



# Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda:



Report on Pilot Study of Persons with Albinism in the Districts of Budaka, Bududa, Butaleja, Buyende, Kamuli, Kumi, Manafwa, Mayuge, Sironko and Soroti.

DECEMBER 2018



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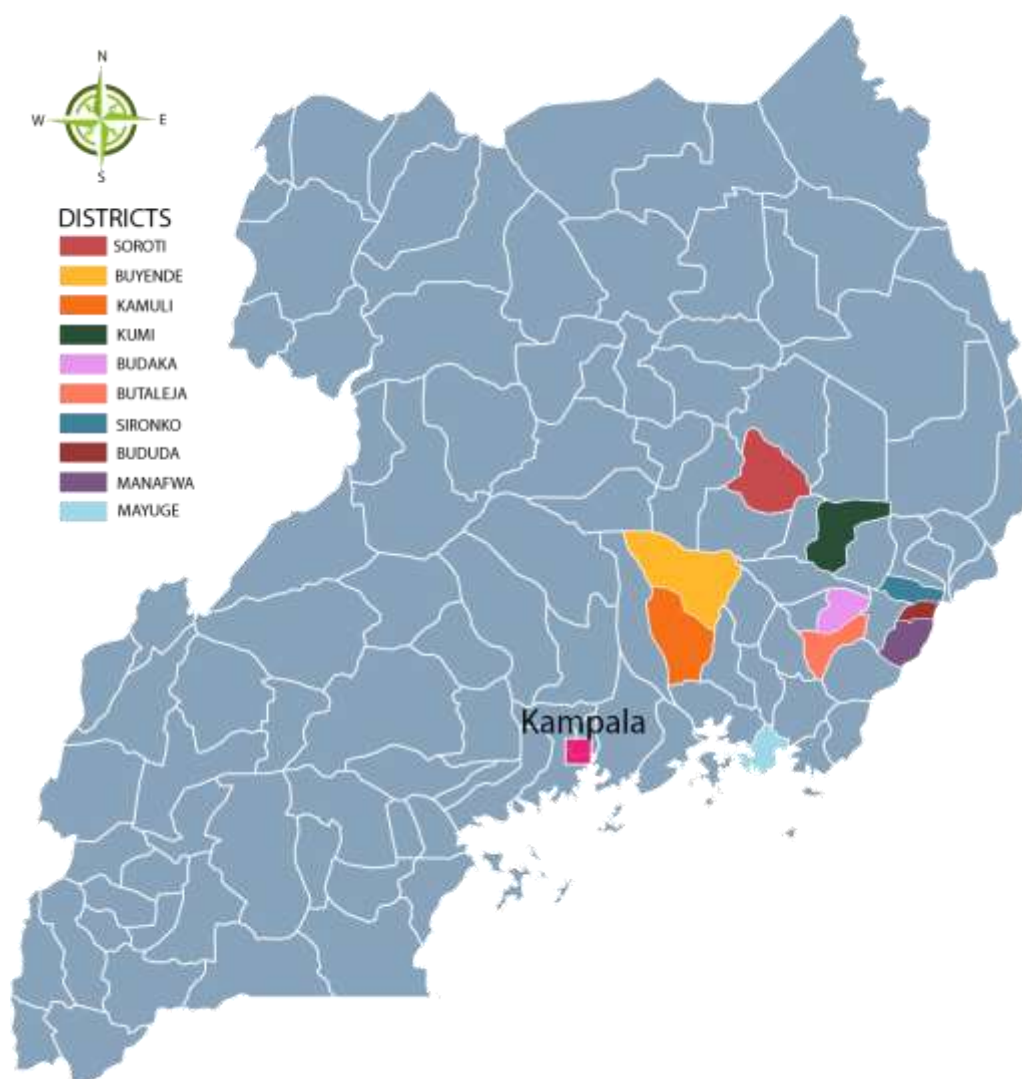
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# **Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda:**

**Report on Pilot Study of Persons with Albinism in the Districts of Budaka, Bududa, Butaleja, Buyende, Manafwa, Mayuge, Kamuli, Kumi, Sironko and Soroti**



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**December, 2018**

## FOREWORD

This work has been prompted by the numerous undocumented reports about Persons with Albinism. Over the years, different myths and misconceptions have resulted in discrimination, stigma, kidnap and attempted capture of Persons with Albinism for ritual sacrifice for blessings and riches.

While most of these reports have been anecdotal, this research study report gives first hand evidence from Persons with Albinism and their care takers. This research study was done in ten selected districts in Eastern Uganda. The exercise began by mapping out where Persons with Albinism stay. using Global Positioning System (GPS) coordinates then went on to profile individual households using ODK- Collect application. It climaxed by capturing sentiments of Persons with Albinism from the individual, interpersonal, community and policy perspectives.

This work would not have been possible without the support from Oxfam in Uganda. The team at Oxfam listened to our plea and decided to provide a seed grant that helped us put together all the information contained herein. Words can not simply explain our gratitude and that of the entire Albinism community.

I wish to thank Dr. Betty Udongo - the Principal Investigator and Lead Consultant, Dr.Arthur Bagonza - Co-Principal Investigator and Biostatistician, Hussein Kato Muyinda - Project Field Co-ordinator, Brian Odoch - ICT specialist, Arthur Muteesasira - GIS support, Janepher Nanyondo - Project Assistant and Ruth Atuhairi – Finance Officer, for all the support they provided towards the success of this project.

I would like to appreciate my colleagues in the struggle of amplifying the voices of Persons with Albinism from different organisations such as; Uganda Albino Association, Source of the Nile Persons with Albinism (SNUPA), Asante Judith Albinism Support Organisation, Local Government Leaders and District Community Based Organisations that made it easy for us to profile Persons with Albinism in their areas.

Lastly I would like to thank the Research Assistants, Persons with Albinism, Research participants, Districts and Village guides who worked tirelessly to give a true picture of what is actually taking place in the lives of Persons with Albinism in the districts of **Budaka, Bududa, Butaleja Buyende, Manafwa, Mayuge, Kamuli, Kumi, Sironko and Soroti**. Our ultimate desire is to map and profile all Persons with Albinism in Uganda. We trust that this report will serve as a turning point in addressing the plight of Persons with Albinism in Uganda and the rest of the world.

**OLIVE NAMUTEBI**  
Executive Director

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## **LIST OF ACRONYMS**

CWA	Child With Albinism
GPS	Global Positioning System
MLGSD	Ministry of Labour Gender and Social Development
NGO	Non -Governmental Organization
NPHC	National Population and Housing Census
ODK	Open Data Kit
OVC	Orphan and Vulnerable Children
PWA	Persons with Albinism
PWD	People with disabilities
UBOS	Uganda Bureau of Statistics
UCHL	Uganda Child Helpline
UDHS	Uganda Demographic Health survey
UN	United Nations
UNCRPD	United Nations Convention on the rights of persons with disabilities



## **OPERATIONAL DEFINITIONS**

**PERSONS WITH ALBINISM (PERSONS WITH ALBINISM):** This term will be used to refer to all people with a rare, non-contagious, genetically inherited condition. The condition results in the lack of melanin pigment in the hair, skin and eyes causing vulnerability to sun exposure.

**Children with Albinism (CWA):** This term will be used to refer to all Children with Albinism which is a genetically inherited condition that result into lack of melanin pigment in the hair, skin and eyes.

**PERSONS WITH DISABILITY(PWD):** This term will be used to refer to people with physical, sensory, cognitive, intellectual and mental impairment. It will also include people with chronic illnesses.



## **DECLARATION**

We the principal investigators declare that this research work is original and is intended to help Persons with Albinism live a much more fulfilling life than what they are living at the moment.

Any reference to work done by any other person, institution or any material obtained from other sources have been duly cited and referenced.

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## **ACKNOWLEDGEMENT**

We would like to thank Voice and OXFAM that availed funds to make this work possible. We would also like to thank in a very special way all the Persons with Albinism who willingly participated and made this work successful.

Last but not least, we would like to thank the organizations as well as local governments that have profoundly helped Persons with Albinism make their lives worth living.

## **DEDICATION**

This work is dedicated to all Persons with Albinism and those who lost their lives as a result of societal negligence. May their souls rest in Eternal Peace.

## ABSTRACT

**Background:** Globally, Persons with Albinism ( PWA) continue to face numerous challenges that include but are not limited to discrimination, stigma and even death due to numerous myths and misconceptions surrounding their existence. Planning for this group of people has had tremendous challenges because of the uncertainty surrounding their numbers, policies in place meant to protect them as well as the few organisations helping them. This research attempts to bridge these gaps.

**Main aim:** To create a data base through mapping all Persons with Albinism and organisations serving these people in 10 selected districts of Eastern Uganda. We also determined perceptions of Persons with Albinism towards the communities they live in and the community perception towards them.

**Methods:** This was a cross sectional study carried out in Eastern Uganda focusing on Persons with Albinism. Spatial mapping was done using Tablets with GPS (Global Positioning System) capabilities. Household and organisational characteristics were captured using a digital structured questionnaire, using ODK (Open Data Kit)-Collect application. Perceptions of Persons with Albinism were gathered using indepth interviews and analysed based on the ecological model.

**Results:** Sironko (20.2%), Bududa (17.9%) and Manafwa (17.5%) had the highest number of Persons with Albinism. Most respondents (56%) in households with Persons with Albinism had primary level education. More than two thirds (67.7%) of the respondents did not know the cause of Albinism. Access to and cost of sunscreen remain major challenges to households of Persons with Albinism. About (86.3%) of Persons with Albinism do not have access to sunscreen. In addition, (75.7%) of Persons with Albinism had eyesight problem. Moreover, (76.8%) of Persons with Albinism had never gone for an eye check up. The main reason for dropping out of school was lack of school fees. Poverty levels were highest among households that had more Persons with Albinism. The richest households of Persons with Albinism (based on the Gramin Poverty Index) were found in Bududa (24%), Buyende (18.7%) and Manafwa (18.4%). On the contrary, the poorest households are in Sironko (27.8%), Bududa (22.2%) and Manafwa (16.7%). Organisations and secondary schools meant to help Persons with Albinism are not within the recommended 5km radius on average.

**Recommendations:** There is need to provide protective clothing, glasses and caps for Persons with Albinism to protect them from harmful sun rays. There is also need to provide free or affordable skin creams and lotions. They should be put within easy access if they can not be distributed free on a more regular basis. For sustainability purposes, Suncreens should be developed locally so that they can be affordable and accessible to Persons with Albinism. In order to increase household incomes, there is need to provide Persons with Albinism with income generating skills which can be done indoors.. Finally, there is need for community sensitisation and better policy inclusion for Persons with Albinism.

## CHAPTER ONE

### 1.0 INTRODUCTION

It is widely believed that 1 in 20,000 people globally are either Persons with Albinism or carry the gene that is responsible for albinism. However, the methods used to arrive at this prevalence and consequently the prevalence reported remains very contentious. This has greatly jeopardised policy and planning for this ever increasing but yet vulnerable group of people.

Among the black people, particularly those from sub-Saharan Africa, Oculocutaneous albinism is the most common inherited pigmentation disorder of the skin [2]. It is characterised by impaired melanin biosynthesis. Whereas all Persons with Albinism are at great risk of developing squamous cell carcinoma of the skin when exposed to the sun, black Persons with Albinism in sub-Saharan Africa are about 1000-fold higher at risk of developing squamous cell carcinoma of the skin than the general population [3].

In Africa, literature reports prevalence as high as 1 in 1,000 for countries like Zimbabwe. Overall estimates point at prevalence ranges between 1 in 5000 to 1 in 15,000 Persons with Albinism in Africa [4]. Weak government policies, poor community perceptions as well as the lack of proper documentation alluded to above have complicated programming and or even led to the death of this vulnerable group of people [1, 5, 6]. This study seeks to bridge these gaps.

**The 2030 Agenda** for Sustainable Development promises to leave no one behind. Unfortunately, Children with Albinism are amongst those who are left furthest behind. With the adoption of the 2030 Agenda and its ambitious vision to build a world free from fear and from violence, it is hoped that no child, including those with albinism, is left behind in the dark.

In Uganda, Persons with Albinism are included among persons with disability. However, there is no clear policy that directly addresses the plights of Persons with Albinism. According to Vision 2040, in order to enhance inclusive growth and development, one of the strategies in the second National Development Plan targets Persons with a Disability (PWD) through equalization of opportunities, rehabilitation and inclusion of PWDs in their communities. Unfortunately, Persons with Albinism are not considered a priority in this policy.

According to the Uganda Demographic Health Survey (UDHS, 2016), the disability module, is based on the framework of the World Health Organization's International Classification of Functioning, Disability, and Health. The indicators for measuring disabilities are limited to physical, blind, deaf, dumb and mental health, but Albinism which is a genetic disorder of lack of melanin on the skin and hair is not identified as a disability. Persons with Albinism only qualify to be categorized under Persons with Disability because of their poor eye sight and yet their greatest challenge is their skin conditions.

Another major challenge that Persons with Albinism face is limited access to legal services. Unfortunately, the laws of Uganda do not specifically include Persons with Albinism as a discriminated minority group. This causes further difficulties in their plight to secure the basic human rights to non-discrimination, equality, liberty, life and security. The human rights of Persons with Albinism is based on the text and principles of the United Nation's "Universal Declaration of Human Rights."

## **1.1 Background**

This study is premised on the numerous yet under reported challenges faced by Persons with Albinism in Uganda that have led to the death of about 50 Persons with Albinism in the last one year alone [7]. Whereas these challenges have been in existence for a long time, the Uganda Bureau of Statistics has never conducted a census to identify Persons with Albinism as a category of vulnerable people except in the Uganda Functional Difficulties Survey 2017.

The Functional Survey is not a tool that can indicate the demography of Persons with Albinism. Moreover, the Ministry of Labour, Gender and Social Development which is responsible for Persons with Albinism has never considered Persons with Albinism as a vulnerable group in its profiling for community development purposes.

The scanty available data on Albinism is one that has been compiled by different organizations working to support Persons with Albinism. Quite often, this data is incomplete and target specific based on the needs of the funding agency. The available data only highlights the number of Persons with Albinism seeking or receiving assistance from community based organizations and NGOs. Such efforts have helped Persons with Albinism live a more fulfilled life. However, the only Persons with Albinism receiving such support are those that have been proactive and live in communities where the threat of being killed is low. It is envisaged that a

large number of Persons with Albinism are not reached partly because of the poor and fragmented documentation, weak policies in existence as well as the stigma passed on by the community to people and households with albinism.

