

THE DEMOGRAPHIC, GEOGRAPHIC AND SOCIOECONOMIC

SURVEY OF PERSONS WITH **ALBINISM** IN NIGERIA

A baseline survey designed to facilitate a framework for developing support systems for the care and protection of persons with Albinism in Nigeria



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INTRODUCTION & BACKGROUND

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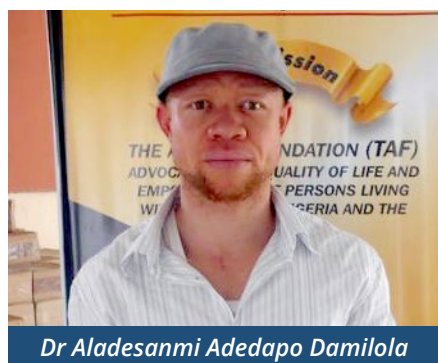
Before this survey was commissioned by the Albino Foundation in association with the European Union (EU), persons with albinism (PWAs) and other people with disabilities (PWDs) had suffered untold neglect from governments at various levels in Nigeria and indeed other parts of Africa. It was commonplace to hear that PWAs are hunted for rituals and or to be treated as reverential beings, where certain beliefs, knowledge, habits and attitudes of the people hold sway.

More often than not, no attention is given to PWAs and PWDs in terms of societal understanding and integration of these sects of people, as it is accorded other people with regular pigmentation. In consequence thereof, this disregard has resulted in little or no information about persons with albinism and persons with disabilities.

It is even an aberration that PWAs and PWDs have never been singled out for inclusion in countless population censuses that have been conducted in Nigeria and neither is there a national policy that seeks to address the plights and challenges of PWAs and other vulnerable persons in Nigeria. Hence, there are no demographic, economic and social data on persons with albinism in Nigeria.

The obvious consequence of this disregard is that PWAs and other vulnerable persons have to navigate the harsh socioeconomic and political terrain as nominal persons within the larger population, whereas they ought to be cared for and treated as special cases in view of their vulnerabilities in terms of access to good health, access to education, access to job opportunities as well as the right to vote and be voted for on a political platform.

In consonance with the attendant and increasing focus on the plight of persons with albinism in Nigeria by some agencies of government, attempts are being made to rehabilitate and integrate them into the society. This attempt required far-reaching demographic information from a national baseline survey, which will help to facilitate policy formulation and implementation of programmes designed to assuage the Nigerian albino, young and old, male and female.



Dr Aladesanmi Adedapo Damilola

The continuous advocacy work of The Albino Foundation (TAF) – a foundation that represents and advances the cause of PWAs in Nigeria¹ – found alignment with the European Union's (EU's) assistance programme to alleviate the sufferings and cause of vulnerable persons in Africa, with Nigeria as a focal point. It is this shared interest that has given rise to the need to conduct the first in a series of nationwide baseline surveys, covering 6 states and Abuja, Nigeria's federal capital territory, to gauge the position of PWAs in terms of their geographic spread, as well as their demographic and socioeconomic makeups.

¹ The Albino Foundation has risen to defend men like Dr. Aladesanmi Damilola (inset), a Nigerian with albinism who was refused employment by the Nigeria Police Service Commission after undergoing training and screening at the Police College Jos, Plateau State

It is believed that these parameters will be used in policy formulation that will be used in providing a national welfare programme for PWAs, redefining socio-cultural nuances and creating a level playing field for PWAs in all facets of life, just as it bodes for people in the larger population.

AIM OF THE SURVEY

The overall aim that this survey sought to achieve was to generate a comprehensive data on the size and characteristics of persons with albinism in Nigeria, in order to provide the basis for informed planning and implementation of appropriate intervention programmes and the appropriate support systems that will facilitate the delivery of relevant, effective and timely services for persons with albinism, and which hopefully will become a new national blueprint that will be used in addressing the cause of persons with disabilities and other vulnerable persons in Nigeria.

SPECIFIC OBJECTIVES

The specific objectives of the survey are to obtain data which will provide information on:

1. The demographic distribution of persons with albinism in Nigeria;
2. The geographical spread of persons with albinism in Nigeria;
3. The nature and extent of albinism among persons with albinism in Nigeria;
4. The requirements or special needs of persons with albinism in terms of health, education, information, employment opportunities, financial assistance and assistive devices, as well as accommodation of the interests of their dependents in Nigeria;
5. The measures in place for taking care of the needs of persons with albinism;
6. The level of educational and health facilities that are accessible to persons with albinism;
7. The various types and forms of discrimination against persons with albinism in the various states of the federation;
8. Such other factors and variables that will enable the formulation and implementation of policies, which will assist in the mainstreaming and empowerment of persons with albinism in Nigeria.

EXPECTED OUTCOME OF THE SURVEY

1. Increased adequate planning, budgeting and implementation of albinism project(s) for persons with albinism in Nigeria;
2. Enhanced mainstreaming of persons with albinism into the socio-economic and political development of the country;
3. Empower persons with albinism to be able to live independent lives;
4. Increased access to health, education and infrastructural facilities by persons with albinism;
5. Enhanced monitoring of albinism project(s) in Nigeria.

KEY DELIVERABLE

The expected output from this survey is a document highlighting the demographic distribution, requirements/needs, nature and extent of albinism among persons with albinism in Nigeria.

EXECUTIVE SUMMARY

The immediate impression emanating from the conduct of this survey research is summarised along the survey objectives, as explained hereunder:

1. The demographic distribution of persons with albinism in Nigeria;

- From the study, there is a higher representation of women living with albinism than men (55% versus 45%). Further stratified, 65% practice Christianity while 33% are Muslims. A very minute minority practices other forms of religion (2%);
- A majority of the people with albinism are single (63%) and is reflected in all geographic locations where surveys took place. Married individuals (32%) occupy the next highest level of concentration and to a lesser degree, Separated and Divorced spouses account for just 2% and 1%) of respondents;

2. The geographical spread of persons with albinism in Nigeria;

- The first impression arising from this survey is the geographic concentration of persons with albinism in Nigeria's middle belt region, extending to the Federal Capital Territory, Abuja and farther to the northern part of the country;
- The population spread of PWAs is less likely to be found in the southern part of Nigeria;

3. The nature and extent of albinism among persons with albinism in Nigeria;

- Several factors conspire to affect PWAs adversely. They include poor vision, unemployment, limited access to healthcare facilities and skin care solutions, as well as discrimination and low literacy level;

4. The requirements or special needs of persons with albinism in terms of health, education, information, employment opportunities, financial assistance and assistive devices, as well as accommodation of the interests of their dependents in Nigeria;

- Some of the common assistive devices used by PWAs to manage their condition include sunglasses, face caps or bowler hats, sun screen creams and umbrellas;

5. The measures in place for taking care of the needs of persons with albinism;

- There is currently no known government welfare programme to cater to the health and education needs of persons with albinism;

- Parents of children with albinism particularly mothers, are the primary caregivers for the children in all manner and form;
- However, to some extent, NGOs such as The Albino Foundation, NITAP, Albino Support Group and Social Inclusion Group are helping to fill the knowledge, educational and awareness gaps on the plight of and ways to manage albinism in various parts of the country.

6. The level of educational and health facilities that are accessible to persons with albinism;

- Generally, neither the federal government of Nigeria nor state governments have a distinct policy footprint to cater for the welfare of PWAs, however, some general hospitals render free treatment of PWAs with skin infections, eye tests and medications.
- The only organs that are providing necessary access to information on the causal factors of albinism and its management are NGOs, notable amongst which are: The albino Foundation, NITAP, Albino Support Group and Social Inclusion Group.

7. The various types and forms of discrimination against persons with albinism in the various states of the federation;

- Discrimination is widely experienced by persons living with albinism across the country, regardless of the background or gender (96%). Females report higher levels of societal discrimination (54%) within family and friends' circles than men (46%);
- Common places of discrimination are public buses (23%), schools (23%) and villages or town squares (20%). Other places with lower reported cases of discrimination are religious centres (5%) and financial institutions (4%). A small category of them (2%) say they have never experienced discrimination at any of these locations before;

8. Such other factors and variables that will enable the formulation and implementation of policies, which will assist in the mainstreaming and empowerment of persons with albinism in Nigeria.

- It was a general consensus that people living with albinism deserve to be treated specially. Being prone to earlier mentioned health challenges, they deserve to be treated differently to enable them adjust well into the society as well as enhance their chances of harnessing their potentials

It is expected that children living with albinism should be:

- Given front seat in class to help them have clearer viewing of the blackboard
- Given extra time during class test and examination bearing in mind their sight challenges which put them at a disadvantage vis-à-vis their classmates

- Encouraged to take leadership roles
- Protected from verbal, physical and other types of assaults from classmates
- Monitored in terms of their participation in outdoor activities

For the adults, it is expected that they:

- Should be protected against assaults and threat to their physical bodies
- Are financially empowered to ensure independence
- Equipped with adequate information on proper healthy practices that enhance healthy living and less health issues
- Given equal employment opportunity
- Posted to duties that ensure that they are protected from the sun

LITERATURE REVIEW

LITERATURE REVIEW 1: THE PHYSIOLOGY OF ALBINISM

To some people, albinism is an occurrence with no consequence or an abnormality that may be taken at face value without more. The truth could not be further, because albinism comes with its medical nuances that place limitations on children and adults with albinism, some of which are discussed briefly:

ALBINO SKIN IN THE TROPICS

Albinism is defined as a set of inherited abnormalities of melanin synthesis that is typically characterized by congenital reduction or absence of melanin pigmentation (the inability of the body to produce melanin, a photo-protective dark pigment that protects skin tissues from ultraviolet radiation (or UVR), which is attributable to the defective production of the enzyme, tyrosinase. Albinism occurs in all groups of people – Africans, Asians, Caucasians, Indians, Aborigines, etc.²

Medically, albinism is classified into four (4) broad groups:

- Ocular albinism (OA);
- Chediak-Higashi Syndrome (CHS)
- Hermansky-Pudlak Syndrome (HPS)
- Griscelli Syndrome (GS)

The CHS and HPS variants manifest with extra-pigmentary defects consisting of leukocyte, platelet, and reticular cell dysfunction while the GS strain can also manifest with immunodeficiency and neurologic defects.

Skin cancer is the most common malignancy among the Caucasians and noted to be rare in the Africans and the negroid skin. However, because of the rarity of skin cancers in Africans, the diagnosis is often delayed with consequent advanced presentation and poor prognosis.

Ultraviolet radiation (UVR) is considered to be the primary agent associated with occurrence of all skin cancers in concert with genetic or constitutional susceptibility and result in ulcers, swelling, abnormal reddish flesh, varigate pigmentation and melanoma.



Photo 1: Advanced Skin Cancer in an Albino Man

² Courtesy: Dr. Olusola Ayanlowo, Physician Dermatologist, LUTH, Lagos "Medical Management of Albinism, 2010"

The common outcomes of these skin defects manifest in:

- Skin photosensitivity and damage, premature aging
- Sunburn: Erythema (redness) – Yellow (tanning) - rhomboids cutis/pseudo pseudoxanthoma (thickening).
- Freckles or lentigines
- Actinic keratosis superficial ulcerations and scaling
- Skin cancers (ulcers, swelling, variate pigmentation).
- Reduced visual acuity
- Social stigma
- Untimely death

CAUSES OF LOW VISION IN PERSONS WITH ALBINISM

While melanin's primary role is protecting humans from ultraviolet light, it also has other important functions in the development of the retina, the brain and their interconnection. Thus, when there is a low production of melanin, it not only results in poor pigmentation, it also affects vision. The hypo-secretion of melanin pigmentation results in vision impairment amongst albinos and is known as oculo-cutaneous albinism or type 1 albinism; this affects hair, skin and eye colour, resulting in discolouration of the hair and skin³.

