

Project title

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

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Lead

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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)

Project leader (Coventry University)

Dr Patricia Lund

p.lund@coventry.ac.uk

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.

Foreword from Tanzania by Jon Beale, Standing Voice

This research project has revealed fundamental learnings for achieving social change, learnings that 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 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. Understanding the importance of this social constellation is key to comprehending how we must collectively apply these research findings. The transcript material demonstrates the positive impact an effective support network can have on the welfare of a person with albinism. Crucially, research participants have in turn repeatedly emphasized the power of people with albinism themselves to engage and recruit these supporters, and to play an active role in determining their own welfare. Both people with and without albinism who participated in FGDs and interviews attested that the agency exercised by people with albinism is often greater than assumed.

This learning is of the utmost 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 effect.

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 interplay within that social fabric.

These key learnings can be considered as navigation aids for stakeholders seeking to apply this research in the field. The challenges and recommendations illuminated by the research—and recapitulated in this report—are not end-points in our journeys, but launch pads for further enquiries and investigations to be reassessed and remodelled over time.

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 research

Uganda- Jane Betts of 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. 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 shared 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.

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 which 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 Kanya, 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.

The research and its social application design

This research investigation was conceived with a view to social application of the findings. This is reflected in the project team: a coalition of academics and non-governmental actors (including one of Tanzania's leading civil society organisations, NELICO, in Tanzania). This has offered tangible avenues for the research to inform stakeholder interventions in future.

Research in Tanzania was geographically concentrated in the districts of Ukerewe and Geita. 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 violence. 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 that will lend expertise and nuance to social applications of the findings.

Effective communication between stakeholders has been critical to lay the foundations for social applications by stakeholders. 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 [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]

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. Understanding the importance of this social constellation is key to comprehending how we must collectively apply these research findings. The transcript material demonstrates the positive impact an effective support network can have on the welfare of a person with albinism. Crucially, research participants have in turn repeatedly emphasized the power of people with albinism themselves to engage and recruit these supporters, and to play an active role in determining their own welfare. Both people with and without albinism who participated in FGDs and interviews attested that the agency exercised by people with albinism is often greater than 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 after admiring the tenacity and resilience of their peers with albinism.

From the perspective of implementers who will use these findings, this learning is of the utmost 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 effect.

It follows that we must holistically engage the entire constellation of actors surrounding persons with albinism when implementing the research recommendations. The transcripts reveal how this network is not simply a static matrix of individual entities operating unilaterally, but rather a shifting 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 the agency of an individual with albinism asserts itself in the face of contrary intervention by others. 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 actors who can provide potential support and promote their individual agency.

Responding to key learnings

The challenges and recommendations illuminated by the research—and recapitulated in this report—are not end-points in our journeys, but launch pads for further enquiries and investigations to be reassessed and remodelled over time. The research demonstrates how social change is a process: many perspectives have surfaced, illustrating how the present predicament of people with albinism is informed by past experiences, and will colour their future ambitions in turn. It is perhaps wise of us to respond to such perceptions by applying this research in the long term, acknowledging that identified challenges can rarely be solved overnight.

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 policies 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 from 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 that has on numerous occasions enabled people with albinism to gain 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 processes, penetrating society on a level that can allow people with albinism to define the collective direction of their community on a spectrum of issues within but also far beyond the confines of their albinism.

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 and has since 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.

Dissemination events to share the findings

In November 2017, the project team returned to both study locations in Tanzania to share research findings with individuals and communities who had previously participated as contributors. This took the form of home visits to hard-to-reach contributors, together with large-scale dissemination events sharing the outputs of the research with an array of stakeholders including health and education professionals, local government representatives, television and radio media, and people with albinism and their families and community members.

The event in Geita was held on November 16 at the Yohanna Memorial Centre (provided courtesy of NELICO). The team were delighted to receive three local government representatives together with 123 community members. The dissemination on Ukerewe Island took place over two days on November 19 and 20 at the Umoja Training Centre (provided by Standing Voice), with seven local government representatives and over 70 community members on each day.

Both dissemination events involved a series of speeches from key project members (Dr Patricia Lund of Coventry University; Sam Clarke of Standing Voice; and Eddy Kennedy of NELICO), TAS representatives, and local government leaders, including the District Commissioner on Ukerewe. Key learnings and recommendations from the research were shared to provide an evidence base informing future interventions. Attendees were additionally able to engage with the project through a series of creative outputs, including a photographic exhibition of portraits of people with albinism and their community members, many of whom participated directly as research contributors; comic strip illustrations produced to reflect project findings, and intended for wider dissemination in the public sphere in future; and printed quotations, lifted directly from the project transcripts as a window into the captured voices of contributors from across Ukerewe and Geita.

Both dissemination events were photographed, with this material collated and repurposed as a slideshow and short film to be housed online via Vimeo and disseminated more widely in future.