense of purpose and friendship with their peers. The participants across the region shared their experiences with generosity and openness. The final dissemination event in this country took the form of a one-day conference on albinism (the first national conference on albinism in Uganda).

The impact of albinism in the Ugandan and Tanzanian communities studied

Interviews and focus group discussions were conducted with 66 participants in Uganda, including families directly affected by albinism and other stakeholders such as a dermatologist, journalists and agencies working with people with disabilities. In the Tanzanian arm of the study 101 participants contributed, of which 38 had albinism and a further 63 were other family members, friends and neighbours who contributed their views either in focus group discussions or on home visits. The analysis has highlighted a range of factors that influence the lives of people with albinism. Prejudice and discrimination is common, with a high prevalence of myths and misconceptions about people with albinism. This had an impact on their school education as well as health implications. On the positive side, the role of government, NGOs and other agencies in supporting families with albinism, and the belief in God are shown to facilitate support for these families.

Each of these factors consists of events and experiences that can be seen to affect the lives of people with albinism in positive and negative ways.

Prejudice and discrimination towards People with Albinism (PWA)

A major theme of the lives of people with albinism (PWA) in the rural regions that were the study sites in both Uganda and Tanzania, is the large amount of prejudice and discrimination that they face.

Rejection from family

> A major part of the life experience of PWA is being rejected by those around them, including from very close family members. Fathers often leave their children with albinism and their wives on the birth of a child with albinism. In other documented cases, despite pressure on partners of PWA to leave their families, they often defy this pressure and stay by their side

Pressure on partners or parents of PWA to leave their families

> Partners often defy prejudice to stay with people with albinism despite any difficulties this may create for them

Fear of people with albinism, which leads to isolation

PWA are often feared by the wider community in rural areas, including fear of physical contact with them. This leads to isolation and perpetuates the cycle of discrimination of PWA. Much of this isolation is imposed by others, but the fear of attacks means that PWA may choose to isolate themselves or their children with albinism. In addition, others outside the family avoid PWA, so PWA come to be marginalised.

Fear and threat of attacks

As a result of the attacks against PWA because of an interest in their body parts, PWA, and their family members, live in constant fear of being attacked or kidnapped.

Name calling

As part of the wider discrimination that PWA experience, they experience name calling and bullying on a regular basis. This often occurs at school or college, but also in other areas of life.

Discrimination at school

In addition to bullying, PWA often experience problems with their teachers, especially regarding misunderstandings relating to their poor eyesight, which can be interpreted by teachers as being rude. Support from friends, family and teachers helps to overcome this discrimination.

Hard to get jobs

The widespread discrimination towards PWA makes it difficult to get jobs. Ideally those with albinism should have indoor jobs to limit their daily sun exposure. The risks to their security means that they cannot work in isolated areas, such as tending their fields. In communities which rely largely on subsistence farming this imposes difficulties in feeding families.

Hard to find a partner and to marry

This includes discrimination from the family of potential partners, who do not want to accept a PWA.

The prevalence and problems of myths and beliefs about PWA

A major feature of the interviews was the prevalence of myths about PWA in Uganda. These myths are particularly damaging and need to be challenged. Fear of the witchdoctors and traditional practitioners was often mentioned by those in both countries; they are viewed as instrumental in the trade of the body parts of PWA, and seen as a major threat, especially regarding the risk of being kidnapped or harmed. There was particular interest in the hair of PWA in Uganda, leading to abuse of young people with albinism as their hair is forcibly cut off. Fear of attack and abuse restricts the movement of PWA, especially at night.

Range of myths about albinism

The myths contribute to the discrimination towards, and isolation of, PWA and demonstrate the general misunderstanding of the genetic cause of albinism.

> *Laughing at PWA can result in having a baby with albinism yourself*
> *PWA don't die, but disappear, suggesting they have magical*
> *powers PWA are viewed as a curse, a punishment from God*
> *PWA can be viewed as demons or ghosts, not 'real' human beings*
> *They are given derogatory names such as 'pig'*
> *Having sex with a PWA can cure HIV/AIDS and lead to easy wealth*

This appears to affect women more than men, with documented cases of rape of women with albinism.