The melanin pigment absorbs stray light and protects the eyes and skin from ultraviolet light. If the pigmentation of iris and choroid is lacking, light penetrates directly through the structures of the eye rather than only through the pupil. Loss of pigmentation in albinism results in extreme light sensitivity, thus the patient has too much light entering the eye, with no way to handle the excess stray light already in the eye.

The first sign of albinism in children is the involuntary rhythmic swinging oscillation (movement) of the eyes. This is referred to as Nystagmus and can occur in many forms leading to a decrease in vision from the rhythmic movement. The resultant effect is that albino persons with this diagnosis tend to tilt their heads or eyes to where they achieve their best vision, called the null position.

Research further shows that children with nystagmus may not do well with timed tests that could put them under stress. Medical doctors have however suggested that shutting of one eye with a hand could cause a change in the vision of the viewing eye due to an increase in nystagmus.

The other optical impairment amongst children with albinism is strabismus or 'crossed eye' symptom. It is usually caused by a loss of binocular vision and reduces depth of optical perception.

³ Courtesy: Dr. Uduak C. E. Udom, FNCO, FAAO, Consultant, Primary Care Optometry, Nigerian College of Optometrists; "Managing Low Vision in Albinism, 2010

LITERATURE REVIEW 2: SOCIAL AND EMOTIONAL ASPECTS OF ALBINISM

Society's attitudes about albinism have a tremendous influence on the person with albinism. These influences will vary from person to person and at different stages of life. Having albinism also has a tremendous emotional impact on the person, which also vary from person to person and vary at different stages of life. It is in the balance and interplay between the external world and each individual's internal response that a sense of self is born and sustained. Albinism is an important part of that sense of self.⁴

THE FIRST INFLUENCE: A DISABILITY OR NOT?

Neither the general public nor those with the condition agree with the fact that albinism is a disability. This ambiguity creates a problem in the language used to talk about albinism.

It also makes it difficult for those with albinism to identify themselves as a group. In many ways, albinism is a unique condition. That uniqueness, however, leads to isolation for many people. Social attitudes toward albinism are often similar to those experienced by other disability and minority groups. These attitudes include a lack of understanding, fear of the unknown, and prejudice based on appearance.

The Americans with Disabilities Act defines disability with respect to an individual as "a physical or mental impairment that substantially limits one or more of the major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment." Since albinism involves a visual impairment, some people consider it a disability. One definition of handicap is "the obstacles a person encounters in the pursuit of goals in real life, no matter what their tribe or creed." Thus, a person with a disability may or may not be handicapped in pursuing the life he or she wants to live.

The identification of albinism as a disability is complicated by the concept of legal blindness. In the United States, a person is legally blind if his or her vision cannot be corrected with glasses or contacts to better than 20/200 in his or her better eye⁵. By this standard some with albinism fit the legal category of visual impairment and some do not. Yet, in spite of varying visual acuity, many of the problems experienced by those with albinism remain similar.

THE SECOND INFLUENCE: PHYSICAL APPEARANCE

The first aspect of albinism which most people notice is the person's unusual appearance. The white hair and skin of oculo-cutaneous albinism is a powerful factor from the moment of birth. The new baby will often be much lighter in colour than any family member. In non-white races the colouring of the baby with albinism is a dramatic contrast to the family and community. Colour is a highly charged characteristic in our culture historically and in now contemporary times. Strangers will often make unwanted and unkind comments about the appearance of a child.

⁴ Source: National Organisation for Albinism and Hypopigmentation, <http://www.albinism.org>

⁵ If a patient sees 20/200, the smallest letter that they can see at 20 feet could be seen by a normal eye at 200 feet. This is the Snellen Acuity (English). In Metric Acuity, 20/20 equals 6/6. The conversion is that 20 feet equals approximately 6 meters (actually 6.096). Source: <http://www.mdsupport.org/library/acuity.html>

Beyond colour, a child's eyes may be moving rapidly and not focusing together. The child may have to squint, tilt his or her head, and hold things close in order to see. Children with albinism often use eye glasses and optical aides to enhance their vision. Therefore, the child with albinism often feels isolated not only in physical appearance but also in the conduct of everyday life.

This perception of being different can lead to an immense effort to act "normal" as much as possible for a person with albinism. Moreover, he or she can feel a lot of pressure, both from within and from other people to minimize the differences albinism causes. This effort can result in a great deal of stress for a person who is continually trying to maintain and maximise his or her visual acuity. The pressure can even lead such a person with albinism to deny entirely that he or she has albinism, thereby losing touch with a very important aspect of their identity.

Family and close friends can counter this isolation and denial. Being prized and valued as a whole person is the foundation for a lifetime of self-esteem and inner strength. This prizing must include an honest acknowledgment and acceptance of the condition of albinism. It is vitally important that families can freely discuss the impact of albinism in each of their lives.

THE THIRD INFLUENCE: LANGUAGE, MYTH AND STEREOTYPES

Language can shape ideas and create reality. The word "albino" is commonly used in many languages including English. Some people are comfortable with the word and prefer being called an albino. However, people often use the word "albino" in hurtful ways. Many feel it is dehumanizing to refer to a person in terms of a condition. Although slightly cumbersome, the terms "person with albinism" and "people with albinism" put the person first and the condition second. Teasing and name-calling are other ways in which language can be very dehumanizing.

Almost all children face teasing during their school years and they need to develop positive coping strategies. Parents, teachers and increased education about albinism can help with this problem.

Throughout the world, people have misconceptions about albinism, ranging from notions that people with albinism have magical powers to the belief they are retarded. These run the spectrum from the notion that those with albinism have magical powers to the belief that they are retarded. Among African-Americans, a common myth is that babies with albinism result from a union between an African-American woman and a Caucasian man. Another common myth is that people with albinism must have red eyes. People with albinism usually have blue or grey eyes which sometimes appear reddish in certain types of light. Sometimes, myths are so widespread even the person with albinism believes them.

The media, including literature and film, have contributed to stereotypes of albinism. The character with albinism is often portrayed as villainous, deviant, supernatural or sadistic. Also, some news reports and encyclopaedia articles have included false or incomplete information about albinism. It is difficult for the public to know what is true and untrue about albinism.

THE FOURTH INFLUENCE: THE FAMILY

It is vital that the family have accurate information about albinism. New parents need support and time to understand the condition of their child. Parents and family members may need to face some unpleasant stereotypes they have learned about albinism. Siblings need to understand why their brother or sister looks different and why they seem to be getting so much attention. There is no single force greater than the family in helping a child understand and accept him or herself.

THE EMOTIONAL COMPONENT OF ALBINISM

Along with the external influences of society, every person has a vital and essential emotional response to their personal experiences with albinism. These personal responses shape who we are and how we adapt to albinism. A strong emotional response is a normal part of living, growing, and intellectual development. Suppressed emotions often turn inward and cause stress, depression and physical maladies.

Emotional responses to albinism will occur throughout life because of the many challenges and frustrations the condition presents and the many societal influences already mentioned. It is very important to develop healthy ways to express and integrate these emotions. First, it is necessary to recognize feelings and determine their source. Parents can help children label the feeling the child feels, then help the child connect that feeling to a specific reason or event. For example, a parent might say, "I know you're sad because you have to put on sunscreen before you go swimming." Then the parent can help the child "do" something with the emotion such as to talk about it, play, yell, run, cry – whatever physical outlet will release the feeling. This validation and release are essential in processing an emotion.

Adults with albinism can go through this process by having friends and family listen to their frustrating, discouraging, or proud experiences. Some ways to release an emotional charge are physical activity, taking action in the form of education or advocacy, journal and letter writing, or doing something nurturing for yourself. Sometimes professional help from a therapist or counsellor can assist a person work through the highly charged issues of albinism. Coping with albinism often is not easy. However, working through the issues albinism causes not only leads to great personal satisfaction, but also to a greater understanding of human kind.

RESEARCH METHODOLOGY & LIMITATIONS

METHODOLOGY

This segment discusses the methodology that was applied during data collection, and includes the locations, sample size definition and distribution, as well as data collection methods, questionnaire administration, enumerator training and field deployment, among other incidental approaches that were applied in conducting this survey.

LOCATIONS

This baseline survey was conducted simultaneously in 6 states and Abuja, the FCT, with each state taken from each of the six (6) geo-political zones (GPZs).

The states that were selected for this first phase of the baseline survey are:

Actual Locations Where Surveys Took Place	
Kogi	
Abuja	
Lagos	
Enugu	
Cross River	
Kano	
Adamawa	

Surveys were not restricted to only urban areas. They were extended to rural areas due to the difficulty in locating PWAs in most parts of the townships.

The proposed and actual samples achieved during fieldwork is discussed below.

SAMPLE SIZES & DISTRIBUTION

At the preparation stage, this baseline survey was designed to target up to 3,500 PWAs in all the six (6) states and Abuja as locations penned down for the survey for the quantitative segment of the study. The intention was to reach as many PWAs as possible from The Albino Foundation's (TAF's) database of members across the states selected for enumeration. However, it soon became clear that some of the PWAs were unreachable as most of them had relocated to other parts of the country from the registered addresses they had given to TAF.

By extension, each state was allocated a sample size in equal number of 500 respondents, totalling 3,500 PWAs. However, due to inequity in the spread of persons with albinism within the larger population, it was difficult reaching these targets within the timeline that the survey was intended to last.

Duration of data collection was therefore extended from the initial 10 days to about 21 days in order to mop up and achieve higher survey numbers. This strategy helped to increase the sample size, eventually resulting in about 57% of initial target of 3,500 respondents.

The summary of provisional versus actual achieved samples is represented on the table below:

Provisional & Actual Achieved Samples as well as Percentage Achievement

GPZ	States/locations	Proposed SampleSize	Achieved Samples	%achieved
NC	Kogi	500	752	150%
FCT	Abuja	500	356	71%
NW	Kano	500	234	47%
SW	Lagos	500	201	40%
NE	Adamawa	500	168	34%
SE	Enugu	500	142	28%
SS	Cross River	500	129	26%
	Total →	3,500	1,982	

By way of cross reference, Kogi state returned 752 respondents or 150% of original sample size. Kogi was trailed at a distance by Abuja, which recorded 356 respondents (or 71% of original target).

Cross River and Enugu states recorded the lowest number of respondents, with 129 and 142 successful interviews, respectively. The field coordinator and team assigned to Cross River state reported that they were faced with the challenge of traversing the state, reputed to be vast and reaching between towns usually took as much as 3 to 4 hours on a one-way trip. These challenges are fully discussed under Limitations.

SAMPLING TECHNIQUE

At the project planning stage, sampling technique was to follow strict scientific rules of multi-stage random sampling method as well as Convenience Sampling methods.

However, as it became increasingly difficult to reach PWAs, the latter method was applied in data collection. It also included selection of PWAs through random route walk or referrals from PWAs themselves.

This strategy helped to increase the success rate of interviews during data collection and also helped to achieve one of the rules of a valid survey: simple randomization.

DATA COLLECTION METHODS

Being a baseline survey, data collection entailed the use of both qualitative and quantitative research methods to completely cover both rational and emotional influences of all the attributes that affect PWAs and were of key interest to the survey. The procedures included:

QUALITATIVE SURVEY 1: (FOCUS GROUP DISCUSSIONS (FGDS))

The first component of the qualitative survey was the use of focus group discussions (FGDs) to gather information from persons with albinism and parents of persons with albinism, conjointly done in two (2) groups per location.