This has led to missed school opportunities for children and poor social economic status for households with Persons with Albinism. This research project will therefore use technology to collect accurate baseline data on Persons with Albinism in Eastern Uganda. This database will be a guide for planning, informed advocacy, protection and provision of services for improvement of the wellbeing of Persons with Albinism.

## **CHAPTER TWO**

### **2.0 LITERATURE REVIEW**

#### **2.1 Magnitude of Persons with Albinism**

##### **2.1.2 Service provision for Persons with Albinism**

Besides being entitled to being protected, Persons with Albinism are entitled to good health facilities given the fact that their skins and eyes are more vulnerable to ultra violet rays compared to the general population.

As such, this vulnerable group of people is entitled to regular medical check-ups. However, the prevailing health systems issues in Uganda and in many parts of sub-Saharan Africa make this right hard for Persons with Albinism to achieve.

In fact, much as there has been lobbying for sunscreens to be exempted from paying duties in Uganda, nothing has come to fruition. This puts children and pregnant women whose immunity is weak at an even greater risk of different types of skin cancers.

In a study by Patricia Lund and colleagues in children in Zambia, only 23% of the sample had ever had their skin examined by a health professional and this was often only when they were babies. As far as other health needs were concerned, less than half of the sample had been to a hospital or private optician for an eye test [8]. This cross cutting lack of health facilities and personnel



dedicated to Persons with Albinism is what has led to the sudden spread of non-governmental organisations offering services in a vertical manner.

As far as education for Persons with Albinism in Africa is concerned, mixed policies abound. In countries such as Tanzania, the government has made a deliberate move to take children away from their parents and educate them in special schools [9].

While the move ensured adequate protection, the break down in family ties was a major criticism. This is because for long, albino children had been considered not able to contribute a lot in society in the same way as others [10]. In Uganda, special amenities for Persons with Albinism are lacking.

### **2.3 Policy Content of Persons with Albinism**

Paucity in policy data about the well being of Persons with Albinism exists in many countries in Africa. A limited understanding of how policy issues affect Persons with Albinism remains the greatest single challenge affecting communities hosting Persons with Albinism.

In some African countries, institutions such as prisons in Ghana have classified albinism equivalent to being disabled [11]. However, in many other settings, this label has been refused. In countries where the term has been accepted, Persons with Albinism are accorded human rights such as the right to life, social protection, equality and non-discrimination, violence and abuse as stipulated by the United Nations Convention on the rights of persons with disabilities (UNCPRD)[12].

To this effect, the 13<sup>th</sup> of June every year has been proclaimed as the International Albinism awareness day by the UN General Assembly [13]. Following this declaration in 2013, another council of independent experts was set up in 2015 by lobbyist groups to ensure that Persons with Albinism enjoy their human rights [14].

Two years later, an international bar association was formed with the sole purpose of making sure that universal standards for the protection and promotion of rights for Persons with Albinism is in full implementation [15].

While the above policies and declarations exist, adoption at country level remain a major challenge impeding the right to protection. In the recent past, major killing of Persons with Albinism have happened in Uganda, Kenya and Tanzania[16]. This resulted in the banning of witchdoctors in Tanzania.

In Uganda and Kenya however, this ban has not even been debated and has seen the proliferation of body part trade thrive. Even when caught, the prosecution of perpetrators is so slow. Infact, the present act under which culprits are prosecuted-the witchcraft act has never been revised since it was made in the colonial days. Such weak policies if unchecked will deter the full enjoyment of human rights for Persons with Albinism.

## **CHAPTER THREE**

### **3.0 PROBLEM STATEMENT**

#### **3.1 THE PROBLEM**

Numerous Persons with Albinism continue to live in fear and an unfulfilling life because of the threat upon their lives. Albinism-a congenital condition resulting in a lack of pigment in the skin, hair and eyes of humans has not been fully addressed partly due to the uncertainty in numbers, service provision as well as weak policies supporting people with the condition leading to mortalities that would have otherwise been avoidable.

##### **3.1.1 Magnitude of the problem**

From January 2017 to date, approximately 50 people including a 39 year old lady have lost their lives due to the exorbitant amounts of money offered for body parts of Persons with Albinism. Whereas these are the well known and documented cases, it is believed the number could be higher than what is reported.

##### **3.1.2 What has been done**

A United Nations declaration has been signed urging Governments and Non Governmental Organisations to protect Persons with Albinism. To this effect, there is an annual charity match spearheaded by the Speaker of Parliament in Uganda aimed at raising funds for an albinism centre. A beauty Pageant for Persons with Albinism was organised by SNUPA in Uganda also helped to create awareness.. Albinism Umbrella and Africa Albino Foundation Uganda have continued to supply sunscreens, counselling and other material support to PWA for the past seven years. These activities together with what the different funding organisations have done has helped curtail deaths and associated threats to Persons with Albinism. However, the lack of documentation of the actual number of Persons with Albinism remains a major stumbling block to service provision.

### **3.1.3 What we planned to do**

We planned to create a data base for all Persons with Albinism in 10 selected districts in Eastern Uganda. We also planned to profile all agencies providing services to Persons with Albinism in the selected districts. In addition, we also planned to assess community perceptions towards Persons with Albinism as well as highlight policy gaps that exist.

## **3.2 JUSTIFICATION**

This work will purge gaps to do with the number of Persons with Albinism especially in Eastern Uganda. It will go a long way in bringing the plight of Persons with Albinism to the lime light. The data collected will provide accurate information to support service delivery, empower, and strengthen lobbying and advocacy capacities.

The data base created will help policy makers and agencies identify areas where Persons with Albinism face the greatest risk or danger of harm and try to find ways of improving their longevity by providing appropriate security or amenities that may be deemed fit. We also hope that this research work will go along way in addressing the existing policies that have not addressed the recurrent issues affecting Persons with Albinism.

## **CHAPTER FOUR**

### **4.0 GENERAL OBJECTIVE**

To spatially map and profile Persons with Albinism in Eastern Uganda using Global Positioning System (GPS) and ODK (Open Data Kit).

#### **4.1 Specific objectives**

1. To identify, map and profile all Persons with Albinism and their households using GPS and ODK.
2. To create a disaggregated database for Persons with Albinism in the 10 selected district in Eastern Uganda.
3. To identify, map and profile all existing service providers for Persons with Albinism in the 10 selected districts in Eastern Uganda.
4. To assess community perceptions about Albinism and Persons with Albinism.

## **CHAPTER FIVE**

### **5.0 METHODOLOGY**

#### **5.1 Study Design**

This was a cross sectional study. Both qualitative and quantitative methods were employed. The quantitative aspects focused on generating empirical evidence needed to assess the objective of the research project. Indepth interviews were held with Persons with Albinism. The assessment framework was based on the ecological model both for interpretation and analysis of results.

#### **5.2 Study Area**

##### **5.2.1 Study Setting and Location**

The study took place in 10 districts in Eastern Uganda. Eastern Uganda was chosen because anecdotal evidence showed that albinism was highest in this region. The 10 districts were randomly sampled from the 4 sub-regions of Teso, Bukedi, Elgon and Busoga in Eastern Uganda. The 10 selected districts were: Buyende, Kamuli, Mayuge, Bududa, Manafwa, Sironko, Soroti, Kumi, Budaka and Butaleja.

#### **5.3 Accessible Population**

The accessible population for this study was all households in the 10 selected districts in Eastern Uganda.

#### **5.4 Study Unit**

The study unit consisted of all households with people living with albinism in the 10 selected districts in Eastern Uganda.

#### **5.5 Study Variables**

##### **5.5.1 Outcomes**

The main primary outcome of interest for our research study (dependent variable) was prevalence of Persons with Albinism and organisations serving them.

#### **5.6 Data Collection**

##### **5.6.1 Training of Research Assistants and pretesting**

Research assistants involved in data collection were carefully chosen. All the 10 research assistants had completed Diploma and Degree levels of education. This was because the digital data collection application ODK (Open Data Kit).. The Research assistants were also selected on the basis of being knowledgeable in the local languages such as Lumasaba, Lusoga, Ateso, Lugwere and Lunyole for efficiency. A total of 6 Persons with Albinism participated in the field work either as research assistants or district, village guides.

### **5.8.2 Quantitative data collection tools**

Household questionnaire was used to gather all household and personal attributes for Persons with Albinism. Another questionnaire was used to gather attributes of organisations serving Persons with Albinism. A tablet with global positioning system was used to collect GPS coordinates from households housing individuals as well as organisations providing services to Persons with Albinism.

### **5.8.3 Qualitative data collection**

A focus group discussion guide with open questions intended to explore community perceptions towards Persons with Albinism was used for data collection. A group of research assistant trained and experienced in qualitative research methods were sent to the 10 selected districts. The qualitative study was done in ten districts of Eastern Uganda.

The researchers conducted indepth interviews with Persons with Albinism. Participants were taken through the objectives of the study and the study justification before any form of discussion ensued. This was done mainly to get informed consent but also to make sure the participants understood what the study was all about. Any feelings that pointed towards a bias that may influence the study were taken note of and addressed before the study began. This enabled participants feel free and respond without any form of fear.

## **5.9 Ethical consideration**

This research was carried out without exposing particular individuals' identities or location to people not part of the research team.. Ethical approval was granted by School of Biomedical Sciences Research and Ethics Committee, Makerere University College of Health Sciences Kampala. Albinism Umbrella finally received the clearance from the Uganda National Council of Science and Technology, a body that certifies all research with a security clearance from State House as ultimate endorsement for compliance.

## CHAPTER SIX

### 6.0 RESULTS

#### 6.1 Social Demographic Characteristics

The main objective of this research study was to map and profile all Persons with Albinism and their households using GPS in 10 selected districts in Eastern Uganda. This was intended to identify systematic and credible disaggregated data such as age group, gender, educational, health and socio economic status on Persons with Albinism. The data collected is expected to provide accurate information on the population and prevalence of Persons with Albinism and their household locations. It is hoped that this information shall help support service delivery, empower, and strengthen lobbying and advocacy capacities for Albinism communities.

The total population and distribution of Persons with Albinism per district is displayed in Table 1. This distribution highlights the prevalence of Persons with Albinism across the 10 selected districts in Uganda.

**Table 1: Distribution of Persons with Albinism by District**

District	N	%
Budaka	14	5.3
Bududa	47	17.9
Butaleja	11	4.2
Buyende	27	10.3
Kamuli	27	10.3
Kumi	6	2.3
Manafwa	46	17.5
Mayuge	20	7.6
Sironko	53	20.0
Soroti	12	4.6
Total	263	100

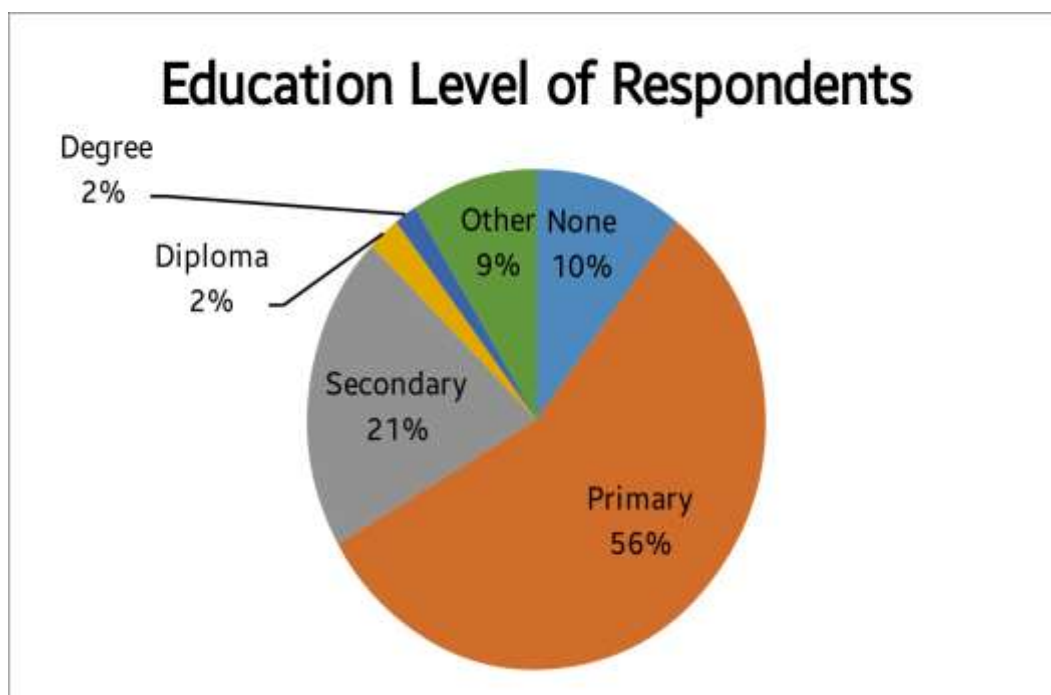
From the 10 districts visited, the highest number of Persons with Albinism were in Sironko (20.2%), followed by Bududa (17.9%) and Manafwa (17.5%) districts. The least number of Persons with Albinism were in Soroti (4.6%), Butaleja (4.2%) and Kumi (2.3%) district

### 6.3 Education of Persons with Albinism

The research also aimed at interviewing women and or mothers of children with albinism. This is because this particular group of household members are very conversant with what goes on in the homestead.

Results in Chart 1 indicate that most (56%) of the interviewed mothers or women had achieved primary education. Very few (2%) of the women had attained either a diploma or degree. Also, the majority of the respondents 112 (42.6%) were protestants followed by 56 (21.3%) who were Roman Catholics. The other religions included Muslims 46 (17.5%), Pentecostal 26 (9.9%) and other religions 20 (7.6%).

**Chart 1: Education Status of Mothers of Children with Albinism CWA)**



### 6.4 Health Status

#### 6.4.1 Skin condition

Besides general characteristics of Persons with Albinism, the study set out to find out about the health of the different individuals. It is well documented that Persons with Albinism have their skin,



hair and eyes as the most vividly affected parts of the body. This section delves in how the different body parts are affected and what Persons with Albinism do to remedy the affected parts.

In Table 2, more than two thirds 178 (67.7%) of the Persons with Albinism did not know the cause of albinism. However, 214 (81.4%) of them knew about the harmful effects of the sun. This may be as a result of the first hand experience they may have had as a result of exposing their skins directly to the sun. Also, many Persons with Albinism (76%) did not know what causes skin cancer and how to prevent it (82.5%). Moreover only about a third of the Persons with Albinism have ever attended a skin clinic.