Key facilitators:

Family acceptance at birth

The support of parents is crucial for a good start in life, but many fathers and, very rarely, mothers abandon children with albinism when they are born, which means that these children start their lives with additional challenges. Acceptance by someone in the family, be it the mother, grandmother or other carer/guardian is critical. A male supporter provides security for the new baby in both safety and economic terms. Given the widespread lack of understanding of the inherited nature of the condition, rejection is sometimes by the wider extended family; acceptance is greater in families where there have been prior cases of albinism in the family.

Role of government and non-governmental organisations (NGOs) in supporting families

The important role fulfilled by SNUPA (Uganda) and Standing Voice (Tanzania) in both advocacy and health services (Sun Protection and Visual Impairment programmes) was mentioned by participants.

Many participants felt the government could do more to support PWA, particularly financially, with help with start up capital to develop small businesses to support their families. They felt the reliance on charities and NGOs was not sustainable and the government should take over responsibility for delivery of health and other services essential to their survival and well being.

The role of faith and belief

For many PWA and their families, God is seen as a major source of support and comfort, worthy of gratitude for helping PWA through difficulties in their lives. Being born with albinism is seen as part of God’s plan and will.

PWA made in God’s image

For some, especially religious leaders, the idea that people are made in God’s image is used to show that PWA are equal to other people.

At school: overcoming security, social and health problems

Barriers to educational inclusion at school include the discrimination, isolation, bullying and problems with teachers, as well as with their visual impairment. Where teachers and friends are supportive, people with albinism are able to succeed in schools.

Fear of the danger of attack on the journey to/from school; vigilance of peers and all members of the community in identifying potential risks help to make children feel safe

Support of friends and teachers at school have a huge impact on the school experience of a learner with albinism

Their short sightedness may not be recognised by teachers and peers at school, so they are perceived as ‘difficult’ as no adjustments have been made to accommodate them in the classroom. Training of teachers on how to manage this vulnerable group of pupils is needed, by being embedded in teacher training manuals from primary level.

Sun protection from birth

The threat of sun exposure, leading to sun-induced skin damage and potentially skin cancer, limits their daily activities including travelling to school and ability to work outdoors.

Participants mentioned various strategies to manage their vulnerability to sun induced skin damage. Some were innovative and practical, as in the case of a mother who had shown a flap of thick hessian fabric to the rear of her son's hat, to provide additional protection to his neck.

Economic status

Working and having a career is an important life stage. For people with albinism this can be complex. A key concern is that they cannot safely work outside because of the dangers of being in direct sunshine. Due to the cycle of deprivation people with albinism face, economic status becomes particularly important. Better economic status can make the lives of people with albinism less difficult in many ways, including making it easier to find a partner.

Community leaders and journalists in Uganda pointed to the role of poverty in the lives of PWA, as do the families themselves in both countries. Difficulties at school and at work can lead to PWA finding themselves in poverty, leading to further hardship. Having a small scale business, a shop or a tailoring business, generates respect and status as well as income. Participants called on the government to provide start up capital for PWA.

Relationships- finding a partner

There is evidence, notably from Tanzania, that people with albinism can form successful relationships, despite barriers. There can be opposition to marrying someone with albinism from the family of the person without albinism, but the (potential) partners of people with albinism show courage and strength of character to overcome this opposition, often at great personal expense. There is also discrimination towards people who associate with people with albinism.

There is a clear disparity across gender, with women more likely to take the burden for albinism than men. It is often the case that mothers are left to care for children with albinism along, which can mean that these children face financial hardships from birth. It also appears to be the case that men with albinism find it easier to marry than women with albinism do.

This gender disparity warrants further investigation to see how women with albinism and mothers of children with albinism can be better supported.

Integration into society; changing attitudes by awareness and education

In Tanzania participants presented a strong sense of improving attitudes towards people with albinism, which is often attributed to successful awareness campaigns and challenging myths about albinism, where understanding albinism and knowing that people with albinism are just like everybody is used to explain a reduction in prejudice. Government and NGO campaigns were praised as the main reason for the improvement in attitudes that are so important for people with albinism.