The Focus Group Discussions (FGDs), usually in groups of 8 people per group were conducted to ascertain the deeper issues that PWAs encounter within their communities, towns/cities and at school, as well as suggestions on how to give them a discrimination-free and healthy lifestyle like other people in society.

For the purpose of this study, a total of 56 respondents were recruited and interviewed in 7 different Focus Group Discussions (FGDs) involving PWAs and their parents/caregivers in each state where studies took place.

Schedule of Focus Groups in Each Location

Locations	Number of FGDs	Number of PWAs per Group
Kano	1	8
Adamawa	1	8
Kogi	1	8
Enugu	1	8
Cross River	1	8
Lagos	1	8
Abuja	1	8
Total ➡	7	58

QUALITATIVE SURVEY 2: IN-DEPTH INTERVIEWS (IDIS)

The input of other stakeholders that have direct or indirect influence on persons living with albinism such as doctors in public health institutions, nurses, policy makers in the education sector, as well as state and local government agencies responsible for youth and child welfare departments, was also included in this survey, via in-depth interviewing procedure from survey instruments structured along the survey questions.

A maximum of 42 respondents were surveyed for this segment and included the following set of stakeholders:

Distribution Table Showing IDIs Conducted in All Locations

Civil Society Groups & Ministries, Departments & Agencies	Total Sample	SE	SS	SW	NE	NW	NE
General practitioner Doctor in each state general hospital	6	1	1	1	1	1	1
General practitioner Doctor in one rural health centre in each state	6	1	1	1	1	1	1
Federal/State Teaching Hospital	6	1	1	1	1	1	1
State Legislative Committee on Women & Youth Development	6	1	1	1	1	1	1
Nigerian Union of Teachers in each state	6	1	1	1	1	1	1
Nurses and caregivers in state general hospital	6	1	1	1	1	1	1
Civil society organizations	6	1	1	1	1	1	1
Total by Locations	42	7	7	7	7	7	7

QUANTITATIVE SURVEY

For the quantitative survey, the target respondents were persons with albinism, male and female, with no age restriction. However, where minors younger aged PWAs were found, their parents were interviewed in their stead.

The quantitative task was implemented via personal interviews with the target audience through pre-designed and pre-tested structured questionnaire that were administered as face-to-face interviews with the use of Computer Aided Personal Interviews (CAPI) data collection devices that can readily be downloaded on Smartphones or tablets and also interfaces with GIS for spatial mapping.

Whilst the terms of reference (ToR) document recommended 10 days for fieldwork to be completed, actual surveys were conducted in 21 days, due to the difficulty in encountering PWAs.

QUESTIONNAIRE ADMINISTRATION

All survey instruments for the quantitative segment were uploaded to a client-user CAPI- account designed for mobile data collection that was provided by GIS Cloud.

By relating seemingly unrelated data, the GIS Cloud helped to better understand spatial patterns and relationships that were used in accentuating this report, especially as with the module, it is easy to see the prevalence or incidence of various characteristics of PWAs, as espoused in the statement of objectives, some of which are:

- Density of PWAs in certain areas (geographic spread);
- Demographic makeup;
- The requirements/needs of persons with albinism in terms of health, education, information, employment, financial assistance and assistive devices, as well as accommodation of the interests of their dependents in Nigeria, etc.

The twin components of the qualitative segment, IDIs and FGDs were conducted separately with the use of structured discussion guides and a moderators' guides, respectively. In order to bridge language gaps,

All three (3) segments of the survey were jointly handled by enumerators drawn from TAF's members in each of the surveyed states and were coordinated by a team of external field consultants recruited by PRL Research and an elite team of coordinators from the National Population Commission (NPC). The field consultants and NPC coordinators provided leadership, direction and quality control during data and information collection. This is discussed below:

QUALITY CONTROL

As stated above, data was collected by a joint workforce, comprising of three (3) members of TAF state chapters, supervised by field consultants from PRL Research and at least 1 highly experienced field coordinator specially chosen by the Head of the National Population Commission, Abuja, to provide oversight and render quality control during the fieldwork that lasted for 21 days across all study locations.

The use of PWAs from the State Chapters was vital to data collection because it was a way of building their capacity in data collection, ensuring ownership of the survey process, and facilitating access to otherwise reluctant PWAs during enumeration in order to secure their participation.

The 'state chapter' slant was to ensure that enumerators communicated in the language of their people and that there was understanding of the questions. This contributed immensely in reaching and including persons with little or no education to be surveyed effectively during the survey.

The participation of National Population Commission (NPC) was important to ensure that quality was not compromised, and that standard protocols during enumeration were observed, which are critical in validating and giving the results of the survey a stamp of reliability, because they are well taught in population-based surveys, nationally.

TRAINING OF TRAINERS

A 1-day training workshop was organized in Abuja for the team of consultants, state chapter members of PWAs, TAF project team members as well as representatives of the National Population Commission (NPC) and the European Union (EU), respectively.

The objective of the training was to enlighten core team members on the modalities for the fieldwork, individual and team responsibilities as well as piloting of survey instruments.

Special lectures on interviewing techniques, code of ethics, rapport building with respondents, how to identify enumeration areas (EAs)/clusters, the role of interviewers in individual-level surveys, field work procedures to identify eligible respondents, consent procedures and back-checking of completed survey instruments, were also included in the training.

PILOTING OF SURVEY INSTRUMENTS

During the 1-day training, the consultants pre-tested the baseline survey instruments. The instruments were administered on the mock respondents in order to simulate the real fieldwork. The objective of this was to ensure that the questionnaire and discussion/moderator's guides met the expected standard for baseline surveys as was contemplated, while guarding against illogical sequencing of questions.

Upon completion of the pilot, a de-briefing session was held with the data collection crew, with the field supervisors and coordinators engaging in pre-fieldwork meetings and familiarization.

LIMITATIONS

Several challenges were encountered in the course of conducting this baseline survey, none, however to be unexpected, especially as no wholesome survey on persons with albinism as this has been conducted before.

These challenges had no crucial impact on the survey outcome, but only on data collection. They are listed hereunder:

- The first challenge was not having enough PWAs in the TAF membership database in each of the state chapters;
- The second challenge was low population of persons with albinism. The effect is that there was no sampling frame to extract respondents from in order to draw scientific deductions beyond actual results. This contributed in non-attainment of original target sample sizes in most locations, with the exception of Kogi state, which recorded 150% over and above its original target of 500 PWAs;
- Resorting to random route walk was even more challenging for our team of enumerators,

simply because there is no known area of concentration of PWAs in each of the states where surveys took place:

- Enumerators in some states faced the hardship of travelling long distances between towns and villages before they could score any number of successful interviews. This was the case in both Cross River and Adamawa states, respectively. In both cases, this was a major handicap, because by the time enumerators arrived at their destination, it would be late to commence fieldwork, and they would still have to travel back to their respective stations;
- Many public officers in hospitals and other similar institutions mounted rigid protocols such as deferment and cancelled appointments for interviews. This affected the timeline within which all in-depth interviews should have been conducted, stretching far into the reporting stage;
- The survey timeline had to be adjusted by one week in order to achieve more calls and this was rewarded because by the end of that extended fieldwork, more interviews were achieved;
- Despite the shortcoming, the results of the survey remain valid in the sense that most aspects of the survey recorded same or similar patterns amongst all the stakeholders that were surveyed;
- These limitations call for a national action for relevant government agencies such as the National Population Commission and the National Bureau of Statistics to urgently carry out a national survey on persons with disabilities and persons with albinism, in order to find ways of formulating a national policy that integrate these vulnerable persons within the larger population for their protection and guarantee their place in legitimately pursuing integration, acceptance and upholding their constitutionally-guaranteed rights;
- It is hoped that government's involvement will go a long way in augmenting the activities of NGOs that have a special interest in creating awareness and providing welfare for persons with albinism and other vulnerable people in Nigeria.

REPORT OF FINDINGS

PART 1: QUANTITATIVE SURVEY

PART 1: ABSTRACT OF QUANTITATIVE SURVEY SEGMENT

SECTION 1: PEOPLE WITH ALBINISM AGED 18-56+ YEARS (1,893 RESPONDENTS)

- From the study, there is a higher representation of women (55%) living with albinism than men (45%). Of this number, most of them are either Christian (65%), Muslim (33%) or practice other forms of religion (2%);
- A majority of the people with albinism are single (63%) and this cuts across all geographic locations. Married individuals (32%) have the next highest level of concentration and to a lesser degree, Separated (2%) and Divorced (1%) people;
- Common places of discrimination are public buses (23%), schools (23%) and villages or town squares (20%). Other places with lower reported cases of discrimination are religious centres (5%) and financial institutions (4%). A small category of them (2%) say they have never experienced discrimination at any of these locations before;
- Both female and male (89%) state that they have been treated wrongly as a result of their condition, and others who are most minors (11%) express that they have never been discriminated against;
- This act of discrimination has a demoralizing effect (24%) on majority of them, others say that it makes them feel less than human (19%) and kills their self-confidence (18%);
- Leading concerns as result of this condition are their inability of access quality medical support for free (18%), the fear of being shunned by friends and family (18%) and non-access to good quality education (15%);
- From a psychological stand point, most of them have a strong desire to see (13%) and do things freely like other people (12%). Most want to feel a higher sense of acceptance by members of society (11%);
- Many of them do not have the required funds to pay for their medical treatment (11%), nor assistive devices (10%). For those still in school (60%), they require funding to pay for their education (11%);
- The primary challenge among people living with albinism in Nigeria is poor vision (86%) and skin related problems (82%) due to exposure to sunlight and harsh weather conditions;
- The difficulty associated with being able to see clearly adversely affects their performance at school (60%) and places of work (56%);

- Discrimination is widely experienced by persons living with albinism across the country, regardless of the background or gender (96%). Females report higher levels of societal discrimination (54%) within family and friends circles than men (46%);
- Due to the effect of visual impairment for 36% of PWAs and inability to see properly, 28% of respondents do not go out in the sun. As a result of the weather conditions, their skin is tough to maintain (17%) and makes them look older than their ages (14%);
- The significant level of discomfort associated with the health conditions brought on by albinism creates a feeling of despondency (21%) and affects their ability to perform efficiently in other areas of life (12%).

SECTION 2: PREVALENCE OF HEALTH CONCERNS BY LOCATION

- While there are common threads of association across each geo-political zone sampled, especially with regards to medical challenges, there are distinct markers which differentiate one city from the other such as Kogi which has a higher prevalence of wrinkles (21%) and discolouration of skin (20%) than other regions.
- Following skin challenges, poor vision (20%) is the next most common medical issue they experience.
- As a result of their rough to maintain skins, they make greater use of sunscreens and lotions (19%) as a protective measure against intense sunlight. At a lesser level, hearing aids (8%) and handheld magnifiers (6%) are adopted to assist with ease of living.
- The most predominant health condition among resident in Abuja is poor vision (54%); others site skin related problems like freckles (20%) and discolouration of the skin (21%) come in at a far second and third. In a sharp contrast to other cities, wrinkles and thickening of skin was not cited as a primary health challenge.
- In spite of the prevalence of visibility problems in Abuja, more people resort to using face caps/hats (26%) and sun lotions (26%) above eyeglasses (18%)
- With Lagos, there are lower records of skin cancers (2%) among individuals sampled compared to cases of poor eyesight (38%). Primary assistive device adopted here are hats (25%) and umbrellas (23%).
- Kano, like Enugu, has high incidences of visual impairment issues among people living with albinism (31%) and (33%) respectively. However, the disparity can be seen with the cases of freckles (12%) and (16%) and wrinkling of the skin (18%) and (14%) separately for both cities.