**Table 2: Health Status of the Skin**

Variable	N	%
Do you know causes of albinism		
Yes	85	32.3
No	178	67.7
Do you know about the harmful effect of the sun rays?		
Yes	214	81.4
No	42	16.0
Don't Know	7	2.6
Do you know what causes Skin Cancer?		
Yes	56	21.3
No	200	76.0
Don't Know	7	2.7
Do you know how to prevent Skin Cancer?		
Yes	39	14.8
No	217	82.5
Don't Know	7	2.7
Have you/child ever attended a skin clinic?		
Yes	73	27.8
No	183	69.6
Don't Know	7	2.7

Special interest was taken in how Persons with Albinism protect their skin from the harmful effects of the sun. Table 3 illustrates responses from the study participants. Persons with Albinism start applying sunscreen as early as the first year of life until a maximum age of 55 years. However, most Persons with Albinism apply sunscreen at an average (standard deviation) age of 12.6 (13.7) years.

**Table 3: Skin protection**

Variable	N	%
Do you know about Sunscreen?		
Yes	156	59.3
No	100	38.0
Don't Know	7	2.7
If yes, do you/child use sunscreens?		
Yes	132	50.2
No	23	8.7
No response	108	41.1
If yes, how often do you use/apply sunscreen?		
Daily	69	52.7
Sometimes	61	46.6
Never	2	0.7
Have you ever received free sunscreen?		
Yes	155	58.9
No	99	37.6
No response	9	3.5
How often do you get the free supply of Sunscreen		
Monthly	7	2.7
3months	22	8.4
6months	31	11.8
After 1 year	115	43.7
No response	88	33.4
Can you easily get sunscreen?		
Yes	29	11.0
No	227	86.3
No response	7	2.7
Do you buy Sunscreens?		
Yes	19	7.2
No	236	89.7
No response	8	3.1

Also, whereas over half of the Persons with Albinism know about, use and apply sunscreen daily, only 11% can easily access it. Most 115 (43.7%) Persons with Albinism rely on non-governmental organisations and well wishers for supplies. Even for those able to buy, the cost ranges between 15,000/= to 90,000/=. About 208 (81.3%) of the Persons with Albinism prefer to get their sunscreen from the nearest Health center. The photograph below shows a woman who has received a Sunscreen.



**Photo 1: Woman with Albinism displaying the Sun Screen she received for protecting her skin**

#### **6.4.2 Eye condition**

Results about the health status of the eyes of Persons with Albinism indicate that 199 (75.7%) of them have an eye problem. However, only 54 (20.5%) have had an eye check up. Whereas government has tried to play a major role in checking the eyes of Persons with Albinism, non-

governmental organisations have done the bulk of the work 29 (53.7%). The costs of the eye check up ranged between 30,000/= to 900,000/= with the average being 173,021/=. By the time of the survey, many Persons with Albinism had not had an eye check up because the health centers were very distant and the costs of transport to the health centers together with the costs of the check up made the whole exercise deterrent.

It was also astonishing to find that 179 (72.2%) of Persons with Albinism could not read clearly because they did not have any reading glasses. Moreover, almost half of the respondents (47.5%) admitted to not using anything to mitigate this challenge. Coping with these challenges included someone having to read for the Persons with Albinism or sitting at the front rows of the class. The photograph below shows the difficulty Persons with Albinism face while reading.



**Photo 2: Person with Albinism experiencing reading difficulty**

#### **6.4.3 Protection from the Sun**

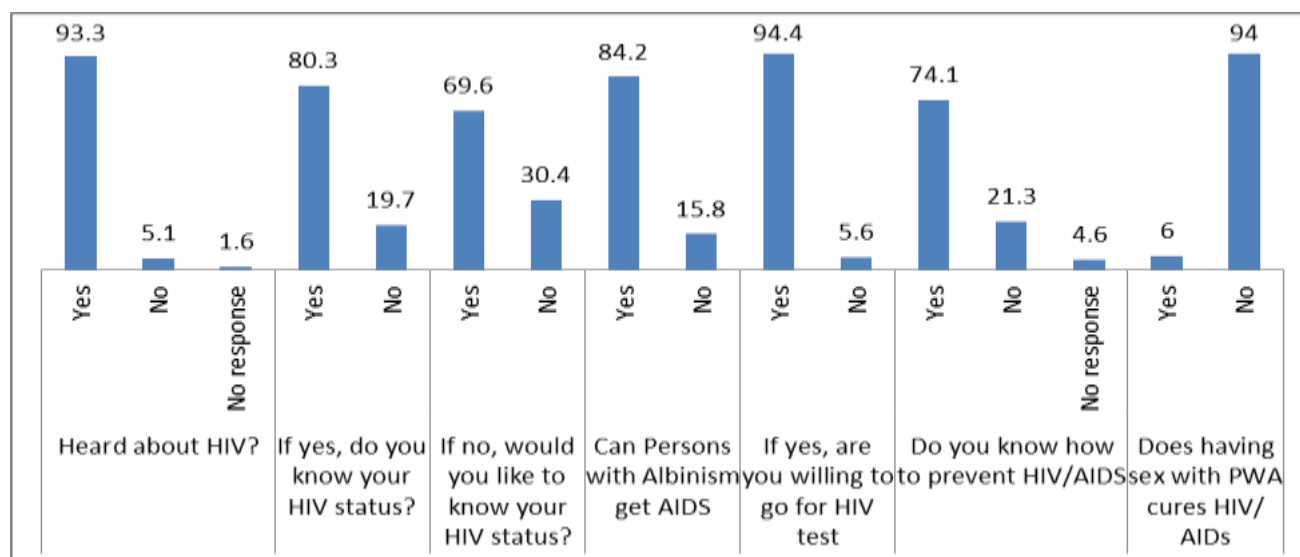
Protection from the sun is cornerstone to the well being of Persons with Albinism due to the lack of melanin pigment in their body. Thus, protecting affected areas such as the hands, eyes and the skin from the sun are paramount..As far as putting on a hat when outside the house was concerned, it was encouraging to find out that (70.4%) of Persons with Albinism made this a way of life. Furthermore,

over (50%) admitted to putting on a hat daily. On the other hand, 70.4% of Persons with Albinism said they did not use a headscarf whilst outside the house. This may point to the fact that hats are the more preferred forms of head gear compared to scarfs. Some of the women complained that the head scarves makes them feel hot. However, braiding of hair especially in the urban areas has been observed as a way of protecting the neck and back among the young ladies with Albinism.

#### 6.4.4 Knowledge about HIV/AIDS

The cross-sectional assessment revealed a high knowledge of HIV/AIDS among Persons with Albinism as displayed in figure 3 below.

**Figure 3 : Knowledge of PERSONS WITH ALBINISM about HIV/AIDS**



The vast majority 237 (93.3%) had ever heard about HIV/AIDS, 188 (80.3%) knew their HIV status. Among those who did not know their HIV status, 32 (69.6%) expressed willingness to know. A good number of Persons with Albinism 213 (84.2%) knew that Persons with Albinism can get infected with HIV/AIDS. Of all those interviewed, 201 (94.4%) were willing to go for the HIV test. Only 71 (28.3%) had never gone for an HIV test even once. It was also encouraging to find that 195 (74.1%) of Persons with Albinism knew how to prevent themselves from catching HIV/AIDS. Additionally, 236 (94%) of the respondents knew that having sex with a Persons with Albinism does not cure HIV/AIDS. It is worth noting that the 6% who think Persons with Albinism can cure HIV/AIDS are a cause to worry because it indicates that the myth still exists.

#### 6.4.5 Knowledge about Malaria

The study also explored knowledge of Persons with Albinism on Malaria because there was a misconception that Persons with Albinism do not suffer from malaria. Many Persons with Albinism 228 (89.8%) knew the actual cause of Malaria. Also, majority 195 (77.7%) knew how to treat malaria. Whereas 152 (60.1%) had suffered from malaria two weeks prior to the study, a large proportion of Persons with Albinism 210 (83.7%) knew how to prevent themselves from acquiring the illness.

#### **6.4.7 School Attendance and school environment**

As far as school was concerned, there was an equal proportion of children at school just as those out of school and the average distance to school from home was 6.6 km. The main reason for children being out of school was that they were still too young (36%) followed by the fact that they had no money to continue with education (27.2%).

Going to School is the first instance where children are exposed to the harmful rays of the sun on their way to school and back. The short sleeve uniforms, shorts and skirts expose the arms and legs to sunshine as they move around and play.



**Photo 4: School Children in Short Sleeved uniforms**

It was good to know that majority of Persons with Albinism who are in school seat in front of class 109 (87.9%) with just a few sitting either in the middle or at the back of the class. This may be due to the fact that more than two thirds of them have a reading problem and teachers know about this challenge.

#### **Bullying and calling of Derogatory names in Schools**

Children who reported to have been bullied or called derogatory names said that they had reported these incidences either to the teachers or parents. Perpetrators are said to have been appropriately punished. Some of the derogative names and nick names include: Pig, Sheep, Thing, Namagoye, Murondo but in some places they are called Muzungu and they feel good about it.

#### 6.4.9 Home Environment

Questions concerning the home environment for Persons with Albinism were also asked. Table 7 gives a summary of responses. It should be noted that whereas less than half (43.5%) of the children reported having been discriminated because of albinism, the discrimination happens both at school by fellow pupils and at home within the community by neighbours.

#### Discrimination and Rejection of Persons with Albinism

The discrimination does not seem to stop at any particular age. Persons with Albinism reported having been discriminated against since childhood to date. Discrimination of Persons with Albinism exists although at a very minimal level.

**Table 7: Home Environment**

Variable	N	%
<b>Ever been discriminated because of Albinism?</b>		
Yes	110	43.5
No	143	56.5
<b>Ever been discriminated by your family because of Albinism</b>		
Yes	39	15.4
No	215	84.6
<b>Rejected by your mother because of Albinism</b>		
Yes	20	8
No	231	92
<b>Do you know of a mother who rejected her child because of Albinism</b>		
Yes	31	12.3
No	222	87.7
<b>Have you/child been rejected by your/child's father because of Albinism</b>		
Yes	29	11.5
No	223	88.5
<b>Have you heard of a Person with Albinism who was kidnapped for sacrifice by witch doctors</b>		
Yes	39	15.4



No	214	84.6
<b>Have they ever attempted to kidnap you/child</b>		
Yes	20	7.9
No	223	92.1

#### **.Case 1: Rejection**

**A mother to a Child with Albinism in Teso was rejected by her husband because to him he can't have such children and that they have never had them in their homes. Because of the rejection and frustration, the lady looked for all possible ways to get rid of the baby. She could carry the baby under heavy rain so that it gets very sick and dies. Fortunately her sister decided to take the baby away from her and she is now the one taking care of this child.**

#### **Attempted Kidnap of Persons with Albinism**

Attempted kidnaps were reported by Persons with Albinism during the survey although the perpetrators either bribed their way out of police custody or were never brought to book because the police station was far.

#### **Case 2: Kidnap and Rescued**

**Five years ago, Ali was going to visit his brother in Tororo from Mbale. He stood by the road to get any vehicle that could take him. A saloon car with two occupants stopped and gave him a lift. After that he did not remember what happened. He thinks he was given Chloroform because he could not remember what happened. He came to his senses when the car was stopped by a traffic police man in Busia. He heard the Police asking the two men where they were taking him. They told the police that they found him unconscious by the roadside and that they were taking him to hospital. He saw them give the police something, he suspected it was money. The Police ordered them to get him out of the car. After some discussions with the policeman, they were left to continue their journey. He told the policeman that he was not sick. He was going to Tororo to visit his brother. Those two men gave him a lift said they were taking him to Tororo. He was surprised to find himself in Busia. The police took him back to Tororo. That is how he survived. He lives in constant fear because strange people keep coming to his home at odd hours of the night and sometimes knock at his door.**

There is therefore more need to protect Persons with Albinism. Again, many Persons with Albinism 111 (43.9%) were very worried about being kidnapped and have resorted to being indoors early.

#### 6.4.10 Family structure

From the 254 household respondents' answers, it was revealed that the average (SD) age of the household head was 45.8 (13.9) years. It was also revealed that there are an average of 8 (4.1%) people per household.

Asked how many siblings were in the household, study results show that there was an average of 4 (2.3%) siblings. It was also shown that from the 133 people that responded to this question, each respondent has 2 (0.9%) siblings that were Persons with Albinism.