Outputs

In addition to academic outputs, evidence based resources produced as a result of this project included development of a children's booklet available at https://pureportal.coventry.ac.uk/en/publications/born-with-albinism-in-africa explaining key features of albinism, making maximum use of text and minimum use of text. The target audience is young people with albinism, but it will also be useful for their mothers. In addition a series of comic strips using humour and scenarios from the study were developed by a local Tanzanian artist which can be used in multiple platforms to raise community awareness. In the final dissemination event in Tanzania these attracted much attention and comment, including from the guest of honour on Ukerewe, the District Commissioner. These have been produced in both English and Swahili and can be accessed via. https://vimeo.com/

Username: info@standingvoice.org
Password: FIRAH17!

Social application of the Research

Foreword from Uganda by Jane Betts, Advantage Africa

The Ugandan element of this research was facilitated by the Source of the Nile Union of Persons with Albinism (SNUPA) working in partnership with Advantage Africa. SNUPA is a Ugandan non-governmental organisation formed in 2012, by and for persons with albinism in Busoga sub-region and its neighbouring districts. SNUPA aims to change attitudes and improve life for people with albinism and their families. Advantage Africa is a UK-based non-governmental organisation founded in 2002 which supports people affected by poverty, disability and HIV in East Africa. In 2013, SNUPA and Advantage Africa began working together to help people with albinism to stay safe from cancer, attend school, earn an income and overcome discrimination and lack of opportunity.

SNUPA's team, composed of grassroots outreach workers relatively new to research, undertook intensive training at the start of this project in order to develop effective facilitation and interview techniques. This training and subsequent sessions to monitor the research's progress provided invaluable benefits in confidence and team-building.

Through the focus group discussions, the SNUPA team have worked closely with people with albinism and their families in eight communities in the Busoga region of eastern Uganda. The fact that all but one of the team have albinism themselves, and that they are not professional researchers, has enabled them to establish a comfortable, mutually trusting atmosphere when meeting with participants. SNUPA team leader Peter Ogik in particular has helped participants feel valued and part of a unified, positive process to bring change in the lives of people with albinism.

The people who took part in the discussions told SNUPA how much they appreciated the opportunity to tell their stories and meet with others in similar circumstances. Many had previously felt isolated and marginalised, but discovered a shared sense of purpose and friendship with their peers. The participants across the region shared their experiences with generosity and openness. SNUPA and Advantage Africa will ensure that their contribution continues to be valued and they are fully included in the ongoing dissemination process.

The research's wide regional scope has enabled SNUPA to interact with new people with albinism. Therefore, alongside the research activities, SNUPA has been able to offer practical support as needed, including protection from skin cancer.

All SNUPA and Advantage Africa team members have been highly motivated and committed throughout this project, driven by the goal of developing evidence-based recommendations and tools to improve the lives of people with albinism. The team will harness the enthusiasm and engagement of all stakeholders involved over the course of the project to widely disseminate these results and ensure the recommendations are implemented.

Foreward from Tanzania by Jon Beale, Standing Voice

This research project has revealed fundamental learnings for achieving social change, learnings which have been illustrated by people with albinism and their communities in response to identified social challenges. It is perhaps with these learnings in the forefront of our minds that we should consider the research findings, in a bid to ensure we achieve tangible impact.

One of pronounced demonstrations of the research is the far-reaching constellation of individuals who define the life experience of people with albinism. This constellation consists of local, national and international stakeholders – ranging from family members and neighbours to key influencers in multi-lateral agencies. Understanding the importance of this social constellation is key to comprehending how we must collectively apply these research findings. The transcript material demonstrates the impact of an individual being surrounded by a supportive network of individuals, with them at the centre. Crucially the research participants emphasize repeatedly how it is the person at the centre of this constellation who has the most impact on how these surrounding people effect the present moment and future social reality of the individual. Both people with and without albinism who participated in FGDs and interviews demonstrated how the sphere of influence of an individual with the condition was far greater than may be assumed.

This learning is of the upmost importance. We have a responsibility to respect that people with albinism have the right to be the centre of influence on their individual social constellation. Participants have spoken of their need to be listened to and have their voice heard. 'Nothing for us without us' is a common expression that has surfaced in the transcripts in numerous different forms. Taking this on board when considering social application of the research findings means that people with albinism are true agents in the social changes we collectively hope to affect.

The second learning of vital importance when reading into the findings is that there is indeed a network of individuals who need to be worked with when implementing the research recommendations. The transcripts reveal how this network is not simply a static matrix of individual entities operating unilaterally, but rather there is a constant process of influence at play within that social fabric.