- Relative to other cities, although discolouration of skin (29%) is the most frequently encountered medical condition, there is a notable occurrence of skin cancers among those living in Adamawa (4%). The most widely adopted assistive device is the face cap/hat (33%) and the least used are eye drops (1%).
- The most common protective gear used by PWAs in Cross River are umbrellas (33%).

SECTION 3: OCCUPATIONAL DISTRIBUTION OF PEOPLE LIVING WITH ALBINISM

- At literacy level, more than half of the respondents are secondary school students (58%), while others have either obtained a university (16) or post-graduate degree (13%).
- Indicative of the general state of education across the country, (10%) of those interviewed have never had any formal education and (13%) have not gone beyond primary level of education.
- Of the sample size of the survey, (40%) were between the ages 18-25 years old, (29%) are within 26-35 years and (16%) are within 36-45 years old. Those not sure about their ages (6%), fall largely within the lower economic class.
- More than half of PWA's (57%) earn less than N50,000 per annum. These individuals are predominantly situated in hinterlands with agrarian lifestyles.
- Majority of the people sampled are within SEC B1, B2 (28%), others are largely distributed within SEC D (23%) and C1, C2 (22%) categories respectively.
- The main occupation of respondents is trading (25%). Others are civil service workers (6%) or unemployed (25%).
- A large group of people who are unemployed and seeking employment cite the discrimination they face during the interview processes as a key factor in their inability to secure jobs.
- There are more self-employed people (10%) and stay-at-home wives (6%) than those in professional services.

SECTION 4: STAKEHOLDER RECOMMENDATIONS FROM PEOPLE LIVING WITH ALBINISM

- The primary care givers among people living with albinism are their parents (44%). Those who do not have this assistance coming from their parents are left to cater for themselves (29%). While some have received some support from non-governmental agencies (2%), others, especially those without any form of employment state that they have no helper (12%).

- In view of other important issues highlighted, they pinpoint inadequate funds required to access medical treatments as a top cause for worry (11%). They also are troubled by having to live with being disregarded by members of society (10%). A high number of PWA's also cite lack of funding for further education, especially at university level.
- The long commute to and from existing medical centres is a problem for many of them living in hinterlands. Parents of those living with albinism also express concern over the frequent bullying of their children at schools.
- Majority of those living with albinism would like government to play a greater role in enlightening teachers and students on the plight of persons with albinism and how they ought to be treated in school environment (21%).
- Those within educational institutions are calling for the provision of free teaching aids as well as free medical care in all general hospitals for persons with albinism (21%).
- As a result of the damaging psychological and social impact caused by discrimination, they would like to see government enact laws that ensure that people who discriminate against them are punished (18%) and create a level playing field so they can secure equal job opportunities like other people.
- They also want to better orientation to the general public on the plight of those living with albinism to allow for a more tolerant, inclusive society.

DETAILED REPORT OF FINDINGS: QUANTITATIVE RESEARCH

SECTION 1 – PEOPLE LIVING WITH ALBINISM AGED 18-56+ YEARS

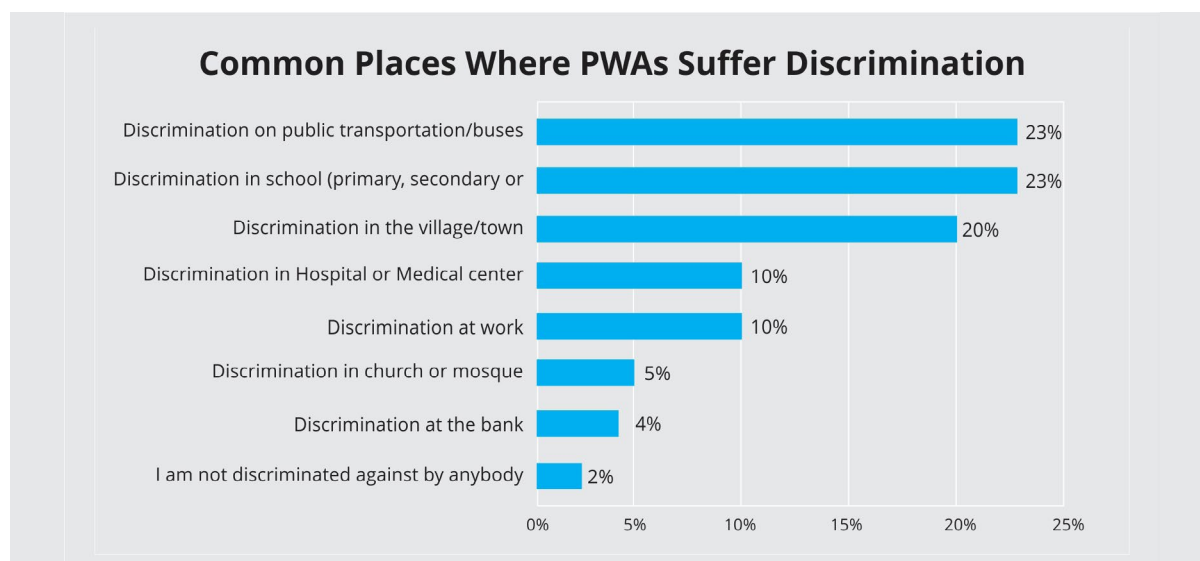
PART A: DEMOGRAPHIC CHARACTERISTICS OF PEOPLE LIVING WITH ALBINISM

Table 1: Background Information

Gender		Religion		Marital status	
Female	55%	Christianity	65%	Single	63%
Male	45%	Islam	33%	Married	32%
		Traditional	0%	Divorced	1%
		Other	2%	Widowed	1%
				Separated	2%
				Declined to Specify	1%

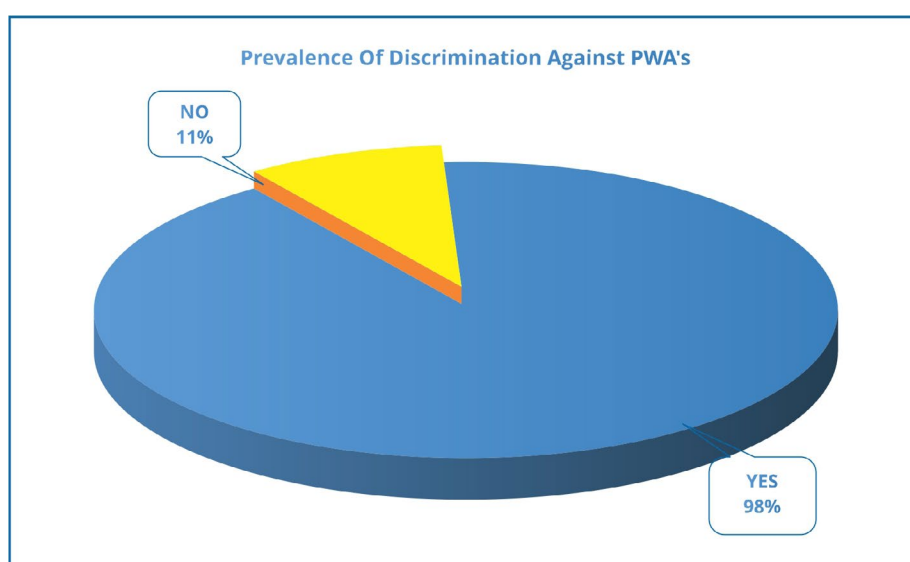
PART B: MAIN REPORT OF FINDINGS

Chart 1: Common Places Where PWAs Suffer Discrimination



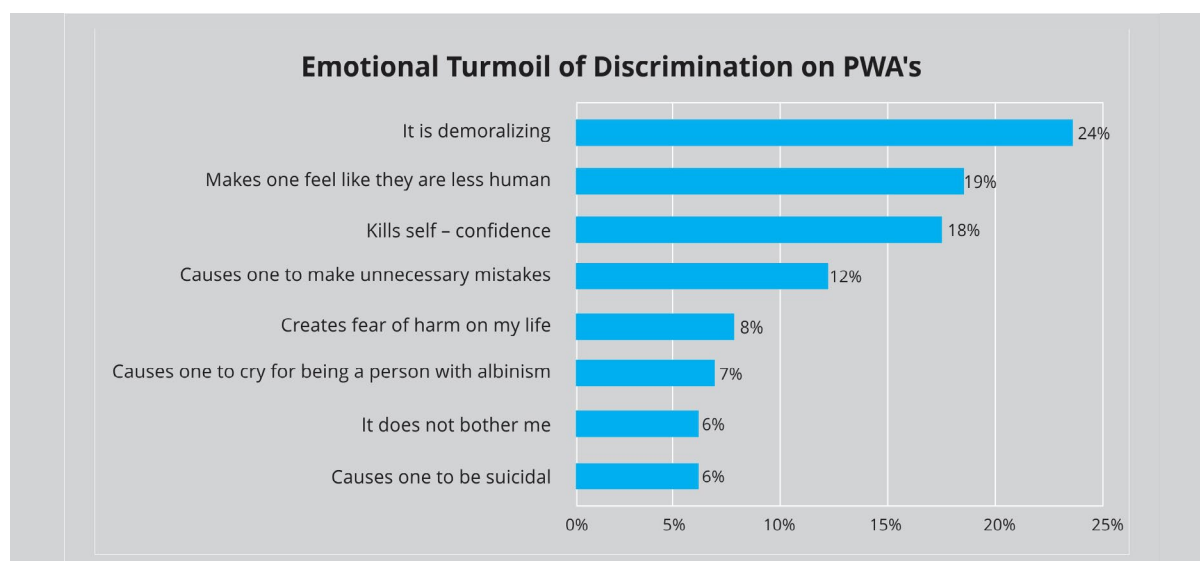
- Due to a wider variety of social encounter with other people in public arenas, they face the most discrimination on buses, in schools and villages where they live;
- Other less common places where discrimination occurs are at the banks or religious worship centres

Chart 2: Prevalence of Discrimination Against PWA's



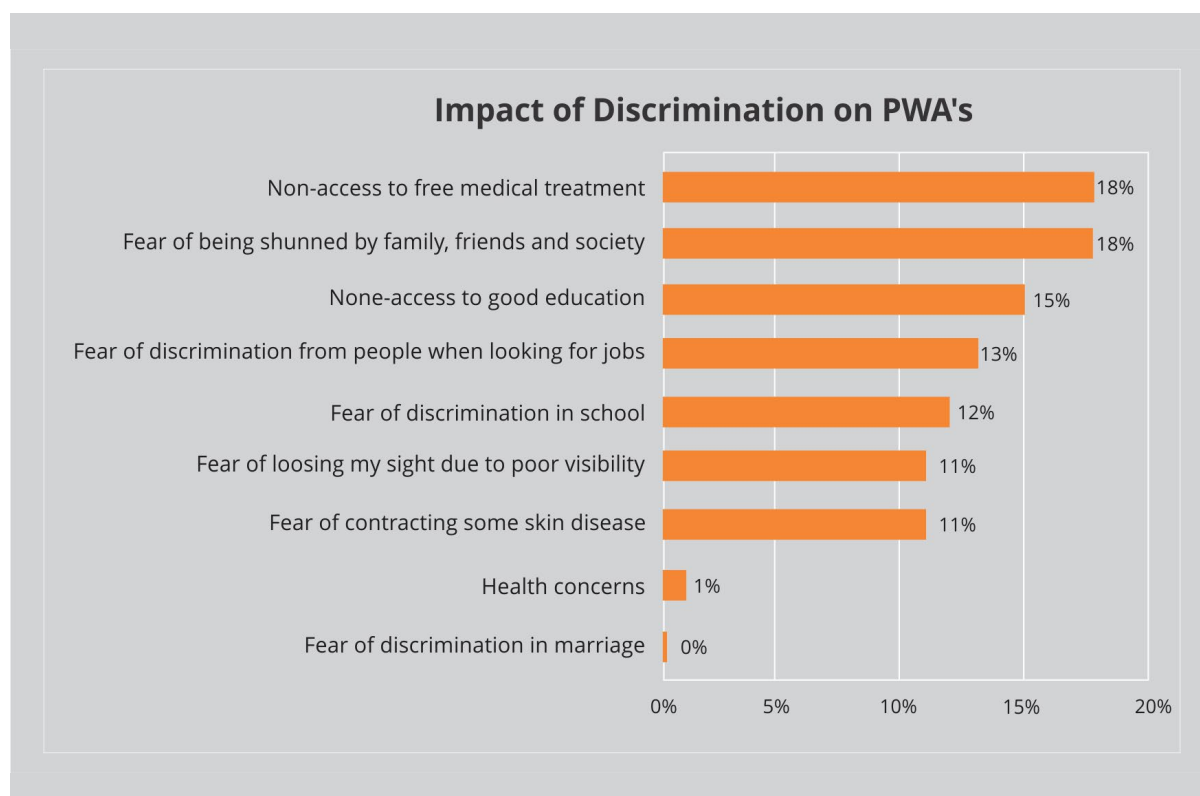
- Most people with albinism confirm that they have at some point been discriminated against and this has a demoralizing effect on them. They also state that it makes them feel less than human.