**Photo 5a: Twin brothers with Albinism**



**Photo 5b: A sister and brother with Albinism**

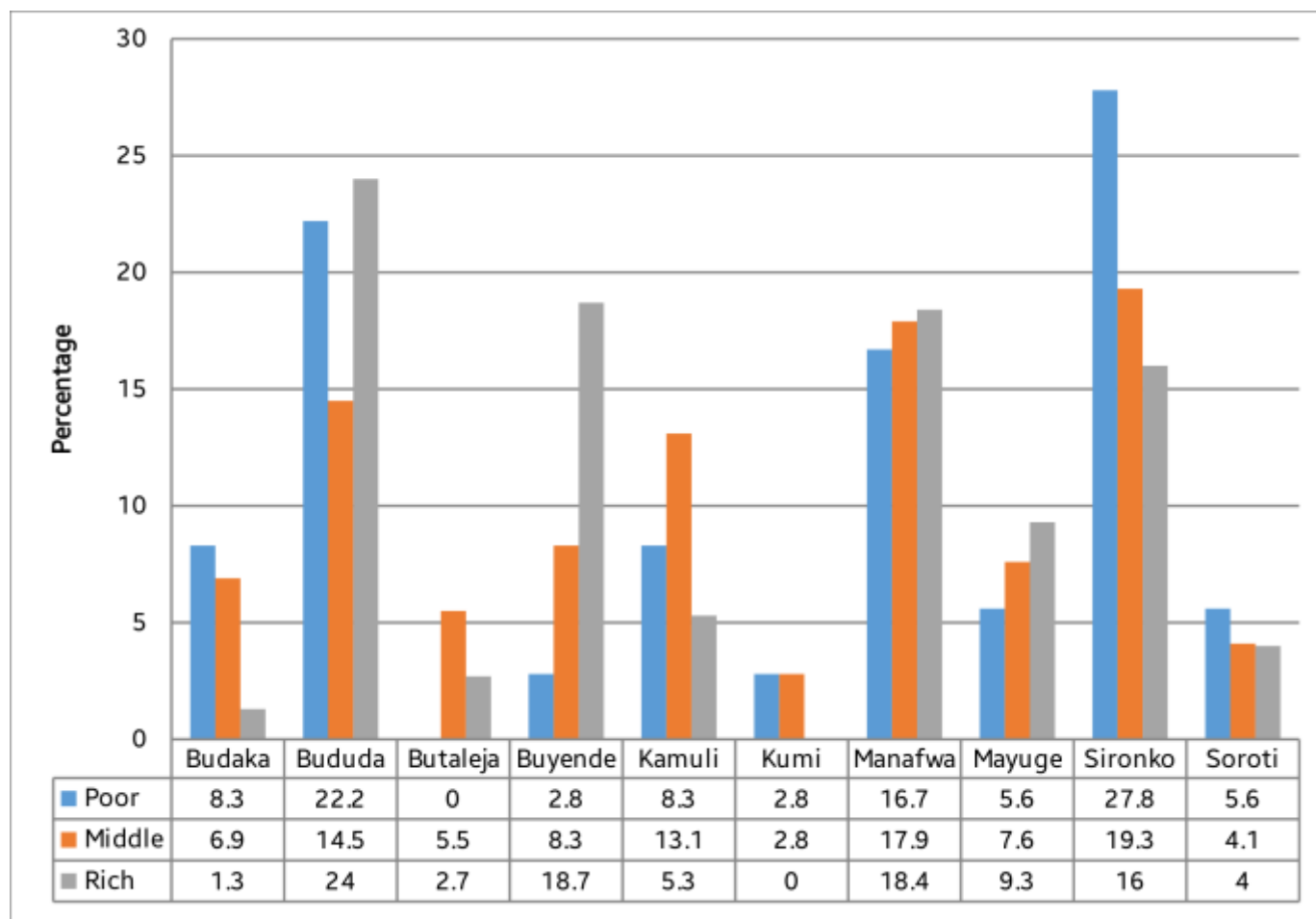
#### 6.4.12 Household Socio-Economic Status

Globally, eradication of poverty in all its forms has been identified as the number one goal in achieving the Sustainable Development Goals (SDG, 2015). Nationally, poverty eradication as indicated in the NDP II is one of the binding constraints to growth and development. Poverty indicators like the poverty head count ratio and Gini coefficient are some of the indicators Uganda uses to assess whether we will achieve the Uganda vision 2040.

The study set out to find out the socio economic status of households in the 10 districts. Results as displayed in Figure 7 indicate that Persons with Albinism in Sironko (27.8%) and Bududa (22.2%) are the poorest. On the contrary, Persons with Albinism in Bududa (24%) and Buyende (18.7%) are the richest. Bududa has fertile land, they grow Coffee, Bananas, Beans, Cabbages and other food

crops. Many of the households in Bududa also have Zero Grazing cows. Only 23 (9%) of the households had an account with any of the banks while only 73 (28.4%) of the households were in a SACCO.

**Figure 7 : Socio-Economic Status of PERSONS WITH ALBINISM Households**



In Manafwa, there was minimal difference between the rich, middle class and the poor. They were evenly distributed. In Buyende, there were more “rich” Persons with Albinism than the middle class and the poor based on the Gini coefficient.

A pearson correlation test was performed between wealth of households and number of people in the households on one hand, and number of people in the household with Albinism on the other. Results in Table 9 indicate that there a positive correlation between number of people in the household and increase in wealth and the results are statistically significant.

However, there is a negative correlation between number of people in the household with Albinism and increase in wealth. This could be due to the fact that Persons with Albinism and parents of Chldren with Albinsim spend a shorter time working in their gardens due to the sun and fear of the

young ones being kidnapped. Consequently, they may not be able to till big chunks of land to get more money than they are currently getting.

**Table 9: Pearson correlation test of household wealth and continuous variables**

Variable	Pearson correlation	P-value
Number of people in household	0.208	0.001
Number of people in household with albinism	-0.022	0.725

#### 6.4.13 Human Rights Provision

Human rights understanding and provisions for Persons with Albinism is based on the text and principles of the United Nation's "Universal Declaration of Human Rights". Responses were sought from households with Persons with Albinism on their understanding of their rights, the results are displayed in Table 10a.

About (40.2%) felt Persons with Albinism are not actually treated with dignity while (15.9%) did not even know whether Persons with Albinism are treated with any dignity. When it came to being treated with respect, (41.1%) indicated that they did not feel that Persons with Albinism were being treated with any respect. This proportion together with (12.6%) of the respondents who said they did know whether Persons with Albinism were being treated with equality and respect put the total number of Persons with Albinism with negative sentiments beyond (50%). More effort is needed to make society treat Persons with Albinism with a lot more dignity, freedom, equality and respect.

**Table 10a: Human rights of Persons With Albinism**

Variable	N	%
<b>PWA are treated with Dignity</b>		
Yes	108	43.9
No	99	40.2
I don't know	39	15.9
<b>PWA are treated as worthy humans</b>		
Yes	134	54.3
No	87	35.2
I don't know	26	10.5
<b>PWA are free, equal and are treated with respect.</b>		

Yes	114	46.3
No	101	41.1
I don't know	31	12.6
<b>Everyone deserves equal rights.</b>		
Yes	208	84.3
No	30	12.1
I don't know	9	3.6

When Persons with Albinism were asked whether they have the basic necessities such as adequate water, food, clothing and medicare, more than half of the respondents (52.8%) were in disagreement. Thus, besides not having the basic necessities, only (34.6%) of the Persons with Albinism felt that their rights are protected throughout the country. Also, only (28%) of the people who responded felt that the legal system provides effective remedies for Persons with Albinism whose constitutional rights have been violated.

A lot of work needs to be done to address the human rights plight of Persons with Albinism. Interventions to address these human rights challenges should target all Persons with Albinism and the institutions responsible for safeguarding these rights such as the police and the courts of law.

#### **6.4.14 Self Esteem among Persons with Albinism**

The study team was interested in knowing how Persons with Albinism feel about themselves. This was important because in order to have any successful intervention, attitude change is paramount. From the study findings, the vast majority of Persons with Albinism felt worthy (84.2%) and good (86.7%) about who they are. However, issues to do with safety, empowerment, discrimination and protection need further inquiry and strengthening.

#### **6.4.15 Facts, Myth and Misconceptions about Albinism**

The study team was also very interested in knowing whether myths and misconceptions that exist among the general population are shared with Persons with Albinism. From the results in Table 11, it was very good to know that there is a wide disparity between the community and Persons with Albinism. For instance, while some members of the wider community believe that body parts of Persons with Albinism possess good fortune when used in rituals, (65.5%) of Persons with Albinism disagreed. Nevertheless, there is more effort needed in sensitising Persons with Albinism about the myths and misconceptions that exist in society for their own safety.

**Table 11: Myths and Misconception about Albinism**

<b>Variable</b>	<b>N</b>	<b>%</b>
<b>PWA are born as a result of the sins of their mothers or parents or family</b>		
Agree	10	4.5
Disagree	186	83.4
I don't know	27	12.1
<b>Albinism is a result of the parent or child being bewitched or cursed</b>		
Agree	7	3.1
Disagree	188	84.3
I don't know	28	10.6
<b>Persons with Albinism are ghosts</b>		
Agree	3	1.4
Disagree	207	92.8
I don't know	13	5.8
<b>Body parts of Persons with Albinism, can be used in rituals for good fortune and riches</b>		
Agree	33	14.8
Disagree	146	65.5
I don't know	44	16.7
<b>The urine of a person with albinism can cure diseases</b>		
Agree	14	6.3
Disagree	149	66.8
I don't know	60	26.9
<b>When the hair of a person with albinism is put in the garden, it can result into good agricultural yield</b>		
Agree	19	8.6
Disagree	140	63
I don't know	63	28.3

#### 6.4.16 Distance of Key strategic places from home

In order to understand to what level Persons with Albinism are served, the investigators asked respondents about the distance from their homes to the different places that are considered strategic to Persons with Albinism as well as the general community.

Table 12 shows that Persons with Albinism have to travel almost 50km (47.5km) before they get any form of help from any organisation. The average distance to the nearest Secondary school was (5.93Km), Health facilities (3.8Km), Primary schools (3.08Km) and Police station (3.8Km).

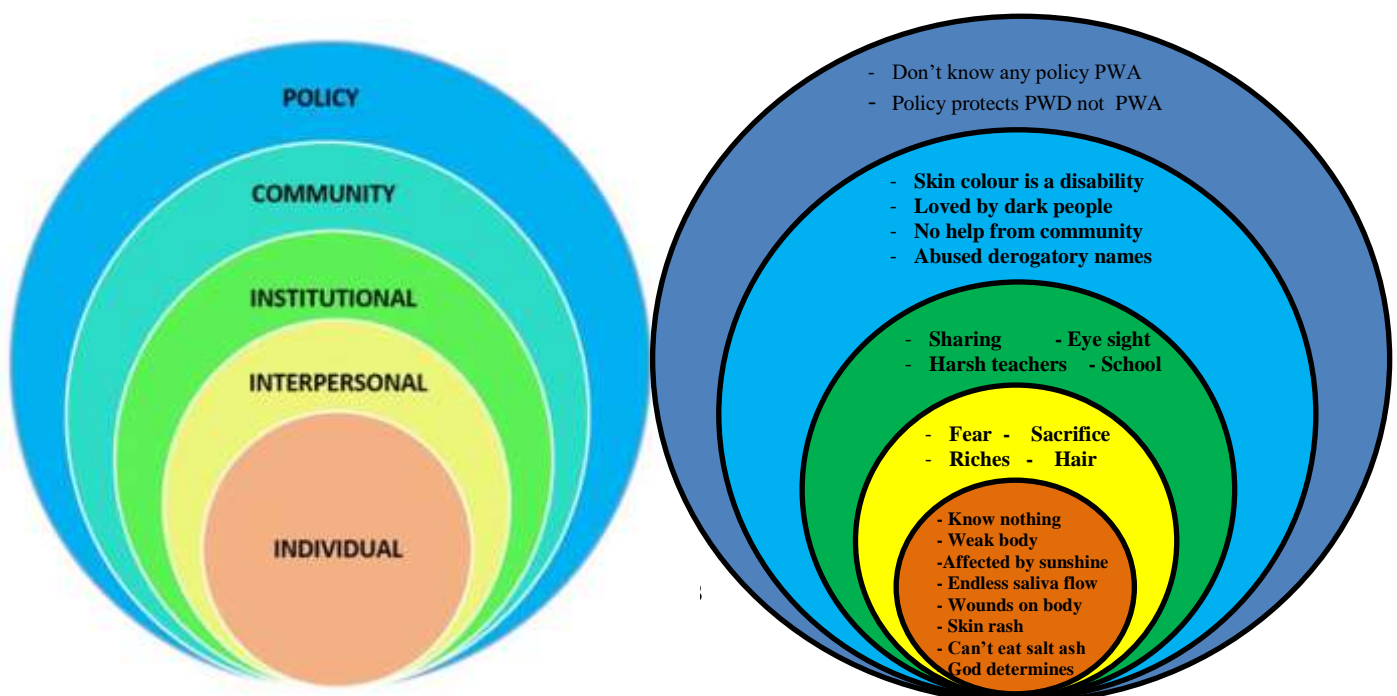
**Table 12: Distance from home to Service Provides or Organizations**

Distance (km)	N	Mean (km)	std. Dev
Distance of nearest Primary school	207	3.08	17.2
Distance of nearest Secondary school	204	5.93	48.8
Distance of nearest Health facility	203	3.8	17.6
Distance of nearest Trading center	198	1.41	0.88
Distance of nearest Police station	206	3.82	17.4
Distance of nearest Organization	13	47.5	75.4

## 6.5 Perceptions of Persons with Albinism towards the Community

We decided to assess the perception of the Persosns with Albinism towards themselves and the community they live in. Perceptions of Persons with Albinism were analysed using the ecological model. The model was used because it has been found to be a useful framework for understanding the range of factors that influence health and wellbeing from a public health perspective.

**Chart 2. Individual and Community Perceptions**





## 6.5 Individual Perception

Individual perceptions were captured by first assessing what Persons with Albinism actually knew as the main cause of Albinism. Notably, **most of the respondents did not know the actual cause** of albinism but rather attributed it to be an act of God.

*“To me I think that it depends on God’s will for anybody to be born or give birth to an Albino”*  
**IDI\_Kumi\_Mother to PWA.**

Even among those who tried to differ from this response, answers were centered about the general description of Persons with Albinism. They said that Persons with Albinism generally have weak bodies, tough skins, their skins are affected by the sunshine, have endless saliva flow, have wounds on their bodies and easily develop skin rash.

*“What I know about them, let me give my own experience. The body is somehow weak, the sun affects it, and we need to be in a good condition. The body doesn’t need to be under a lot of sunshine. We have to put on long sleeved clothes, boots, caps. We also need to have oils for smearing to help the body. The bones in the body, I’m giving a lived experience, if you strain them you need to have tablets to take to relieve the pain. Some people don’t want to associate with me and also when I am eating food the saliva flows endlessly. The eyes are can’t see very far (short sightedness)”*

**IDI\_Budaka\_Male PWA\_**



**Photo 6a: Chronic Ulcers on the leg**

Photograph 6 above, is an example of a chronic ulcer on the leg of a Person with Albinism from Budaka. He has had this wound for 5 years. He used to work as a taxi conductor but stopped because of the painful wound and people shunning his taxi because of the smell of the wound.

Cases of wounds and chronic ulcers were common among Persons with Albinism. Most of them when asked why they never sought for medical treatment they *indicated lack of money and discrimination by medical staff*. Since few of them have attended skin clinics, they do not know whether the wounds are cancerous or not.

*“I came back like I used to carry some merchandise (the raw sweet bananas) and I take to the market I kept on but as time went on i saw that the residue from these sweet bananas was falling on my body and it was getting dark and then I changed to selling hens and through that I also sold some goats but at times when I go and the sunlight is too much or the rain it beats me I have just left and I said that let me go and I stay maybe I can get what we can use to help the children and they also maybe get some knowledge, my friends who I can get in some money for business like a loan and I tried and remained with whatever I was doing because it didn't work out where I took the sweet bananas up to now I got very little so I didn't get and I remained working like that and I tried to get whatever I get.”* **IDI\_Bududa**

### **6.5.2 Interpersonal Perceptions**

Interpersonal perceptions were marred with a lot of fear. Persons with Albinism had either heard of a Person with Albinism being captured else where or unsuccessful attempts were made on them. They said that unless they moved in the company of people well known to them, the fear of having their hair and other body parts taken for sacrifice to witch doctors was not far fetched.