These key learnings can be considered as navigation aids for us as stakeholders tasked with applying this research. The challenges which surface in the research are associated with proactive solutions which react to and anticipate the experiences of people with albinism, based on evidence-based findings. These solutions feature in the project Recommendations, primarily generated my members of TAS. These recommendations are not end points in our journeys, but rather actions to aim for that will require constant reassessment and evaluation.

In using these findings to continue our journeys towards the goal of true social inclusion for people with albinism in Africa, we should be reminded of our research participants who emphasized the powerful influence different stakeholders can have on their lives whilst keeping in mind the fact that only people with albinism are able to define who these stakeholders should be and how they should act. If we are to truly take this research on board as coalitions and individuals, we will understand that it is only by promoting people with albinism as centres of influence in their own right that we achieve true social change. This research seeks to platform the voice of these individuals, so we may respond accordingly in fellowship and with respect for people with albinism as agents of change.

Social application of the reseach

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The ultimate purpose behind this project is to inform the work of government, including health, education, and justice, civil society organisations, media and other stakeholders so that their support to people with albinism is based on sound evidence, is of good quality, offers value for money and achieves high impact. We are also hopeful that the research will prompt action from stakeholders who are currently doing little or nothing to address the stigma and exclusion it exposes and so result in new services in currently neglected areas of Uganda. We aim for the clear and eloquent local voices of persons with albinism to deepen understanding of the condition and result in lasting change in their communities and across Uganda.

SNUPA and Advantage Africa aim to ensure that the project participants' experiences and views are incorporated directly into the services they offer to persons with albinism. They also aim to publicise the findings and recommendations to all relevant stakeholders as an integral part of their strengthened advocacy activities. The research dissemination in Kampala on 24th November 2017 aims to share the voice and experience of people with albinism among 100 such stakeholders, raising their consciousness of the stigma they face with albinism, enabling them to reflect on their role in reducing it and even starting and improving vital services. The dissemination event also aims to review and strengthen the recommendations, promote ownership of them by relevant stakeholders and secure pledges of commitment to implementing them.

Many of the themes emerging from the research exposed the diverse negative impact of prejudice and discrimination and myths experienced by persons with albinism. It is notable that where the role of SNUPA (and NGOs), and faith was discussed that more positive responses were observed: Kirunda (Journalist): *But when SNUPA came up with this association, we got to know and we knew how we could get (information). Actually, for a long time, we have been longing to write about this (albinism). I could say it was a minority group among the people living with disabilities simply because these people had no platform, had no spokesperson and with news, we always need to attribute, but when SNUPA came up with an organized group that is having a chairperson, the coordinator and other members, now the information started flowing.*

Samuel (24-year-old with albinism): *We are now grown up and SNUPA started giving us support when we were in a better situation as compared to other persons with albinism because some persons have poor skins compared to us.*

Fred (religious leader): *Some people segregate and we really want to tell people in our country that God created everyone in his own image and all people created no matter how he/she looks, is an image of God*

Adam (religious leader): *I started understanding the cause. I realized they lack melanin but I knew in my understanding that they are normal people, only lacking that pigment. So it’s only the colour of the skin that differs. … . In Islam, one with albinism is not different from other people*

It is therefore important that NGOs and religious leaders continue in their work to address the discrimination of persons with albinism and the myths that give rise to them, provide practical services and attract new associations and NGOs that will ensure a greater reach across Uganda.

When it came to the government, research participants observed a lack of recognition of persons with albinism and the challenges they face, together with little support to help them overcome them. The lack of finance was particularly highlighted.

Paul (man with albinism): *The government should also make sure find a way of supporting our finance, the way we survive. Because I love to do hard activities like carpentry but because of my skin, am hindered.*

Joseph (NGO Director): *So the government I think needs to do some more, maybe providing tax waivers and incentives to organizations that make* *cosmetic products in Uganda to begin to manufacture those protective gear that people with albinism need (such as sunscreen).*

Fred (religious leader): *Grants and other protective materials for persons with albinism should be provided by the government.*

Given the highly increased reach that government interventions could bring about, the potential social application of the research is national support for education campaigns, strengthened legal frameworks to protect persons with albinism and practical services to ensure their health and well-being. These are all issues addressed by the project dissemination to ensure the potential social application of the research is most effectively realised.