Chart 3: Emotional Turmoil of Discrimination on the PWA's



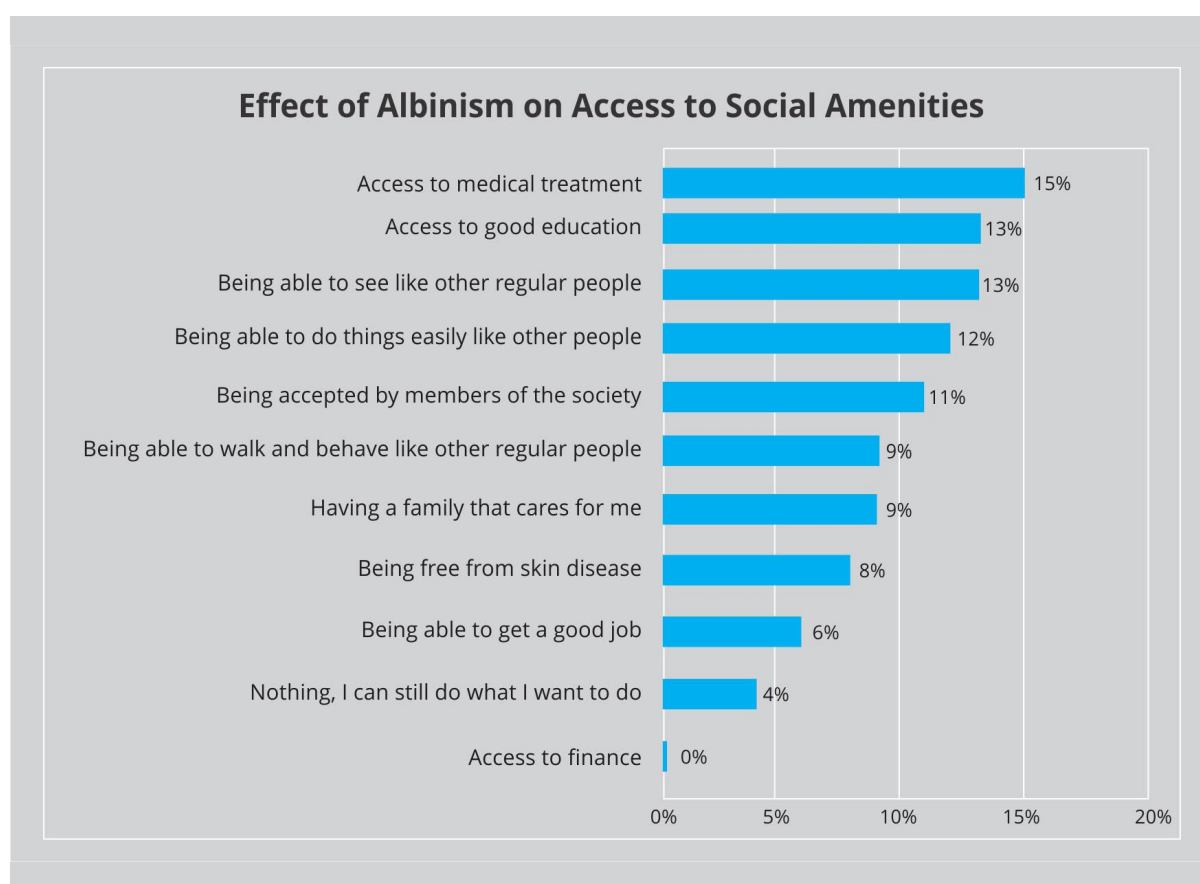
- The impact of discrimination on PWA's has a wide range of effects from the loss of self-confidence to the feeling of being less than human and the total discouraging picture about life they are often presented with;
- Suicidal thoughts and the fear of being harmed also gives them cause to live rather closeted lives.

Chart 4: Impact of Discrimination on PWA's



- Most people with albinism are worried about the limited access they have to free medical treatment; at a lower level, they have mentioned financial challenges as a critical issue faced.
- The constant fear of being ignored by those within their close circles, such as family members, friends and colleagues also takes its toll on them psychologically.
- Due to the delicate nature of their skin, they are forced to take extra care when mingling with people or going out in public.

Chart 5: Effect of Albinism on Social Interaction and Access to Welfare



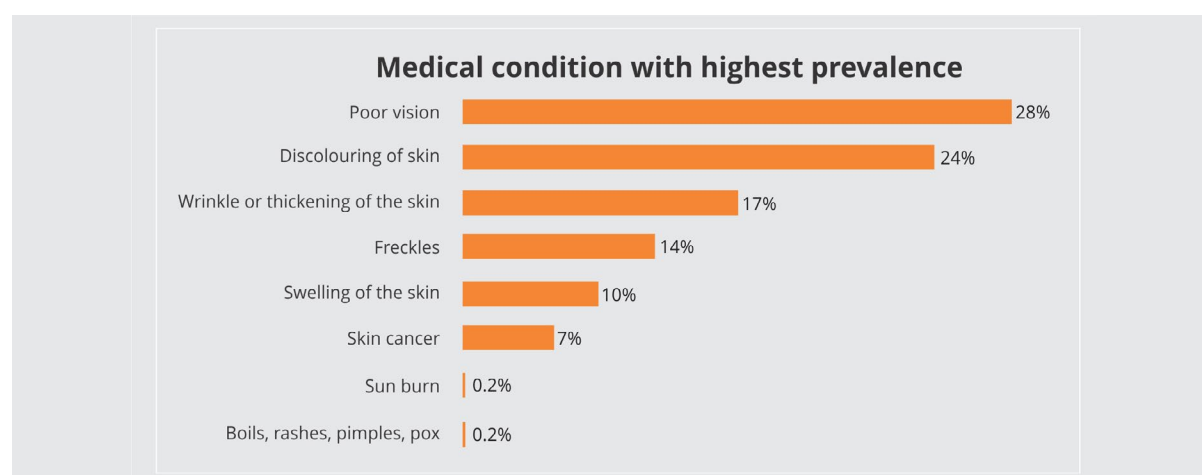
- The poor access to medical treatment is a major factor in their wellbeing; being able to see properly and quality education also had high levels of concerns;
- From a social point of view, many would like to have families that care for them, being accepted by members of society and getting good jobs like their peers.

Table 2: Other Challenges associated with Albinism

Challenges associated with Albinism	%	Remedial Measures Required	%
Sensitivity to light	11%	Avoidance of the sun	20%
Lack of funds to pay for medical treatment in hospital	11%	Sunscreen lotion	20%
Being shunned by some people	10%	Face cap/Hat	19%
No money to buy assistive devices	10%	Sunscreen cream	19%
No money to pay for school fees/further education	8%	Umbrella	18%
Inability to secure a job	7%	Eyeglasses	17%
Inability to move freely	7%	None	17%
Inability to secure a job	7%	Scarf	9%
Swelling of the skin when exposed to sunlight	5%	Eye drops	5%
Cannot do anything due to poor vision	4%	Long dresses/Hijab	5%
Bullying of my child by other children at school	2%	Hearing aid	4%
My child complains that he or she cannot see the blackboard clearly in class	2%	Handheld Magnifier	3%
I cannot afford medical expenses to take care of my child	1%	Long sleeves	1%

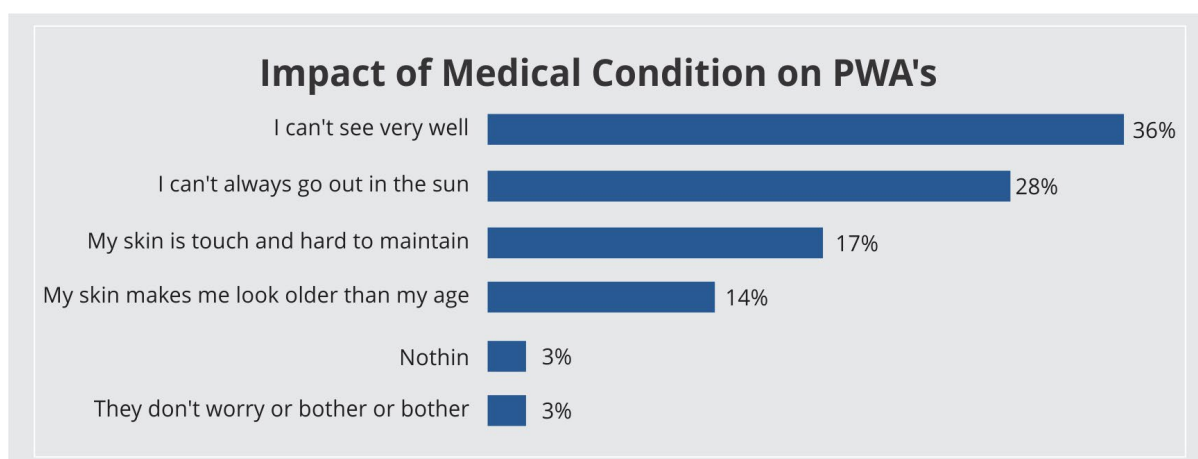
- Apart from sensitivity to light and funds for medical treatment, the other challenges faced by PWA's are mainly social issues;
- They also express a higher need for sunscreen lotion, umbrellas and eyeglasses.

Chart 6: Medical condition with highest prevalence



- Poor vision (28%), discolouration of skin (24%) and wrinkles (17%) are the major health challenges mentioned by PWA's due to frequent exposure to sunlight;
- The least challenges on the scale are skin cancer, sunburns and skin irritations (boils, rashes, pimples or small pox), etc.