*“About albinos, we give birth to them but we are worried because they tell us that albinos have wealth; they want nails, the hair and everything that is on the body of an albino so I find that I am worried all the time, witch doctors need that child, people with spirits need the same child, that the hair costs millions so I find that I am scared/worried, protecting and looking after the child is not easy it is really hard time for me. This child's body is weak, this skin if there is nothing to smear on it dries up and looks bad and when the sun hits on the skin it really looks bad, develops wounds and if you are not the mother and God gave you such a child plus rumors from community members; those children are referred to as curses, bad luck, ekikulejje, my dear they refer to you as the one who gives birth to Bikulejje children”* **IDI\_Buyende\_Mother to PWA**

### **6.5.3 Institutional Perceptions**

The school environment was what was considered as the institution. Perceptions of children who were school going were either obtained from the children themselves or the care takers. When interviewed, some of the care takers said that their children faced challenges at school when it came to sharing. They said that fellow students at school did not want to share or sit near children with albinism. This was driven by the fact that such children feared that their skin colour would also change. Individually, many children with Albinism had dropped out of school because they had poor

eyesight which necessitated either using glasses or sitting at the front of the class. While many of them admitted that they had been allowed to sit at the front of the class, they said this was not enough because they had to strain a lot. This resulted in their dropping out of school.

*“Yes in English they say that somehow they segregated because even the teachers taught but we acted as an example to our colleagues in class because our eyes couldn't see very well on the black board so you had to go in front and see well before you write because you can't write what you have not seen and these friends are saying go away and when I add on the segregation I had to give up because as if I was wasting my time just.”* **IDI\_Manafwa**

School drop out was also rampant if the household head was a Person with Albinism. This is because such a person could not withstand long hours in scorching sunshine while gardening. As a result, income of such households was low leading to school drop out.

*“They tell you that the child needs to go to modern schools but you don't have money, they tell you the child needs to dress up well but at that moment you even don't have money to cater for those needs yet you also want the child to go to school, but when you don't have, when there is no where you can get it, you also admire your child to be in good conditions but you cannot make it”*

**IDI\_Buyende\_Mother to CWA**

#### **6.5.4 Community Perceptions**

In a bid to understand how Persons with Albinism live within their communities, different questions were asked to which variant responses were given. The perception of the community towards Persons with Albinism varied across the study districts. The community perception depended on the myth and misconceptions they held about them. In areas where they were considered ghosts who could bring bad omen and curses, community attitudes were negative towards them, thus they were discriminated against. In some parts of Elgon region, there are certain clans that people fear to marry from due to fear of producing Children with Albinism because Persons with Albinism are common in those clans.

However, in communities where they are referred to as “Muzungu”, they are accepted and empowered. For example, in the districts of Bududa, Manafwa and Sironko, the perceptions of community towards Persons with Albinism is positive. They are called Muzungu and greatly loved by the community. They mix freely with the community, drink and eat together with them unlike in other places where they are alienated and segregated. In Manafwa, one of the district councillor is a Person with Albinism who contested and won the election on merit.

In Teso Subregion, the community were ignorant about Albinism. They thought that they are like muzungus but they are shocked that they even speak the local language, they thought they are supposed to speak a certain kind of language. This shows that there is need to sensitize and educate the community on Albinism. Interesting to note, that even the district officials were ignorant about Albinism and their plight. Busoga Region was no exception, the community were also ignorant about albinism. What they know are the common myth and misconception.

When asked about marriage, respondents said that they were very much loved and preferred for marriage by dark skinned people than fellow albinos. However, they indicated to the researchers that they knew it was not a taboo for fellow albinos to get married to each other.

*“You never know but dark people want us a lot. And the number of albinos being small we can’t if we were many like we are here in this community it becomes easy to marry a fellow albino”*

**IDI\_Budaka\_Male**

When asked how much help Persons with Albinism get from their communities, many of the respondents said their communities which included the police, health facilities and churches were not helpful at all. Infact, in some instances, health workers feared to treat Persons with Albinism because **they feared their skins would get wounds**. Many of them decried the fact that they were not getting any organisational help.

*“when you go there in the health facility a person who doesn’t know you and fear to give you an injection, recently I fell sick I have been working hard I had cattle here and I suffered from Brucella so when I went there they tested me and found out I had it but they were fearing to inject me, so I told them it is okay, I have no problem, even putting on me a cannula they were fearing”*

**IDI\_Kamuli\_Kabukye**

In many communities, Persons with Albinism are called derogatory names such as pigs, demons, being mad, spirits and “muzungu” meaning white person. This to many, is very detasteful and demeaning.

### **6.5.5 Policy issues**

As far as policy issues were concerned, many interviewed Persons with Albinism confirmed to the researchers that they were not aware of any policy that protects Persons with Albinism. Even the few Persons with Albinism who knew of such a policy were grossly disappointed that they had been lumped together with people with disabilities. They said that because the policy was skewed not in their favour, even district meetings targeting people mentioned in this policy are mainly championed

by people with other disability. Infact, even when money meant to cover all persons mentioned in this policy reaches the district, it is only people with disabilities that benefit most.

*“Now like us we are here and we hear that your money has come at the District but when we go there they don't give it to us and we look on like the ones who are the leaders of the Disabilities are the ones to get hold of this money yet we were also elected like them and we are there like members and now we fail how do we get this help and now that's why i say that maybe like the CAO comes up and says your money has come and you plan for it as your money and this money reaches us but now to reach through these Councilors of the District we don't reach the money”* **IDI\_Buduuda\_TC**

## **6.6 Types of Albinism**

During the profiling of Persons with Albinism in Eastern Uganda, the research assistants were directed to homes of people whom the communitiess consiered to be “strange” because of the color of their eye, skins and hair. Although they did not fit the description of the Persons with Albinism we were looking for we decided to profile them because this was an interestng research finding that could inform future research studies on Albinism.

Albinism are generally divided into 2 types. Oculocutaneous (OCA) and Ocular Albinism (OA). OCA involves decreased pigment in the eyes, hair, and skin. There are 4 types of OCA that have been described depending on the type of genetic defect. According to Liz Freeman (2013) The most common type of albinism is called OCA2.

People with OCA2 can make some pigment, and the amount they make can vary a lot. They can look very light, or they can look almost like they don't have albinism at all. However, they will still look lighter than their siblings or family. Africans with OCA2 can actually get fairly dark skin, and they can have blue, green or hazel eyes. People with OCA2 can also get darker as they get older.

## CHAPTER EIGHT

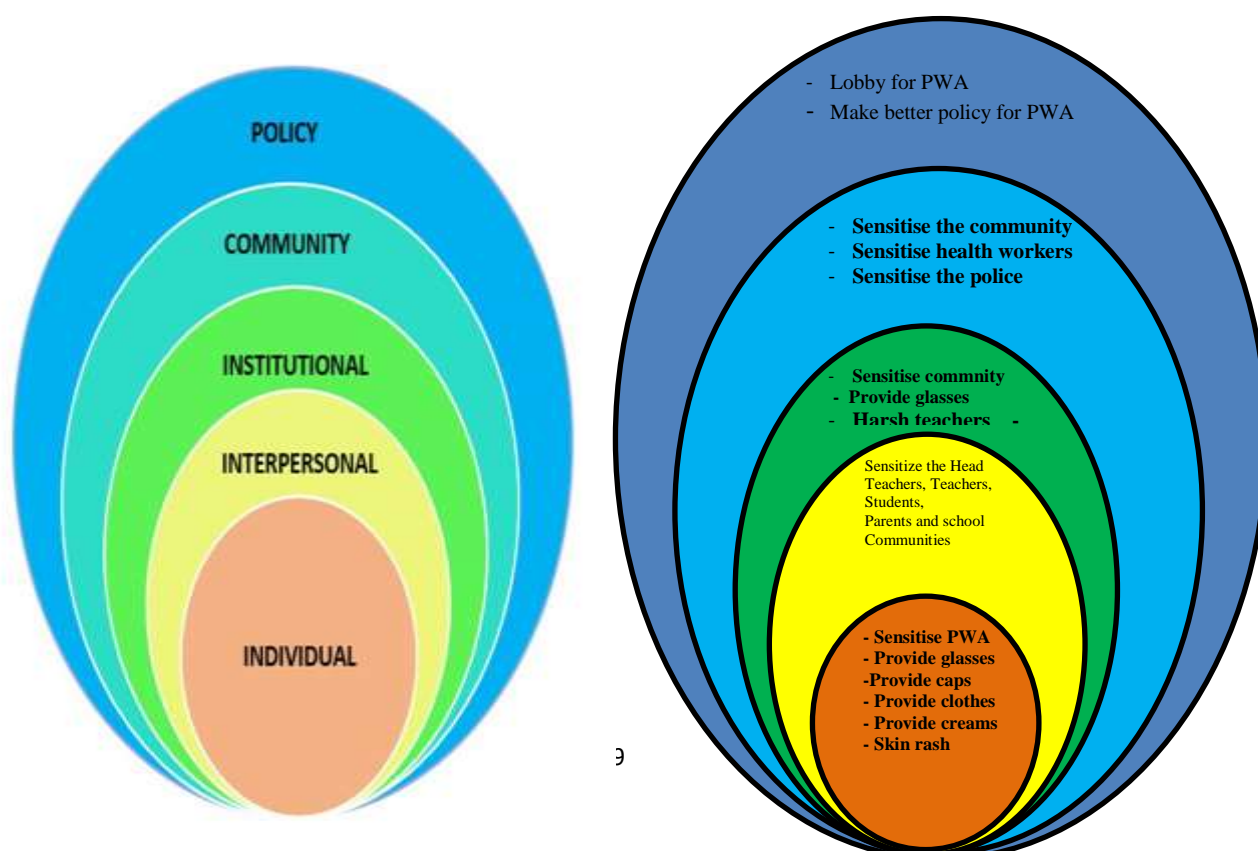
### CHAPTER 8

#### 8.0 CONCLUSION AND RECOMMENDATIONS

Conclusions of the research findings are based on the objectives of the study as well as responses from the participants. We identified, picked GPS coordinates and profiled 263 households of Persons with Albinism. Overall, there were more males than females profiled in the 10 selected districts except for Kamuli and Kumi where there were more females than male.

We also identified, mapped and profiled all existing service providers for Persons with Albinism in the 10 selected districts in Eastern Uganda. It was observed that there were very few organizations specifically serving Persons with Albinism and they were far. The most prominent is SNUPA (Source of the Nile Union of Persons with Albinism). There were a few Albinism Associations serving Persons with Albinism but they were newly formed and lacked funding. Furthermore, the study was interested in assessing community perceptions about albinism and Persons with Albinism on one hand and the perceptions of Persons with Albinism towards the community on the other hand. The findings are summarized in Chart 2 above.

**Chart 3: Ecological Model**



## 8.1 Conclusion

The research study also wanted to assess gaps in the current policies aimed at protecting Persons with Albinism. It was observed there is no specific policy that targets Persons with Albinism as a vulnerable population but they are lumped under Persons with Disability. As a result their unique needs and interest are normally ignored hence they do not benefit from Disability funds that come to the districts. The recommendations were guided by the ecological model above.

Persons with Albinism face a multitude of challenges that range from what affects the individual to what affects Persons with Albinism as a whole. Glaringly, fear and lack of self esteem remain the greatest challenges affecting the individual. The communities in which they live offer not very much beneficial help; and the schools, the police and church and the mosque which should be emotional cushions do not play their role. The policy meant to protect Persons with Albinism is not explicit enough and seemingly offers more protection to people with disability.

## 8.2 Recommendations.

### 8.2.1 The Individual

- **Persons with Albinism should be sensitised about the causes of albinism.**

This will be the starting point in the prevention pathway. With adequate knowledge, Persons with Albinism will be able to protect themselves from the harmful rays of the sun as well as put in place measures to mitigate harm that may be directly or indirectly related to them. Provision of glasses, caps, hats, long sleeved clothes is another consideration that should be made if Persons with Albinism are to live a more fulfilling life.

- **Making sun protection creams and lotions more accessible and affordable.**

For sustainability, research, development and production of Ugandan Sunscreens from locally available organic oils should be considered as an alternative. As a short term solution, government should import suncreens and make them available in health centers for free like other medicines. Government should also waive tax on the importation of sunscreens,

### 8.2.2 Interpersonal considerations

- **Sensitisation of the schools administration for all levels up to University.**

A lot of effort should be directed at sensitising the general school going community together with the teachers. Circulars or policy statements from the Ministry of Education can be an entry point into this sensitisation. A message to the effect that Persons with Albinism are

human beings just like the rest of the community should be a rhetoric emphasis year in-year out.

- There should be deliberate effort to identify and place children with albinism in schools.

The National Council for Children and the National Council for Disability should work with the Ministry of Education and Sports, local councils and local organizations of persons with albinism to identify, assess their educational needs and ensure that they are enrolled and supported in schools as a matter of affirmative action.

### **8.2.3 Institutional considerations**

- Institutional sensitisation should be done at national, regional and district level.

There is need for a lot of sensitisation for people in all institutions as PWA are served by various organisations eg, ministries, departments agencies, The police for instance should be prompted to act quickly when there is eminent danger and should offer services free of charge as mandated by the constitution of Uganda. The same should happen with hospitals, schools and potential employers.

- Other development partners need to support the spatial mapping of other regions.

This is a maiden research which highlights the voice of the vulnerable and represents a regional bias. This ought to be done in other parts of the country so as to make national conclusions for PWA.

### **8.2.4 Community Considerations**

- Demystify myths, superstitions and stereotypes about albinism

The biggest plea of Persons with Albinism towards the community is that the community should talk to them without being derogatory or disrespectful. There is need to be accorded the dignity so needed so as to restore confidence in Persons with Albinism. Myths, superstitions and stereotypes about albinism is due to ignorance or lack of information about albinism leading to strongly held beliefs at society level including in public and private institutions that provide services

### **8.2.5. Social Protection**

The Ministry of Gender, Labour and Social Development should liaise with other ministries like Ministry of Youth and Children, Finance to,



- ▶ include social welfare and poverty alleviation programmes for PWA.
- ▶ Recruit and train specialized teams including PWAs to provide counseling services to PWA and their caretakers.
- ▶ Encourage the formation of community self-help groups for PWA or the integration of PWA into such groups.