Jon Beale, Standing Voice

The research and its social application design

This research investigation was conceived with social application as its defining feature. This is reflected in the team involved, a coalition of academics and non-governmental actors, including one of Tanzania's leading civil society organisations, New Light Children's Center Organisation [NELICO] in Tanzania). This has offered tangible avenues for the research to be applied in society in a meaningful and long-term fashion.

The focal points of the research in Tanzania comprised Ukerewe and Geita Districts. These locations offered gateways into communities where the challenges faced by people with albinism are particularly pronounced. In Geita there are 308 people with albinism registered with the Geita Albinism Society. This is a particularly dangerous area for those with the condition, with seven reported murders since 2007 and eight survivors of attack. Ukerewe Island in Lake Victoria is also a challenging environment for people with albinism, with reported abuses a common feature of participants' stories from FGDs and interviews. Targeting these locations meant the research team on the ground, fronted by NELICO researchers, could gain insights into some of the most revealing life narratives in terms of the experienced life challenges associated with having albinism and how the community can both facilitate and impede empowerment and agency. Gaining this access has given the research a depth of perspective which, when it comes to applying these findings, will prove essential.

To ensure we have traction for this social application, communication with multiple stakeholders throughout the research process has been crucial to laying the foundations for using these findings in our respective work. Consultation with ministries, government teams, CSOs/DPOs and the wider community in the research areas and at the national and regional level began from the onset of the project and continues to be ongoing. Indeed, multiple stakeholders must now define the true long-term impact of our findings.

Participants including members of Tanzania Albinism Society (TAS) have defined the following tiered recommendations: National government[TIER1]

Local government in coalition or collaboration with the community {TIER2]

People with albinism and their families [TIER 3]
Non-Governmental Organisations (NGOs) [TIER 4]

Key learnings for social application

However, all stakeholders should respond to the recommendations whether or not they can be defined by one of the above categories. One of the pronounced demonstrations of the research is the far-reaching constellation of individuals who define the life experience of people with albinism. This constellation consists of local, national and international stakeholders – ranging from family members and neighbours to key influencers in multi-lateral agencies. The transcript material demonstrates the impact of a supportive network on an individual's life opportunities. Crucially the research participants emphasize repeatedly how it is the person at the centre of this constellation (i.e. a person with albinism) who has the most impact on how these surrounding people effect the present moment and future social reality of the individual. Both people with and without albinism who participated in the study demonstrated how the sphere of influence of an individual with the condition was far greater than may be assumed. This is such that a man who spent many tough years fighting stigma became a successful business owner employing black tailors, and neighbours turned their ignorance into companionship following witnessing the sheer strength of their peers with albinism.

From the perspective of implementers who will use these findings, this learning is of the upmost importance. We have a responsibility to respect that people with albinism have the right to be the centre of influence on their individual social constellation. Participants have spoken of their need to be listened to and have their voice heard. Taking this on board when considering the social application of the research findings means that people with albinism are true agents in the social changes we collectively hope to affect.

It follows then that we must engage that social constellation hollistically when implementing the research recommendations. The transcripts reveal how this network is not simply a static matrix of individual entities operating unilaterally, but rather there is a constant process of influence at play within that social fabric. Take for example, the experience of one woman in our research whose open windows were bricked up for 'protection' by her community, following an attempted abduction. Her reaction was to eventually remove those bricks, gradually taking back control of her own day to day existence. Here the state's anxiety had influenced the community members to take action on behalf of the individual. Interestingly this meant the community and local government had taken over guardianship of the women, so that her capacity to make her own decisions had been infringed upon. Her choice to remove the bricks demonstrated her own agency and determination to maintain herself as the centre of influence over her own life. The fact that the government, local community and individual all took powerful decisions here reflects how an individual with albinism is influenced by multiple stakeholders at all levels, whilst their inevitable ability to maintain their own agency remains constant. If we, as influential stakeholders, can promote that individual agency we will be finding success in our work. To do this most effectively we must also work with people with albinism to identify the social groups who make up this social constellation, and find ways to engage these actors in ways which promote that individual agency.