Chart 7: Degree of Impact of Medical Condition on People Living with Albinism

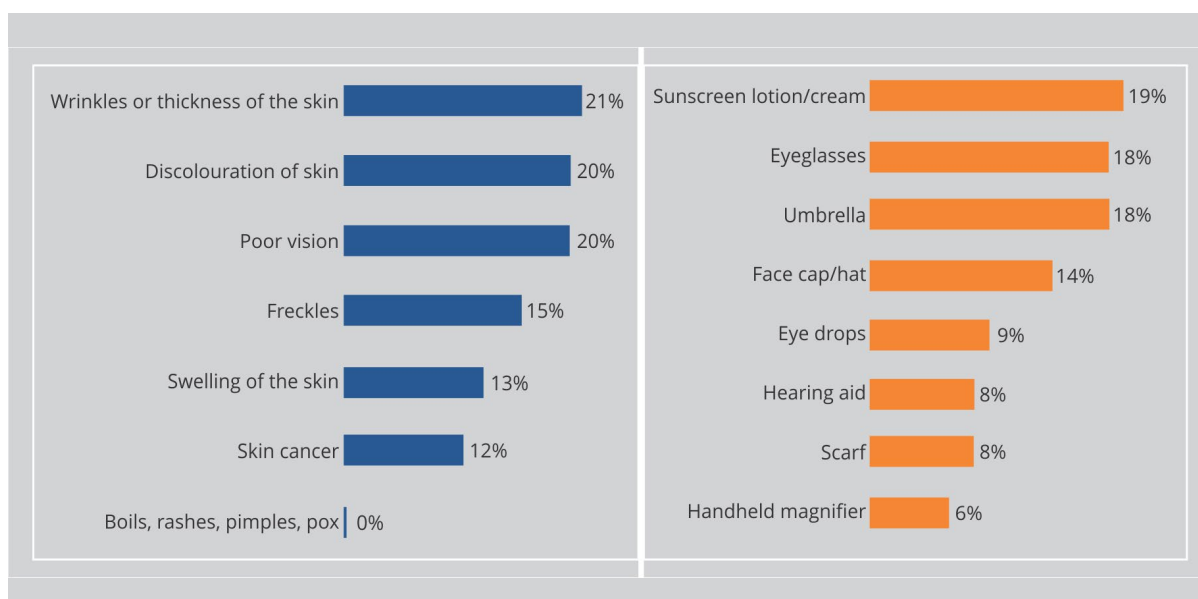


- As a result of the condition, a higher proportion of PWA's say they suffer from a significant level of visual impairment and cannot go out in the sun freely; this is irrespective of gender or developmental stage.
- Others allude to the hard nature their skin takes on due to the climatic conditions; while a small group from those interviewed state that it does not bother them.

SECTION 2 – PREVALENCE OF HEALTH CONCERNS BY LOCATIONS

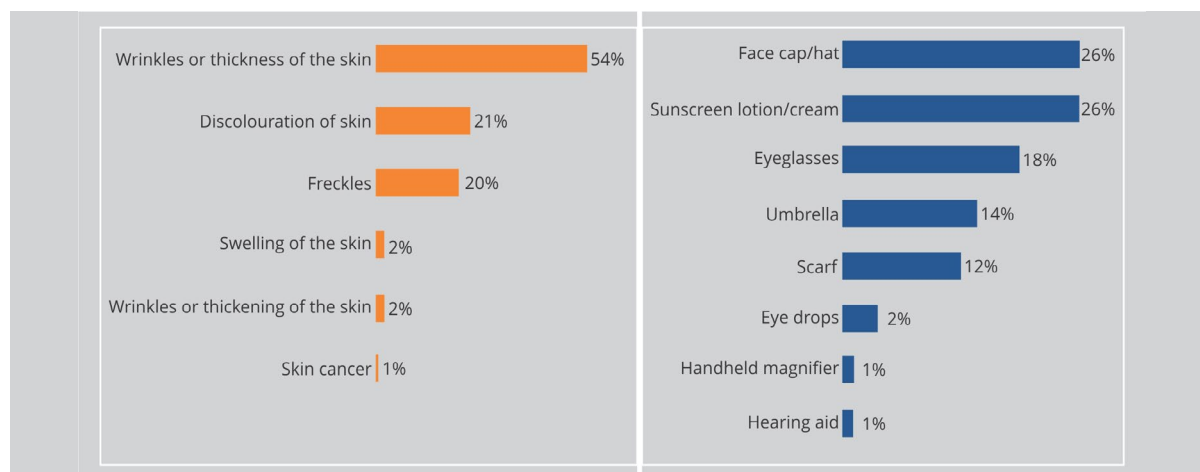
Geographic representation of medical issues faced by PWA's and protective measures adopted

Chart 8: Predominant medical challenges experienced by PWA's and current protective measures in KOGI State



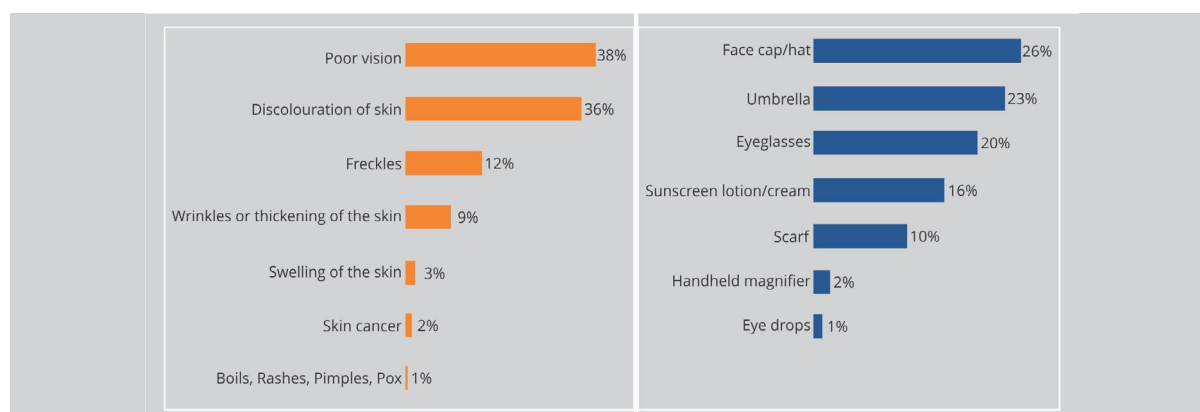
- Wrinkles or thickening of skin is a leading health condition among PWA's in Kogi State; at a lower level are irregular body temperature, boils and body itches.
- With skin conditions and visual challenges being rampant within this region, there is a large adoption of sunscreen lotions, umbrella's and eyeglasses to ease living.

Chart 9: Predominant medical challenges experienced by PWA's in ABUJA and current protective measures



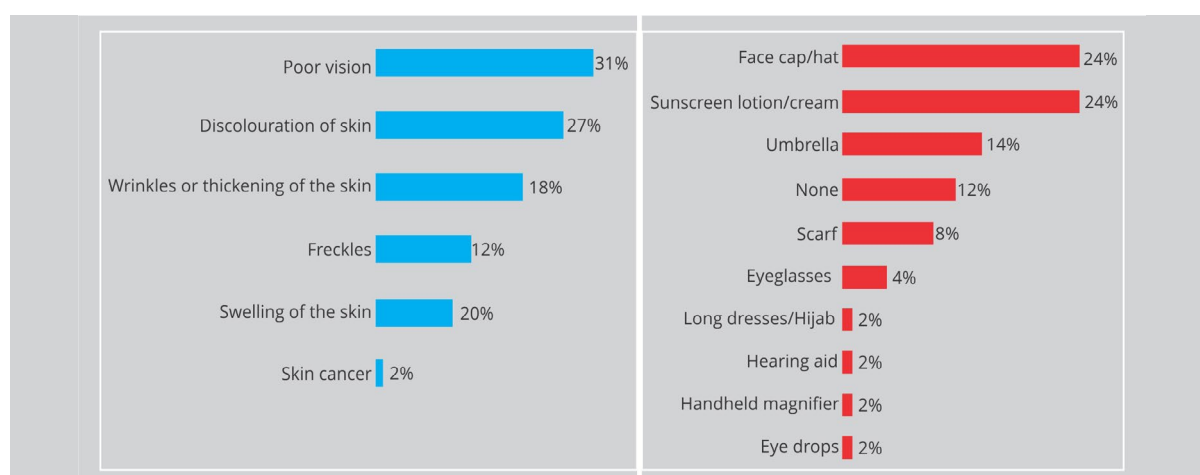
- Most PWA's resident in Abuja complain primarily about their inability to see clearly; others site skin related problems like freckles and discolouration of the skin a major concern.
- In a sharp contrast to other cities, wrinkles and thickening of skin was not cited as a primary health challenge.
- Although the use of face caps and sunscreen lotions were mentioned by the respondents, it is important to note the high number of PWA's in this location (6%) who do not use any protective measures at all.

Chart 10: Predominant medical challenges experienced by PWA's in LAGOS and current protective measures



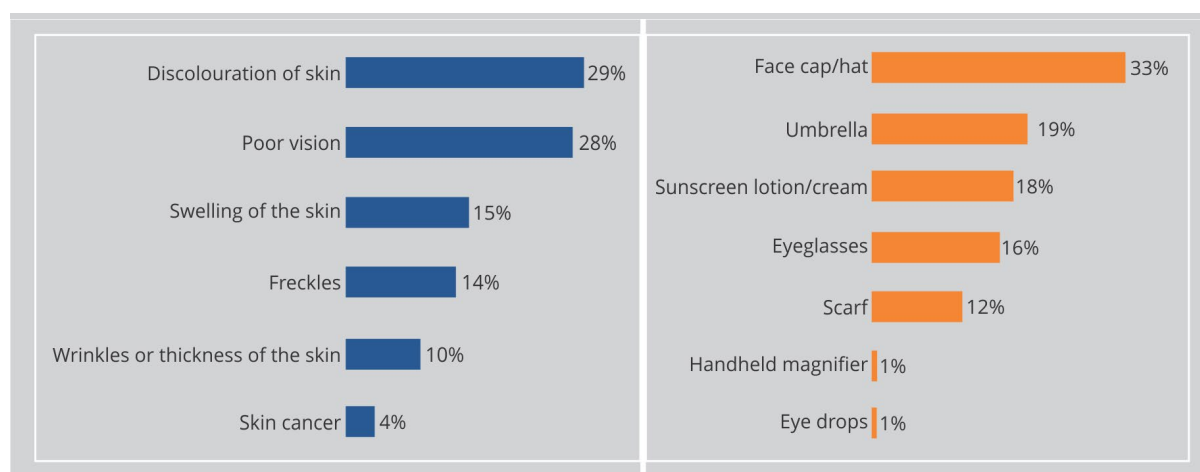
- Although there are records of skin cancers within Lagos, they have a lower rate of occurrence than the more rampant discolouration of skin and eyesight problems
- There is higher usage of scarfs, umbrella's and face caps/hats here; at a lower level are hearing aids, long dresses and eye drops.

Chart 11: Predominant medical challenges experienced by PWA's in KANO



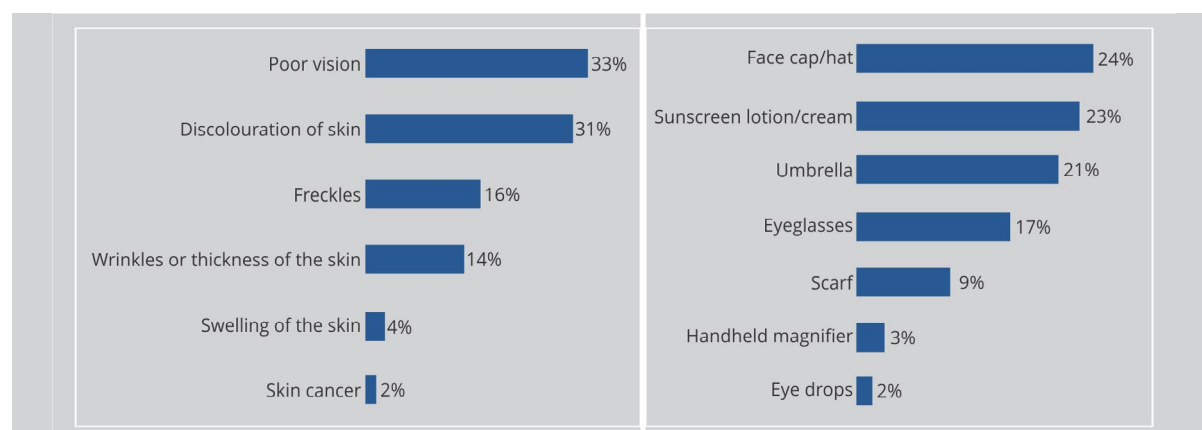
- As evident in other locations, poor vision, exacerbated by the intense amount of sunlight the nation is known for is a health issue affecting those with albinism.