### 8.2.6 Challenges and Limitations

- Due to the scare of being kidnapped, some of the Persons with Albinism hid from the research assistants, therefore they were not profiled.
- In Sironko, the Research Assistants were chased from two homes. We were later informed that those households belong to a certain religion where they are not supposed to be counted. They do not allow their children to be immunized and they don't allow them to go to school.
- In one of the homes the head of the home came out with a panga. Luckily the research assistant had gone with the LC1 Chairman of the village.
- In Bududa and some parts of Manafwa, the Persons with Albinism live high up on the mountains. It could take the research assistants 2 hours to walk up the mountains because no bodaboda could reach there.
- The weather also posed a challenge because it would rain almost daily in the afternoon making the roads slippery and impassable both by cars and boda boda.
- Some of the respondents were fatigued by the endless interviews that bears no fruit to them, hence the unwillingness to participate in the research.

### 8.2.7 Interventions

*As part of the research activity, Albinism Umbrella distributed Sunscreens to all the Persons with Albinism that were profiled. The Suncreens were donated by Africa Albino Foundation.*

*Majority of the household visted had never heard of Sunscreens. The Executive Director, Albinism Umbrella also made arrangments with Mbale Referral Hospital to provide medical care for Persons with Albinism*

*teacher from Bududa who had cronic wound on his neck for 18 years. He had given up hope of any medical care because of lack of money and descrimination at the health facilities. He recently lost his teaching job because of the smell of the wound. At home, he was sleeping in the same room with chickens. The Principal Investigator took him to the hospital and he was admitted. Albinism Umbrella provided food, clothing and bought the prescribed medicines. After treament for one week, the wound got better and the bad smell was gone. He was discharged from the hospital, luckily some*

*well wishers contributed money and sent him to Nairobi Hospital for further treatment. This is an example of HOPE RESTORED!*

### **8.2.8 Expectations of the Respondents and Way forward**

They hope that Albinism Umbrella:

1. Will not forget to go back and check on them.
2. Will keep supplying them with the sunscreens so that they can also live longer.
3. Will help in providing education, reading materials and support to their children
4. They hope that some day they will be represented in Parliament
5. They request that Government offers them monthly eye checkup and skin clinic
6. Some PWA would like to get start- up capital or income generating activities

## **CHAPTER NINE**

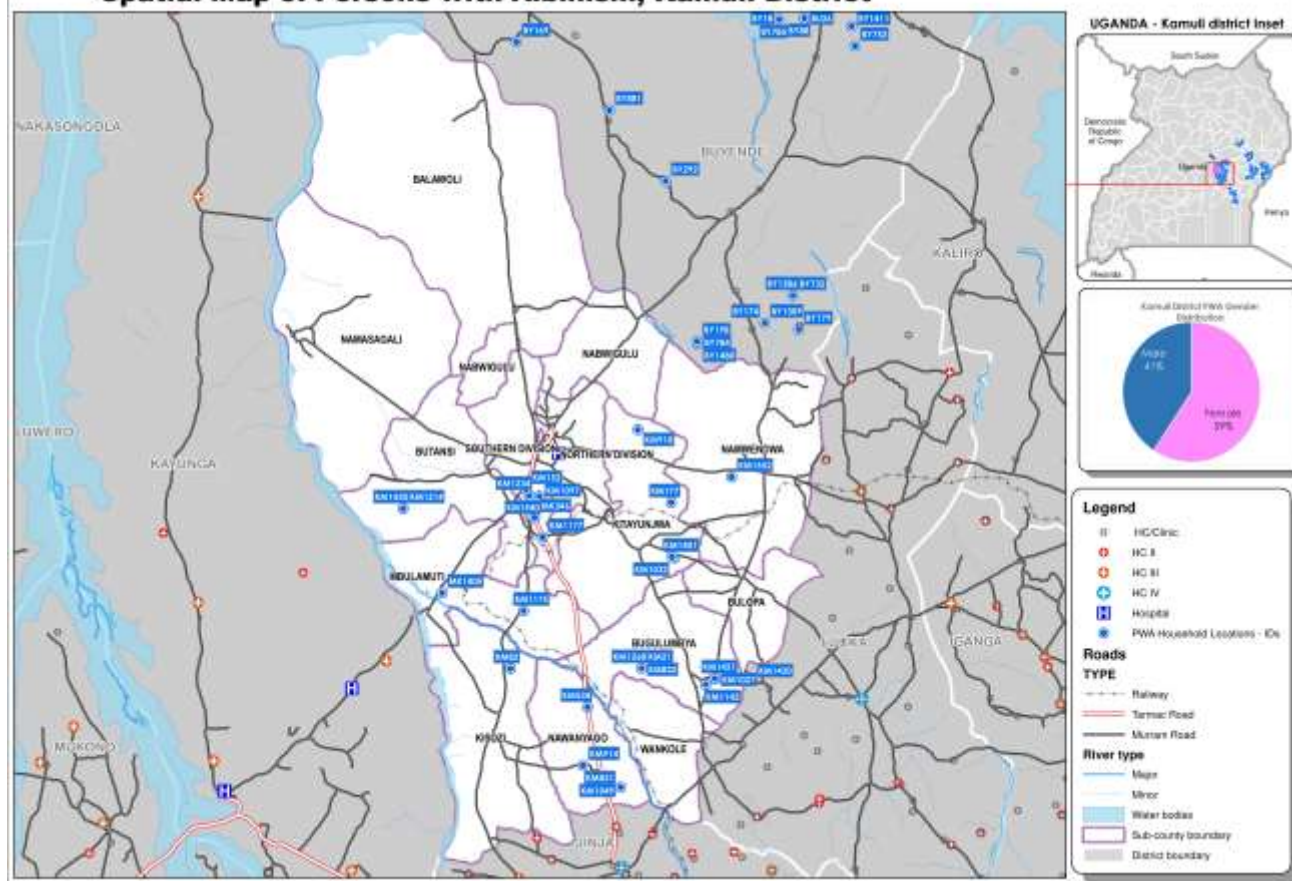
### **CHAPTER 9**

#### **9.0 SPATIAL MAPS SHOWING THE LOCATIONS OF PERSONS WITH ALBINISM**

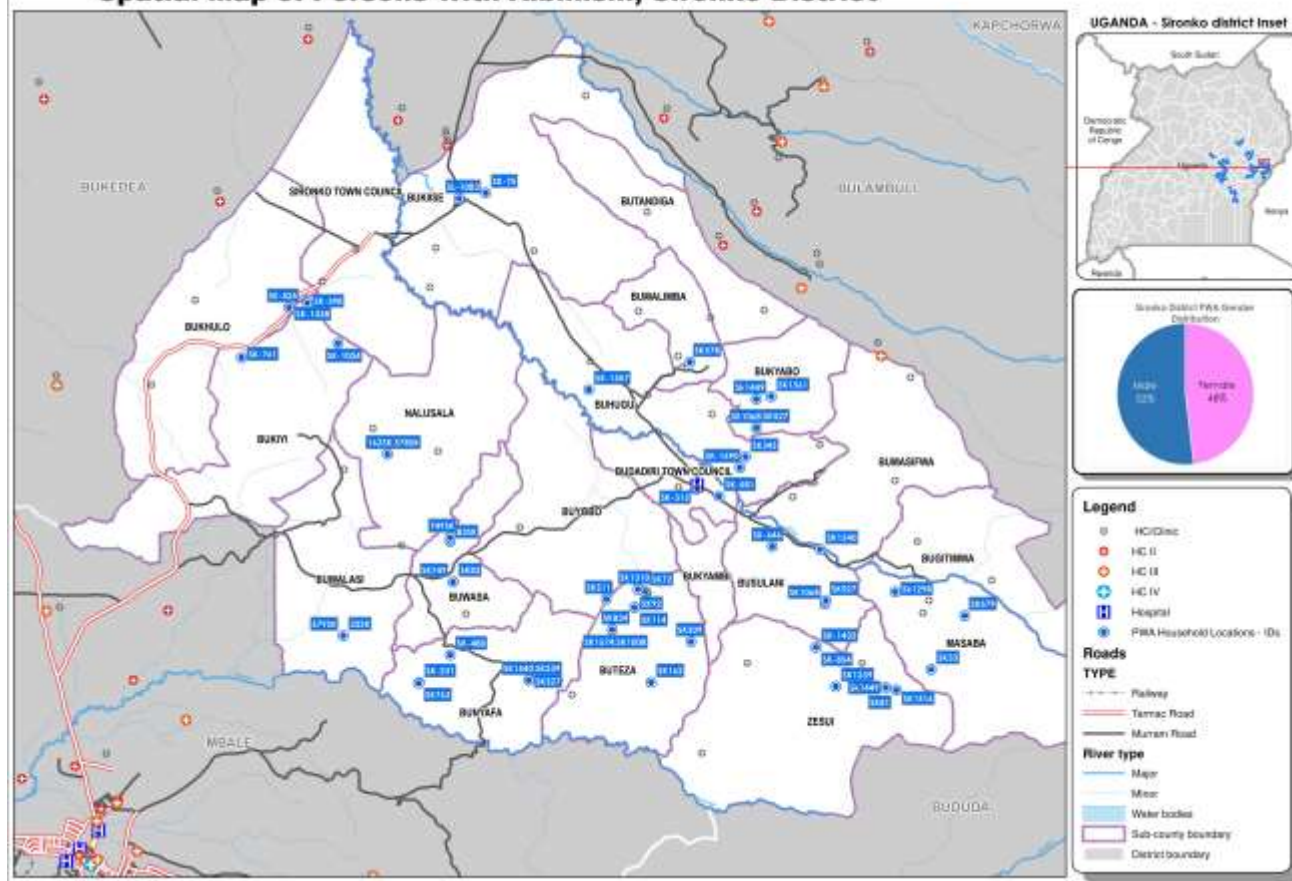
The main objective of this research study was to find out the households and distribution of Persons with Albinism in 10 selected Districts in Eastern Uganda.

Phones with Global Positioning System (GPS) capability was used to collect GPS coordinates from the households of Persons with Albinism. The coordinates were plotted using Geographical Information Systems and presented as geographical (Spatial) maps. Two examples of the patial maps showing the locations of Persons with Albinism is hshown below. Sironko district had the highest number of PWA.

**Spatial Map 5: Persons with Albinism, Kamuli District**



**Spatial Map 9: Persons with Albinism, Sironko District**



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## APPENDIX A: HOUSEHOLD QUESTIONNAIRE FOR PEOPLE WITH ALBINISM

### SECTION 1: INDIVIDUAL DATA FORM

#### A. BIO-DEMOGRAPHIC INFORMATION

1. ID/ PIN.....
2. (Develop an ID code).....
3. Name of PERSONS WITH ALBINISM.....
4. Gender ☐ Male ☐ Female
5. Age.....
6. Date of birth..... (dd mm-yyyy)
7. Which Category do you belong?
  - ☐ Parent of Child with Albinism (7 years and below)
  - ☐ Child with Albinism (8-17 years)
  - ☐ Adult with Albinism (18 years and above)
  - ☐ Persons with Albinism with Child With Albinism
8. Marital Status ☐ Single ☐ Married ☐ Cohabiting ☐ Separated ☐ Divorced
9. Education Level ☐ Not educated ☐ Primary ☐ Secondary ☐ Diploma ☐ Degree
10. Religion
  - ☐ Roman Catholic ☐ Church of Uganda ☐ Pentecostal ☐ Muslim
  - ☐ Others (Specify).....

#### B GEOGRAPHICAL LOCATION

1. District.....
2. County.....
3. Sub county.....
4. Parish.....
5. Village.....
6. **GPS Coordinates:** Latitude (x.y °) longitude (x.y °) altitude (m) accuracy (m)

## SECTION 2: HEALTH STATUS

### A. SKIN CONDITION

1. Do you know what causes Albinism condition (Lack of black pigment)?  
☐ Yes ☐ No  
a) If Yes (Explain) .....
2. Do you know about the harmful effect of the sun rays?  
☐ Yes ☐ No  
a) If yes, how do you protect yourself/child from the sun ray? .....  
b) What happens to your/child's skin when you/child stay in the sun for a long time?  
Explain briefly .....
3. Do you know what causes Skin Cancer?  
☐ Yes ☐ No  
a) If Yes  
b) Explain).....
4. Do you know how to prevent Skin Cancer?  
☐ Yes ☐ No  
a) If Yes  
(Explain).....
5. Do you know about Sunscreen?  
☐ Yes ☐ No  
a) If yes, do you/child use sunscreens?  
☐ Yes ☐ No  
b) If yes, at what age did you/child start using sunscreen?..... Why? .....  
c) If yes, how often do you use/apply sunscreen?  
☐Daily ☐sometimes ☐Never
6. If you/child use sunscreens daily, where do you get the Sunscreen from? .....  
a) If you have never used sunscreen, can you tell us why? .....
7. Have you ever received free sunscreen?  
☐ Yes ☐ No  
a) If yes, who (individuals or organization) gives/gave you? .....  
b) How often do you get the free supply of Sunscreen? .....  
c) If No, what do you apply on your skin? .....
8. Can you easily access sunscreen?  
☐ Yes ☐ No

9. Do you buy Sunscreens?

☐ Yes ☐ No

- a) If yes, where do you buy from? .....
- b) How much do you pay? .....
- c) What quantity in (grams/mls) is the Sunscreen.....
- d) What is the brand name and where is it manufactured?.....
- e) If no, why don't you buy? .....

10. Would you prefer to receive the sunscreen form the health center nearest to you?

☐ Yes ☐ No

### **B. Eye Condition**

11. Do you/your child have any problem with the eyes?

☐ Yes ☐ No

- a) if yes, what is the problem with the eyes? .....

12. Have you ever gone for an eye checkup?

☐ Yes ☐ No

- a) If yes, where did you go for the check up? .....
- b) Who conducted the eye checkup
  - ☐ Government doctors ☐ Lions Club ☐ other organizations
  - (Specify) .....
- c) If no, Why not? .....

13. Did you pay for the eye checkup?

☐ Yes ☐ No

- a) If yes, how much did you pay? .....
- b) When did you last go for an eye checkup? .....
- c) Where did you go for the eye check-up .....