Responding to key learnings

Recommendations, primarily generated my members of TAS are not end points, but rather actions to aim for that will require constant reassessment and evaluation. The research demonstrates how social change is a process – many perspectives have surfaced which illustrate how the present situation of people with albinism relates to past experiences, and consider what future ambitions may look like. It is perhaps wise of us to respond to such perceptions by applying this research in a way which acknowledges we cannot solve the identified challenges over night, but we can contribute significantly to a process of social change that can gather pace with our collective efforts.

With this in mind we can find ways to meaningfully add to this collective process through responding to participants' priority areas of implementation:
Promoting security
Implementing progressive polices and laws
Promoting access to education and health services
Promoting financial stability and employment
Building awareness
Promoting political inclusion and legal capacity
Improving sustainability and future planning.

Research participants have expressed challenges that span these categories. Time and again we have heard of the health crisis facing this group; the obstacles to education access; hardship in achieving employment and financial stability; the challenges of security; difficulties relating to political inclusion and legal capacity; regressive state responses; and the challenges of sustainability. In a more positive vein we have heard form participants how their social constellation, including the organisations and agencies we as stakeholders represent, can facilitate real progress in these areas. This could be an NGO responding progressively to a need, or a teacher in a community school taking the time and effort to guide a child with albinism to achieve their ambitions.

It is reflective of these positive influences that people with albinism have spoken of their neighbours helping them to achieve true social inclusion, and as a result have improved security. We have also heard how achieving security positively influences access to education and health services. Returning to the theme of individual agency, we have heard how people with albinism have defined their experience by being visible, confident, determined members of their community willing to pick themselves up and keep striving for what they desire in the face of adversity. It is this determination which has on numerous occasions meant they have had more power as decision-makers in their communities, resulting in their access to livelihood opportunities and improved security. In many instances this has resulted in better community awareness. We hope through the communication of these findings the

achievements of those stoic individuals will come to effect rapid and widespread policy change across the African region.
These categories of recommendations are interrelated and mutually enforcing, uniting multiple stakeholders in their implementation. If we achieve progressive policy change through platforming the voices of those who have contributed to this research we will have forged a pathway of influence ensuring the community voices we have captured are heeded on a national and regional level.

National governments can respond to these recommendations by ensuring meeting the challenges faced by people with albinism is maintained as a government priority, despite inevitable competing demands on the state. Specifically: policies, laws, and services should be proportionate to the extent of the challenges encountered by citizens who have albinism.

Local governments can respond by ensuring people with albinism are afforded voice and influence on a local government level, such as through ensuring these individuals are included on government committees. We have seen in this research a frustration at the limited opportunities available to contribute to society's decisions. An adequate response to this will be to open opportunities for such contributions. There is a desire to have agency on a political level.

This is a call to be given more entrance points into societal process, penetrating society on a level which can allow people with albinism to define the collective direction of their community when it comes to valuing difference and promoting social inclusion.

Local communities can respond by finding ways to promote people with albinism's access to their human rights without infringing upon other human rights in the process. Like in the example given above of a woman whose windows were bricked up for her protection, we cannot limit agency and freedom if we seek to empower. Communities can seek to understand albinism and value the true wellbeing of those with the condition as a precondition of their own collective welfare.

People with albinism and their families can promote positive attitudes by being brave and influential on their community. This is not a call to be heroes, or become an extrovert as a prerequisite for your human rights. Quiet bravery is indeed evidenced as being as effective as any other method of self-empowerment. One woman interviewed spoke of her determination to be tailor; at first laughed at for her inability to thread a needle, she overcame this mockery she has become renowned for her beautiful embroidery, without a word said to her tormenters.

Families can seek knowledge of the condition, and through doing so realise the use of knowledge as a tool of empowerment for the whole community and a weapon against ignorance.

Non-Governmental Organisations (NGOs) can be vehicles for greater cohesion, and practical impact shared by all stakeholders making up a person with albinism's social constellation. Through doing this NGOs can provide channels of influence, allowing people with albinism and civil society more broadly to hold those to account who seek to influence their lives. We can also find ways to work with each other closely to achieve these courses of action.

Crucially our research participants have emphasized that these stakeholders are powerful influencers on their lives with the ability to impact positively as well as negatively. If we are to truly take this research on board as coalitions and individuals, we will understand that it is only by promoting people with albinism as centres of influence in their own right that we achieve true social change. We are merely part of a social constellation and it is those we seek to empower who define our collective direction.