Chart 12: Predominant medical challenges experienced by PWA's in ADAMAWA



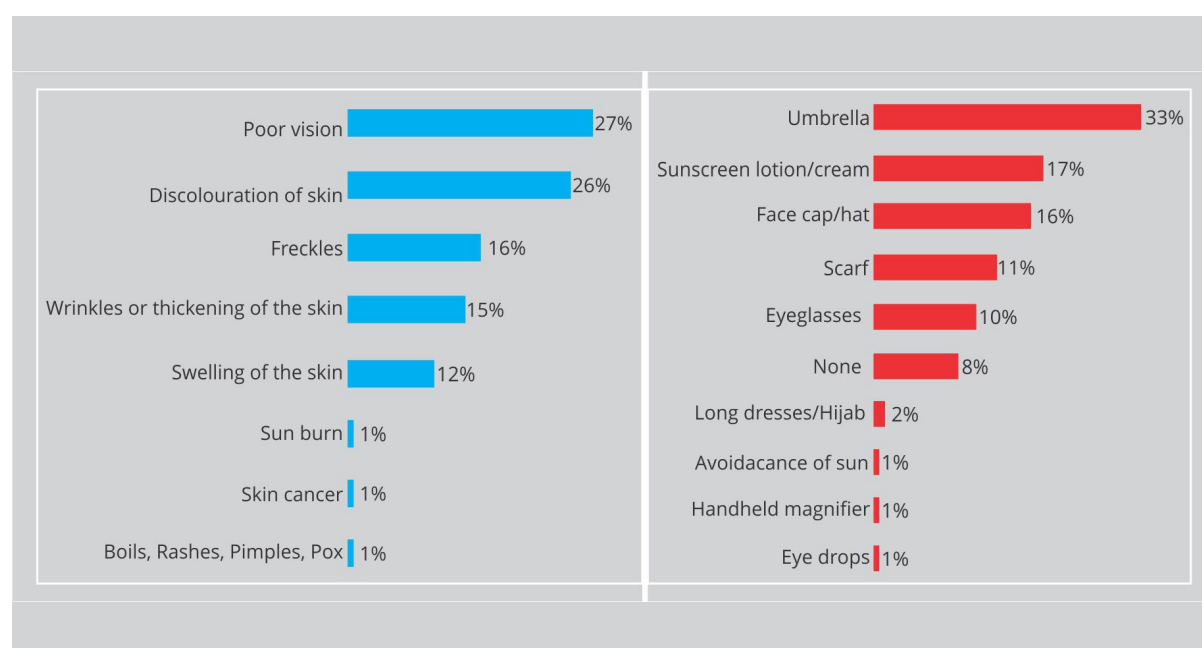
- Compared with other regions, there is a significant prevalence of skin cancers among PWA's living in Adamawa; at a higher level is discolouration of skin, poor vision and freckles.
- The use of face caps/hats are most predominant in this city; handheld magnifiers and hearing aids come in at a lower level.

Chart 13: Predominant medical challenges experienced by PWA's in ENUGU



- PWA's in Enugu have cited poor vision as the main medical condition they are faced with, next to this are skin related issues;
- As a protective measure, many PWAs resort to the use of sunscreens, eyeglasses and hats to ward against the harsh weather conditions.

Chart 14: Predominant medical challenges experienced by PWA's in CROSS RIVER



- With Cross River, there is a wider range of medical ailments recorded. Although cases like poor vision are predominantly high, boils, rashes and sunburns are also experienced at a lower level;
- Most popular protective measure adopted is the use of umbrellas.

Frequently requested assistive devices by PWA's

Gender		Location		Assistive Devices	
Male	55%	Kogi	23%	Eyeglasses	27%
Female	45%	Abuja	33%	Sunscreen	26%
		Lagos	35%	Handheld Magnifier	15%
		Enugu	30%	Hearing aid	9%
		Cross River	37%	Medicines	19%
		Kano	39%	None	3%
		Adamawa	27%		

N/B: Adamawa has an alarmingly high incidence of people who do not use any form of assistive devices to aid with ease of living. This could also be a trigger for the higher rates of skin cancers recorded in the region.

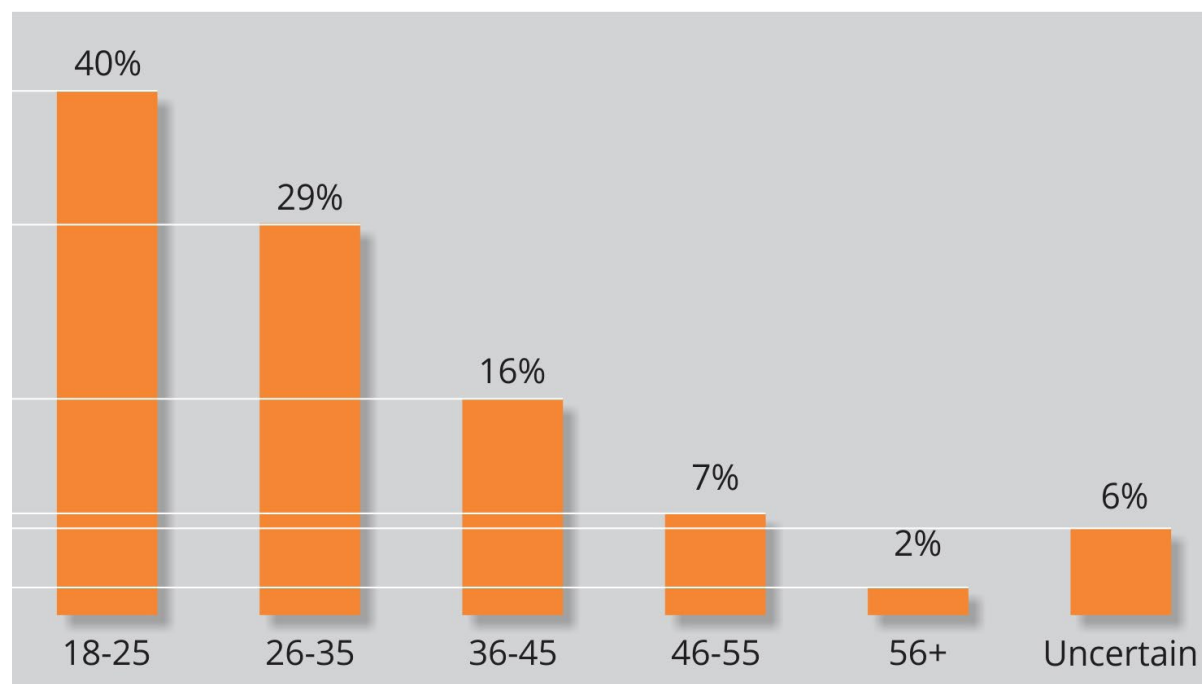
SECTION 3 – OCCUPATIONAL DISTRIBUTION OF PEOPLE LIVING WITH ALBINISM

PART A: BACKGROUND INFORMATION

Gender		Literacy Level		Age group	
Male	55%	None	10%	18-25	40%
Female	45%	Primary	13%	26-35	29%
		Secondary	58%	36-45	16%
		University	16%	46-55	7%
		Post-graduate	3%	56+	2%
				Uncertain	6%

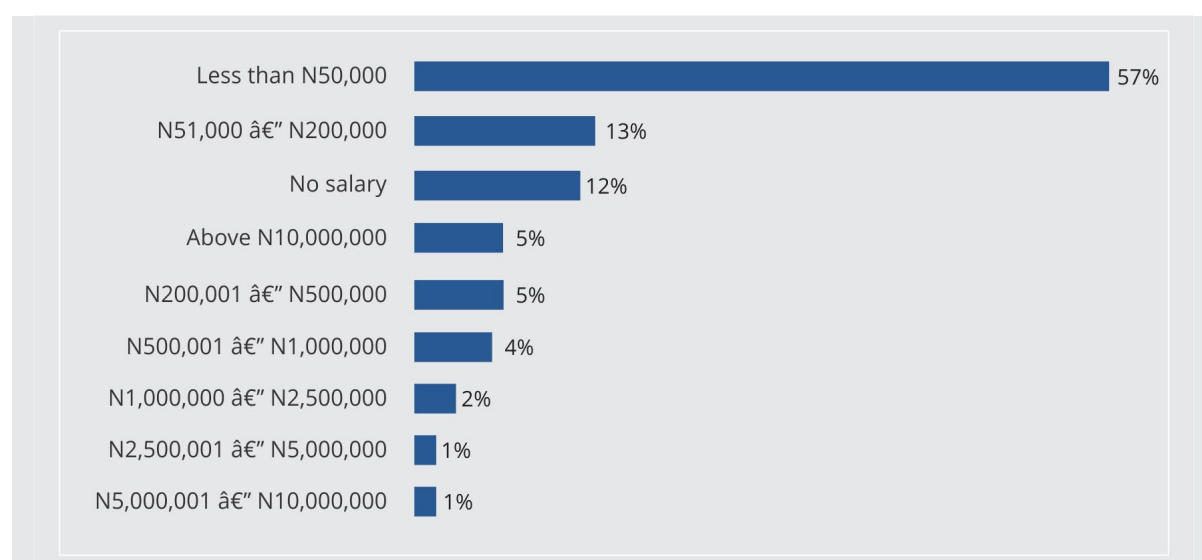
PART B: MAIN FINDINGS

Chart 15: Age distribution of People with Albinism from survey conducted



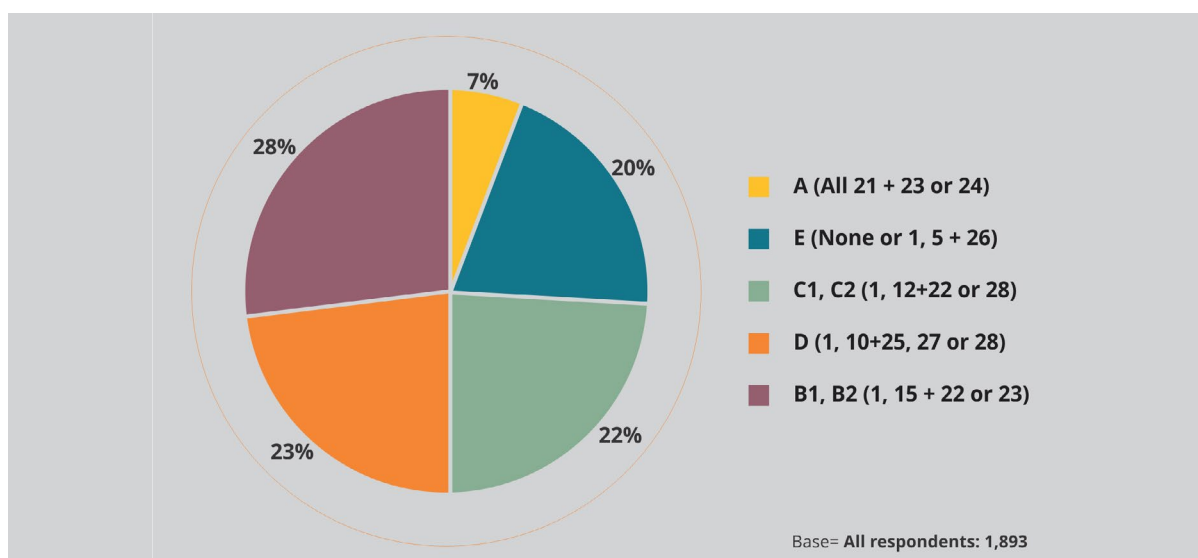
- Almost half of the respondents are within the range 18-25 years old.
- Reflecting the literacy level across the country, more than 5% are not sure about their ages.