14. Can you read clearly without a reading glass?

☐ Yes ☐ No

- a) If no, what do you use?
  - ☐ Spectacles ☐ Magnifying glass ☐ Binoculars
- b) Where do you buy the reading aids from? .....

### C. Protection from the Sun

15. Do you use a Sunglass when you are out in the sun?

☐ Yes ☐ No

a) If yes, how often?

☐ Daily ☐ sometimes ☐ Never

b) If no, why not? .....

16. Do you use a hat when you are out in the sun?

☐ Yes ☐ No

a) If yes, how often?

☐ Daily ☐ sometimes ☐ Never

b) If no, why not? .....

17. Do you use head scarf when you are out in the sun?

☐ Yes ☐ No

a) If yes, how often?

☐ Daily ☐ sometimes ☐ Never

b) If no, why not? .....

18. Do you wear long shirt or blouse?

☐ Yes ☐ No

a) If yes, how often?

☐ Daily ☐ sometimes ☐ Never

b) If no, why not? .....

19. How many hours a day to you work under the sun? .....

### D. Knowledge about HIV/AIDS

20. Have you heard about HIV?

☐ Yes ☐ No

a) If yes, do you know your HIV status?

☐ Yes ☐ No

b) If no, would you like to know your HIV status?

☐ Yes ☐ No

21. Can Persons with Albinism get AIDS?

☐ Yes ☐ No

a) If yes, are you willing to go for HIV test?

☐ Yes ☐ No



22. When did you last test for HIV?

☐ Never ☐ Less than 6 months ago ☐ One year ago ☐ Two years ago ☐ More than 3 years

23. Do you know how a person can get infected with HIV/AIDS?

☐ Yes ☐ No

a) If yes, explain .....

24. Do you know how to prevent HIV/AIDS?

☐ Yes ☐ No

a) If yes, explain .....

25. Has anyone ever told you that having sex with Albino cures AIDS?

☐ Yes ☐ No

a) If yes, explain .....

### **E. Knowledge about Malaria**

26. Do you know what causes Malaria?

☐ Yes ☐ No

a) If yes, explain .....

27. Do you know the treatment of Malaria?

☐ Yes ☐ No

a) If yes, what medicine do you normally take? .....

b) Where do you get treatment from? .....

☐ Village Health Team (VHT) ☐ Drug shop ☐ Health Centre ☐ Hospital

28. Which health facility do you go to when you are sick? .....

a) How far is the health facility from your home (Miles/Km) .....

29. Do you know how to prevent malaria?

☐ Yes ☐ No

a) If yes, explain .....

30. Have you suffered from malaria in the past two weeks?

☐ Yes ☐ No

### **F. Other Health Conditions**

31. Do you have any chronic health conditions/complications?

☐ Yes ☐ No

a) If yes, what is the health condition? .....

32. Do you know of any albino who has died?

☐ Yes ☐ No

- a) If yes, what was the cause of the death? .....
- b) At what age did he or she die? .....

### SECTION 3: SOCIAL STATUS

1. Are you/child currently in school?
  - ☐ Yes ☐ No
  - a) If no, explain .....
  - b) If yes, which school do you/child go to? .....
  - c) How far is the school from your home? .....
  - d) Where do you sit in class?
    - ☐ Front ☐ Middle ☐ Back
2. Do you have a problem reading what the teacher writes on the blackboard/white board?
  - ☐ Yes ☐ No
  - a) If yes, have you inform the teacher/administrator about this problem?
    - ☐ Yes ☐ No
  - b) If yes, what did the teacher/administrator do to address the problem? .....
  - c) Did you inform your parents/guardian about the problem of not reading what is written on the black board?
    - ☐ Yes ☐ No
  - d) If yes, what did your parent/guardian do? .....
3. Do/did children bully or call you derogatory or nick names at school?
  - ☐ Yes ☐ No
  - a) If yes, what name do/did they call you at school? .....
  - b) When they bully you or called you names do/did you report them?
    - ☐ Yes ☐ No
  - a) If yes, who do/did you report them to? .....
  - a) If no, why not? .....
  - (Stage in life)
4. What do they call an Albino in your local language? .....
5. Have you/child ever been discriminated because you/child is an albino?
  - ☐ Yes ☐ No
  - a) If yes, by who? .....
  - b) At what age/stage in life? .....
  - c) Where?.....

6. Have you/child ever been discriminated by your family because you/child is an albino  
☐ Yes ☐ No
7. Have you been rejected by your mother because you are an albino?  
☐ Yes ☐ No
8. Do you know of a mother who rejected or abandoned her child because she/he was albino?  
☐ Yes ☐ No
9. Have you/child been rejected by your/child's father because you/child is an albino?  
☐ Yes ☐ No
10. Have you heard of albinos being kidnapped for sacrifice by witchdoctors?  
☐ Yes ☐ No
11. Have they ever attempted to kidnap you/child?  
☐ Yes ☐ No
- a) If yes, when? (Date, month, year and time, if you remember) .....
- b) Where? .....
- c) How did you/child escape? .....
- d) Did you report the case to Police?  
☐ Yes ☐ No
- a) If yes, what did the police do? .....
- b) If no, why didn't you report? .....
12. Are you afraid or worried that you/child could be kidnapped and killed one day?  
☐ Yes ☐ No
- a) If yes, how can you protect yourself/child and avoid being kidnapped? .....
13. Do you know any Albino who has been by kidnapped?  
☐ Yes ☐ No
- a) If yes, when? .....
- b) Where did they take him or her? .....
- c) What did they do to him or her? .....
14. Do you know any Albino who has been by killed?  
☐ Yes ☐ No
15. Do you know any Albino girl who has been rape?  
☐ Yes ☐ No
16. Do you know any Albino girl who was defiled?  
☐ Yes ☐ No
- a) If yes, was the case reported?

☐ Yes ☐ No

b) If yes, to who was the case reported? .....

☐ Police ☐ The LC1 Chairman ☐ Other (specify) .....

c) Was the defiler caught?

☐ Yes ☐ No

d) If yes, what did they do to the defiler? .....

17. Do you know any Albino girl who was raped?

☐ Yes ☐ No

a) If yes, was the case reported?

☐ Yes ☐ No

b) If yes, to who was the case reported? .....

☐ Police ☐ The LC1 Chairman ☐ Other (specify) .....

c) Was the rapist caught?

☐ Yes ☐ No

d) If yes, what did they do to the rapist? .....

18. What do you want to become when you finish school? .....

(For Persons With Albinism only)

#### **SECTION 4. FAMILY STRUCTURE**

1. What is the name of the household head? .....

2. What is the age of family head? .....

3. How many people are in the family? .....

4. How many number of siblings do you have? .....

5. What is your Birth Order? (First born, middle or last born) .....

6. How many of your brothers and sisters are albinos (Persons With Albinism)? .....

7. Do you know of any relatives who are albinos?

☐ Yes ☐ No

a) If yes, who? (Specify) .....

8. Is your father/child's father alive?

☐ Yes ☐ No

a) If no, what was his age at death .....

b) If no, what was the cause of father's death .....

9. Is your mother/child's mother alive?

☐ Yes ☐ No

- a) If no, what was her age at death .....
- b) If no, what was the cause of mother's death .....
10. If the your/child's father is alive, what is the current occupation/ main economic activity of father? .....
11. If the your/child's mother is alive, what is the current occupation/ main economic activity of mother? .....
- a) How many children did mother produce? .....
- b) How many are alive? .....
- c) How many died? .....
- d) How many of the children are/were albinos? .....
12. Who do you/child live with?
- ☐ Father and mother ☐ Father ☐ Mother ☐ Aunt ☐ Uncle ☐ Grandparents
- ☐ Other .....
13. What is the highest level of education attained by the head of the family?
- ☐ None ☐ Primary ☐ O' Level ☐ A' Level ☐ Certificate ☐ Diploma ☐ Degree ☐ Masters ☐ PHD
14. What is the main sources of household income? .....
15. If both parents are alive, are they living together? ☐ Yes ☐ No
- a) If no, why not? .....

## **SECTION 5. HOUSEHOLD CHARACTERISTICS (Poverty Index)**

Note to Research Assistant : (You can ask any member of the household).

1. Do you have electricity in your house?  
☐ Yes ☐ No
2. Do you have a radio?  
☐ Yes ☐ No
3. Do you have a television set?  
☐ Yes ☐ No
4. Do you have a refrigerator?  
☐ Yes ☐ No
5. Do you have a bicycle?  
☐ Yes ☐ No
6. Do you have a motorcycle (Boda Boda)?  
☐ Yes ☐ No
7. Do you have a car/truck?

- ☐ Yes ☐ No
8. Do you have a mobile phone?  
☐ Yes ☐ No
9. Do you share toilet/latrine with others?  
☐ Yes ☐ No
10. Do you own a toilet?  
☐ Yes ☐ No
11. Do you own an engine boat?  
☐ Yes ☐ No
12. Do you own land for Agriculture?  
☐ Yes ☐ No
13. Do you own any animals?  
☐ Yes ☐ No  
a) If yes, specify the number .....
14. Owns cattle  
☐ Yes ☐ No  
a) If yes, specify the number .....
15. Owns goats  
☐ Yes ☐ No  
a) If yes, specify the number .....
16. Owns sheep  
☐ Yes ☐ No  
a) If yes, specify the number .....
17. Owns chickens  
☐ Yes ☐ No  
a) If yes, specify the number.....
18. Owns pigs  
☐ Yes ☐ No  
a) If yes, specify the number.....
19. Has bank account(s)  
☐ Yes ☐ No
20. Has savings with the local Sacco  
☐ Yes ☐ No

21. Has tables

☐ Yes ☐ No

22. Has Chairs

☐ Yes ☐ No

23. Has a sofa set

☐ Yes ☐ No

24. Has beds

☐ Yes ☐ No

25. Has a cupboard

☐ Yes ☐ No

26. Has a clock

☐ Yes ☐ No

27. Has land for farming

☐ Yes ☐ No

a) How many acres of land for farming.....

28. What is your source of farming land?

☐ Own ☐ Hired or leased ☐ Community ☐ Other .....

a) Specify other source of land if any .....

29. Has land for grazing

☐ Yes ☐ No

## **SECTION 6: KEY HEALTH INDICATORS**

1. Do you have a toilet?

☐ Yes ☐ No

2. What is the type of toilet or latrine?

☐ VIP latrine ☐ Flash toilet ☐ Latrine without roof ☐ Latrine without walls ☐ Mobile toilets

☐ Latrine ☐ None

3. What is the type of house?

☐ Permanent ☐ Semi-Permanent ☐ Temporary ☐ Others .....

4. How many rooms are in the house? .....

5. What is the type of wall?

☐ Cement ☐ Cow dung ☐ Mud ☐ Tiles

a) Specify other type of wall if any .....

6. What is the type of floor in the house?

☐ Cement ☐ mud and wattle ☐ Exposed Bricks

- a) Specify other type of floor if any .....
7. What is the type of roof on the house?
- ☐ Iron sheets ☐ Roofing Tiles ☐ Grass ☐ Tarpaulin
- a) Specify other type of roof if any .....
8. What is the source of lighting?
- ☐ Main Grid Electricity ☐ Solar ☐ Kerosene Lamp ☐ Chargeable lamp ☐ Candle
- ☐ Poorlamp (Tadoba)
- a) Specify other type of lighting if any .....

## SECTION 7. HUMAN RIGHTS PROVISION

This questionnaire is aimed at assessing human rights understanding and provision for Persons With Albinism in the Constitution of Uganda. It is based on the text and principles of the United Nation's "Universal Declaration of Human Rights."

### A. In Uganda:

1. All people deserve to be treated as free and equal.  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
2. Persons with Albinism are treated with Dignity  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
3. Persons With Albinism are treated as worthy humans.  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
4. Persons with Albinism (Persons With Albinism) are free, equal and are treated with respect.  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
5. Everyone deserves equal rights.  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
6. Equal rights are extended to people regardless of race, color, religion, social origin, or natural origin.  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
7. Persons with Albinism enjoy equal rights like other Persons With Disabilities (PWDs)  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
8. Persons with Albinism feel safe  
☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree
9. Persons with Albinism have the right to employment  
☐ True ☐ False ☐ I don't Know



10. Persons with Albinism have a standard of living adequate for health and wellbeing.  
☐ True      ☐ False      ☐ I don't Know
11. Persons with Albinism have adequate water, food, clothing, housing, and medical care.  
☐ True      ☐ False      ☐ I don't Know
12. Persons with Albinism have needed social services  
☐ True   ☐ False   ☐ I don't Know
13. Rights of Persons with Albinism are protected throughout the country.  
☐ True   ☐ False   ☐ I don't Know
14. The laws do not discriminate against Persons with Albinism.  
☐ True   ☐ False   ☐ I don't Know
15. The Legal System provides effective remedies for Persons with Albinism whose constitutional rights have been violated.  
☐ True   ☐ False   ☐ I don't Know

**B. As a Person with Albinism:**

16. I feel worthy.  
☐ Yes      ☐ No
17. I feel good about who I am.  
☐ Yes      ☐ No
18. I feel safe in my community  
☐ Yes      ☐ No
19. I feel empowered  
☐ Yes      ☐ No
20. I feel discriminated  
☐ Yes      ☐ No
21. I feel protected  
☐ Yes      ☐ No

**C. Uganda Constitutional provision**

22. Everyone in Uganda is protected equally by the law.  
☐ True   ☐ False   ☐ I don't Know
23. As a Persons With Albinism, I am recognized by the Constitution of my country.  
☐ True   ☐ False   ☐ I don't Know
24. Social protections extends to all children with albinism

☐ True ☐ False ☐ I don't Know

25. Children with albinism have free access to education

☐ True ☐ False ☐ I don't Know

## SECTION 8: FACTS, MYTH AND MISCONCEPTIONS ABOUT ALBINISM

1. Persons with Albinism are born as a result of the sins of their mothers or parents or family;

☐ Agree ☐ Disagree ☐ I don't know

2. Albinism is a result of the parent or child being bewitched or cursed

☐ Agree ☐ Disagree ☐ I don't know

3. Persons with Albinisms are ghost?

☐ Agree ☐ Disagree ☐ I don't know

4. Body parts of Persons with Albinism, can be used in rituals for good fortune and riches

☐ Agree ☐ Disagree ☐ I don't know

5. The urine of a person with albinism can cure diseases

☐ Agree ☐ Disagree ☐ I don't know

6. The hair of a person with albinism can put in the garden can result into good agricultural yield

☐ Agree ☐ Disagree ☐ I don't know

7. Persons with Albinism cannot get married

☐ Agree ☐ Disagree ☐ I don't know

8. Marrying a Persons with Albinism brings good luck or fortune to the couple

☐ Agree ☐ Disagree ☐ I don't know

9. Persons with Albinism are evil cannibals (Eat human flesh) they especially eat naughty or misbehaved children

☐ Agree ☐ Disagree ☐ I don't know

Children with albinism are a result of a black mother reproducing with a white man

