

### **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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### **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)

### **Project leader (Coventry University)**

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# 1. Project summary

**Patricia Lund, Coventry University**

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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 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 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; 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 (available [here](#)) which has been translated into Swahili, 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. Videos and other outputs of this project can be viewed at <https://vimeo.com/user75356817>

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.