☐ Agree ☐ Disagree ☐ I don't know

10. Having sex for albinos is by chance and not by choice

☐ Agree ☐ Disagree ☐ I don't know

11. Persons with Albinism are sterile (cannot produce children)

☐ Agree ☐ Disagree ☐ I don't know

12. A person with albinism cannot be successful in life

☐ True ☐ False ☐ I don't know

13. There is no cure for albinism, but some symptoms can be treated.  
☐ True ☐ False ☐ I don't know
14. Albinism is a genetic condition.  
☐ True ☐ False ☐ I don't know
15. Primarily, albinism affects the hair, eyes, skin, and vision.  
☐ True ☐ False ☐ I don't know
16. Albinism is caused by lack of production of melanin in the skin, hair and eyes.  
☐ True ☐ False ☐ I don't know

## SECTION 9: DISTANCE AND LOCATION OF SERVICE PROVIDES

1. What is the distance to nearest Primary School in Kilometers? .....  
GPS Coordinates.....
2. What is the distance to nearest secondary school in Kilometers?.....  
GPS Coordinates.....
3. What is the distance to nearest tertiary institution in Kilometers?.....  
GPS Coordinates.....
4. What is the distance to nearest Health Facility in Kilometers?.....  
GPS Coordinates.....
5. What is the distance to nearest Town/ urban/trading center in Kilometers?.....  
GPS Coordinates.....
6. What is the distance to nearest police station/post in Kilometers?.....  
GPS Coordinates.....
7. What is the name of the nearest NGO where you get any form of  
help?.....
8. What is the distance to the nearest service provider (NGO) in Kilometers?.....  
GPS Coordinates.....

Name of the research Assistant.....

Mobile number .....

Signature..... Date.....

## APPENDIX B: QUESTIONNAIRE FOR ORGANIZATIONS SERVING PERSONS WITH ALBINISM

1. Name of the organisation.....
2. District.....
3. County.....
4. Sub county.....
5. Parish.....
6. Village.....
7. GPS Coordinates: Latitude (x.y °) longitude (x.y °) altitude (m) accuracy (m)
8. Age of organisation head.....
9. Number of years of organisation existence.....
10. Number of staff members in the organisation.....
11. Services offered by the organisation
  - a) Health
  - b) Education
  - c) Finance
  - d) Security
  - e) Counselling
  - f) Job seeking
12. Do you have agencies that fund you                      Yes                      No
13. How much do you receive per year (skip if answer in 7 is No).....
14. How many Persons with Albinism do you take care of.....
15. What is the average distance between the office and the households you serve?.....
16. What is the average age of the people you look after.....
17. What are the major constraints you experience as a service provider?
  - a) Funding
  - b) Under staffing
  - c) Bad government polices
  - d) Weak prosecution of offenders
  - e) Long distance to hoseholds
  - f) Bad roads
  - g) Lack of transport
  - h) No support by village leaders
  - i) Lack of awareness that we exist

## **APPENDIX C : INTERVIEW GUIDE FOR COMMUNITY LEADERS, CARETAKERS AND SERVICE PROVIDES**

1. What do you know about Persons with Albinism?

Probe: for beliefs on whether body parts of Persons with Albinism possess magical powers.

2. How do yo feel they should be living in the society?

Probe: for special schools and amenities

3. How do you feel about the difference between you and Persons with Albinism?

4. To what extent do you think the community has been helpful to Persons with Albinism

Probe for: help at school,hospitals, police etc

5. In your view, what problems do Persons with Albinism face?

6. What do you think should be done to improve the living conditions of Persons with Albinism?

**Thank you for your time**

## **APPENDIX D: FOCUS GROUP DISCUSSION GUIDE FOR POLICY ANALYSIS**

**Introduction:** Purpose of this focus discussion is to understand the context in which the policy of Persons with Albinism was formulated. We will begin by exploring your knowledge about Persons with Albinism

- a. Please tell us your experience with Persons with Albinism (*probe for the challenges they go through*)
- b. How do the views of Persons with Albinism always get to leaders in your community?
- c. What policies protect Persons with Albinism? (*Probe for name and number of policies the community knows*)
- d. How were you involved in formulation of this policy (*probe involvement, stakeholders and inclusion.*)
- e. To what extent do you feel the plight of Persons with Albinism are addressed by this policy? (*Probe for barriers and facilitators*)
- f. How do you use the current policy to help Persons with Albinism? (*probe for implementation and execution*)
- g. What happens when Persons with Albinism feel their needs are not met (*probe for evaluation*)
- h. In your opinion, in what ways can we improve the current policy to be more helpful to Persons with Albinism? (*Probe for suggested policy corrections and reversals*)

**Thank you for your time**

## **APPENDIX E: KEY INFORMANT INTERVIEW GUIDE FOR POLICY ANALYSIS**

**Introduction:** Purpose of this interview is to understand the context in which the policy of Persons with Albinism was formulated. We will begin by exploring your knowledge about Persons with Albinism Please tell us your experience with Persons with Albinism (*probe for the challenges they go through*)

- a) How do the views of Persons with Albinism always get to policy makers
  - a) What policies protect Persons with Albinism? (*Probe for name and number of policies key informant knows*)
  - b) How were you involved in formulation of this policy (*probe involvement, stakeholders and inclusion.*)
  - c) To what extent do you feel the plight of Persons with Albinism are addressed by this policy? (*Probe for barriers and facilitators*)
  - d) How do you use the current policy to help Persons with Albinism? (*probe for implementation and execution*)
  - e) What happens when Persons with Albinism feel their needs are not met (*probe for evaluation*)
  - f) In your opinion, in what ways can we improve the current policy to be more helpful to Persons with Albinism? (*Probe for suggested policy corrections and reversals*)

**Thank you for your time**

## **APPENDIX F: INFORMED CONSENT FORM**

MAKERERE UNIVERSITY COLLEGE OF HEALTH SCIENCES  
SCHOOL OF BIOMEDICAL SCIENCES HIGHER DEGREES RESEARCH AND ETHICS  
COMMITTEE (SBSHD-REC)

### **INFORMED CONSENT FORM**

**Title of the proposed study: Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda**

**Investigators:**

Dr. Betty Udongo: Systematic Limited /Albinism Umbrella

Dr. Arthur Bagonza: School of Public Health, Mulago

Ms. Olive Namutebi: Albinism Umbrella

You are being invited to participate in a research study: **Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda**. This form is designed to provide you with information about this study. The Investigator or his/her representative will describe this study to you and answer any of your questions. You are entitled to a copy of this form.

**Procedures:**

You are requested to participate as a respondent, to answer questions to be asked by our research assistants. This participation is voluntary and you will not be disadvantaged in any way if you decide not to participate.

**Who will participate in the study?**

All Persons with Albinism and their parents from 10 districts in Eastern Uganda are requested to participate in the research project. The research assistants will ask you questions and enter your responses in a tablet. The research assistants shall also be looking for personal stories to share, therefore they shall ask for your permission to video record, take your photo and the photograph of your home. You are free to accept or refuse for your photo or video to be taken and it will not disadvantage you.

**Risks/Discomforts:**

The possible risk is that your photograph or video may appear in the print and social media.

**Benefits:**

The benefit of conducting this study is that with GPS we shall know the locations of Persons with Albinism so that they can be provided with services and protection in a timely manner. This is beneficial to the participants because in the past they have been hunted for ritual sacrifices. This study shall help to determine areas of high concentration of Persons with Albinism so they can benefit from service delivery because in the past they were left out. The database for Persons with Albinism will be a guide for planning and provide informed advocacy for the inclusion and improvement of the wellbeing and safety of Persons with Albinism. The participants shall receive free sunscreens for participating in this research study.

**Confidentiality:**

Persons with Albinism are at risk of being kidnapped hence personal privacy shall be protected and confidentiality of data maintained. The digital survey form that shall be used to collect information is programmed to automatically encrypt the data collected instantly in real time. The data collected



shall be stored in a cloud server. We shall not use names but generate identification codes for the participants so that their identity cannot be traced. In circumstances where we obtain photo and video release, real names shall not be used and locations shall not be disclosed.

**Alternatives:**

Participation in this study is not mandatory, so you can decline to participate or respond to the questions at any time during the interview process.

**Cost:**

There is no cost associated with this study since the research assistants shall interview you at your home or any place that is convenient to you.

**Compensation for participation in the study:**

There is no compensation for participating in this research study. It is voluntary.

**Reimbursement:**

There shall be no reimbursement because you shall be interviewed from your home. Only those who shall be invited for Focus Group Discussion shall receive transport refund.

**Questions:**

You can call Dr. Betty Udongo on Tel.0775582283, if you have any questions or concerns about your participation in the study

**Questions about participants rights:**

If you have questions about your rights as a research participant, you can contact IRB School of Biomedical Sciences, Makerere University College of Health or call Dr. Erisa Mwaka the IRB chairperson on 0752575050 for any concerns related to the conduct of the study.

**Consent:**

The above research study has been explained to me, and I voluntarily give my consent to participate in this research project. I had the opportunity to ask questions. In the future if I have questions about the research study, this will be answered by one of the investigators listed above. I will receive a copy of this consent form. I give permission to the investigators to use the collected information from this research study.

Name of consenting person.....

Signature..... Date.....

Administered by:

Name.....

Signature..... Date.....

## **APPENDIX G: ASSENT FORM**

### **MAKERERE UNIVERSITY COLLEGE OF HEALTH SCIENCES**

#### **SCHOOL OF BIOMEDICAL SCIENCES HIGHER DEGREES RESEARCH AND ETHICS COMMITTEE (SBSHD-REC)**

### **ASSENT FORM**

This informed assent form is for children with albinism between the ages of 12 and 17 years.

#### **Title of the proposed study: Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda**

##### **Investigators:**

Dr. Betty Udongo: Systematic Limited /Albinism Umbrella

Dr. Arthur Bagonza: School of Public Health, Mulago

Ms. Olive Namutebi: Albinism Umbrella

Your child has been identified to participate in the study: **Spatial Mapping and Profiling of Persons with Albinism in Eastern Uganda** because he/she is a child with albinism (CWA). The purpose of this research project is to use Global Position System (GPS) to locate households of Persons with Albinism and collect information on their socio-economic status in order to provide services and protection for the albinism community in Eastern Uganda.

##### **Background and rationale for the study:**

Currently there is scanty information or data on the population, distribution and socio-economic status of Person with Albinism in Uganda. It is estimated that there are approximately 20,000 Ugandans living with some form of albinism but there is no concrete evidence to support or confirm that number. This research project seeks to use technology to collect accurate baseline data on Persons with Albinism in Eastern Uganda where the prevalence is reported to be high. This database will be a guide for planning, informed advocacy, protection and provision of services for improvement of the wellbeing of Persons with Albinism.

##### **Purpose:**

The purpose of this research project is to use Global Position System (GPS) to locate households of Persons with Albinism to create a database in order to provide services and develop Technology-based Security Tracking Systems and devices to protect Persons with Albinism. Your child is being asked to participate so that we document the total number of Persons with Albinism in Eastern Uganda and create a gender aggregated database which shall guide planning, informed advocacy, protection and provision of services for improvement of the wellbeing of Persons with Albinism.

##### **Procedures:**

You are requested to participate as a respondent, to answer questions to be asked by our research assistants. This participation is voluntary and you will not be disadvantaged in any way if you decide not to participate.

**Who will participate in the study?**

All Persons with Albinism and their parents from 10 districts in Eastern Uganda are requested to participate in the research project. The research assistants will ask you questions and enter your responses in a tablet. The research assistants shall also be looking for personal stories to share; therefore they shall ask for your permission to video record, take your photo and the photograph of your home. You are free to accept or refuse for your photo or video to be taken and it will not disadvantage you.

**Risks/Discomforts:**

The possible risk is that your photograph or video may appear in the print and social media.

**Benefits:**

The benefit of conducting this study is that with GPS we shall know the locations of Persons with Albinism so that they can be provided with services and protection in a timely manner. This is beneficial to the participants because in the past they have been hunted for ritual sacrifices. This study shall help to determine areas of high concentration of Persons with Albinism so they can benefit from service delivery because in the past they were left out. The database for Persons with Albinism will be a guide for planning and provide informed advocacy for the inclusion and improvement of the wellbeing and safety of Persons with Albinism. The participants shall receive free sunscreens for participating in this research study.

**Confidentiality:**

Persons with Albinism are at risk of being kidnapped hence personal privacy shall be protected and confidentiality of data maintained. The digital survey form that shall be used to collect information is programmed to automatically encrypt the data collected instantly in real time. The data collected shall be stored in a cloud server. We shall not use names but generate identification codes for the participants so that their identity cannot be traced. In circumstances where we obtain photo and video release, real names shall not be used and locations shall not be disclosed.

**Alternatives:**

Participation in this study is not mandatory, so you can decline to participate or respond to the questions at any time during the interview process.

**Cost:**

There is no cost associated with this study since the research assistants shall interview you at your home or any place that is convenient to you.

**Compensation for participation in the study:**

There is no compensation for participating in this research study. It is voluntary.

**Reimbursement:**

There shall be no reimbursement because you shall be interviewed from your home.

**Questions:**

You can call Dr Betty Udongo on Tel.0775582283, if you have any questions or concerns about your participation in the study

**Questions about participants rights:**

If you have questions about your rights as a research participant, you can contact IRB School of Biomedical Sciences, Makerere University College of Health or call Dr. Erisa Mwaka the IRB chairperson on 0752575050 for any concerns related to the conduct of the study.

**Consent:**

The above research study has been explained to me, and I voluntarily give my consent to participate in this research project. I had the opportunity to ask questions. In the future if I have questions about the research study, this will be answered by one of the investigators listed above.

I will receive a copy of this consent form.

I give permission to the investigators to use the collected information from this research study.

Name of Assenting person .....

Signature..... Date.....

Administered by:

Name.....

Signature..... Date.....