Chart 16: PWA's Average Annual Income



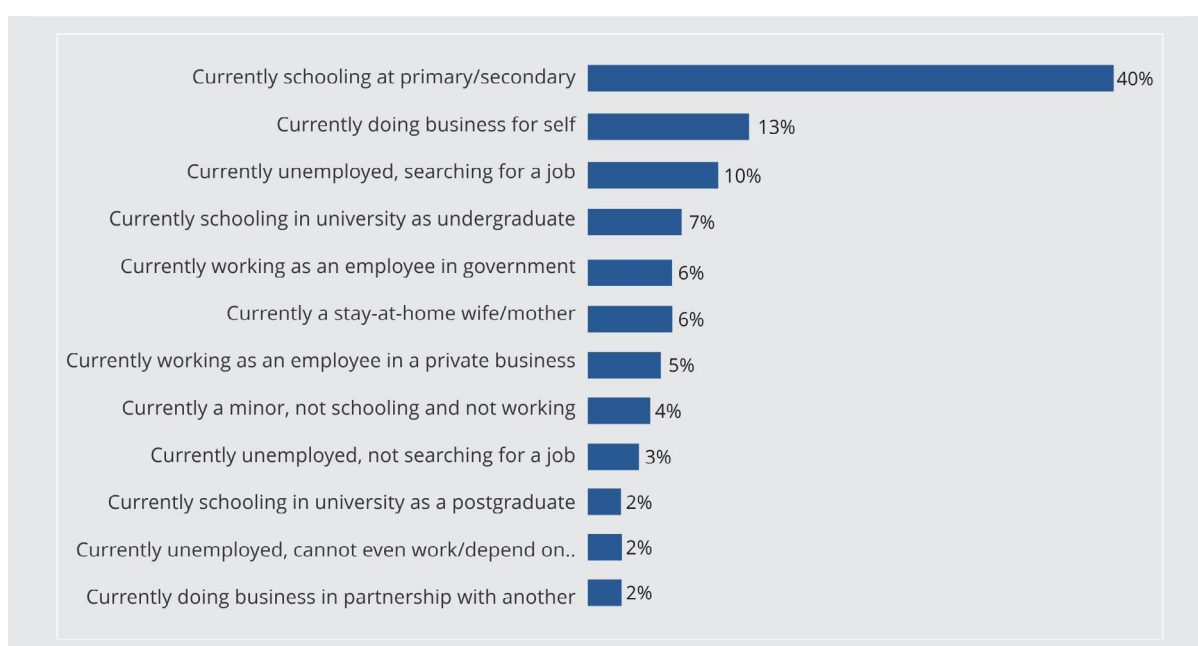
- Perhaps a pointer to the low standard of living among Nigerians who earn within the bracket minimum wage of N18,000 and are largely agrarian in the hinterlands of the country, more than half of PWA's earn less than N50,000 per annum.

Chart 17: Socioeconomic Classification of PWA's



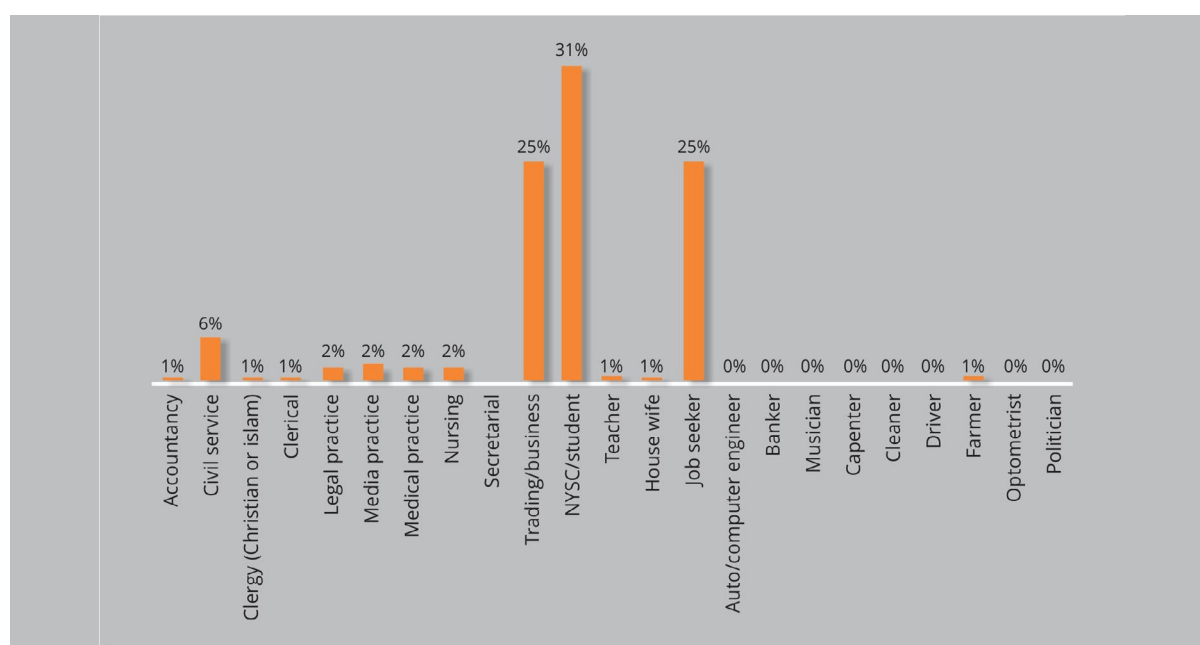
- Most PWA's are within SEC B1, B2, others are largely distributed within the C1,C2 and D categories respectively.

Chart 18: Employment ratio among PWA's



- Majority of the respondents are either primary or secondary school students. Others are either self-employed or undergraduates at the university;
- A significant group of people are unemployed and seeking employment but due to the discrimination they face during the interview processes are unable to secure jobs required to provide the finances needed for daily living.

Chart 19: Occupational Distribution among PWA's



- Respondents for this survey were largely National Youth Corps Members or students within educational institutions. Apart from the Civil Service, there is a low representation of PWA's in professional occupations;
- Unemployed individuals and traders or self-employed personnel occupy a significant but lower share of this category.

SECTION 4 – STAKEHOLDER RECOMMENDATIONS FROM PEOPLE LIVING WITH ALBINISM

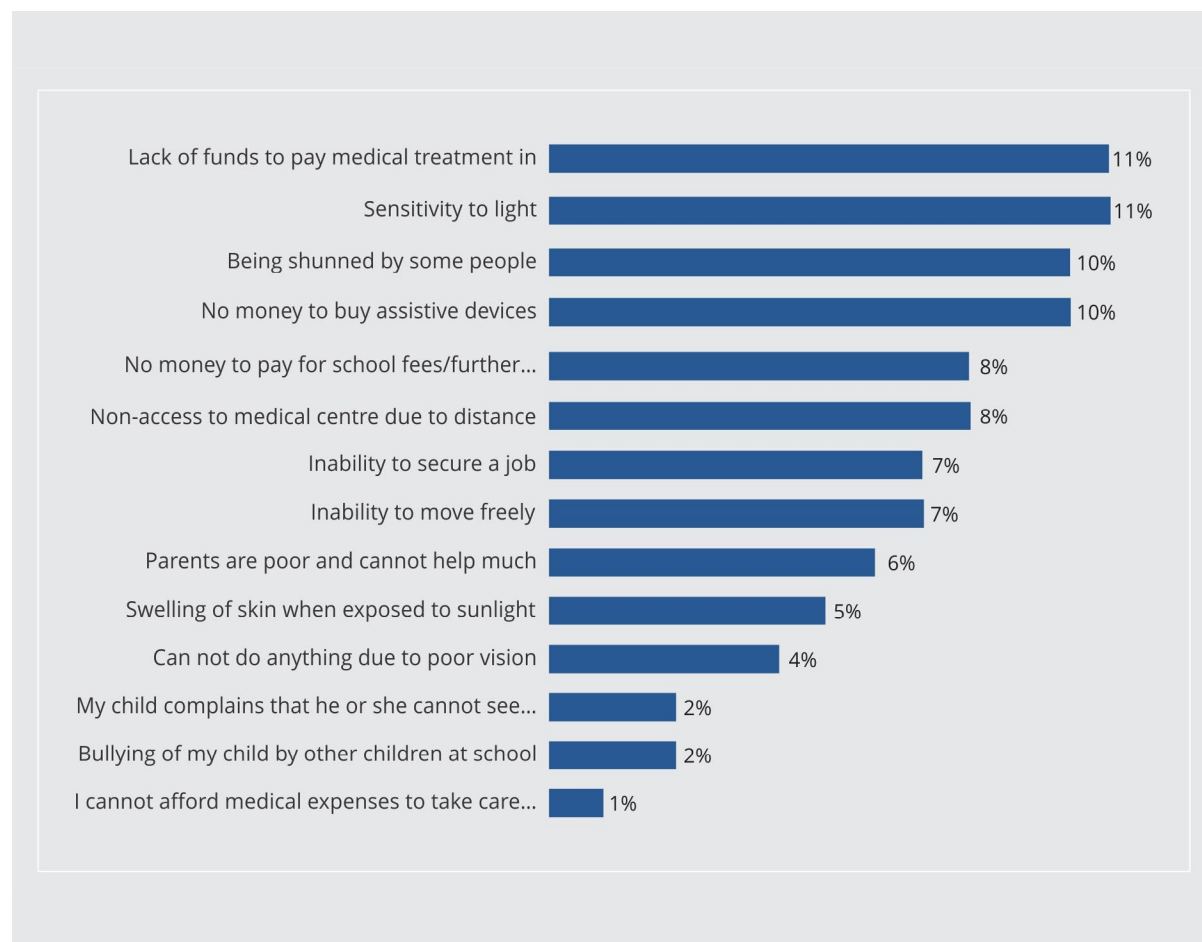
Table 5: Recommendations on improving the plight of PWA's

Social Support System	%	Recommendations	%
Parents	44%	Enlighten teachers and students on the plight of persons with albinism and how they ought to be treated in school environment	21%
Self-dependent or self-sponsored	29%	Provide teaching aids for persons with albinism	21%
Nobody. I have no helper	12%	Provide free medical care for them in all general hospitals	21%
Other family members	11%	Ensure that people who discriminate against them are punished	18%
Friends	3%	Ensure they have equal job opportunities with other people	18%
NGO that supports Persons with Albinism	2%	Provide social welfare	1%
Government pensions	0%	Better public orientation on albinism	1%

- More than half of the people with albinism confirm that better care in educational institutions and punishment for those who discriminate are priority;
- A high number of PWA's are also being supported by their parents.

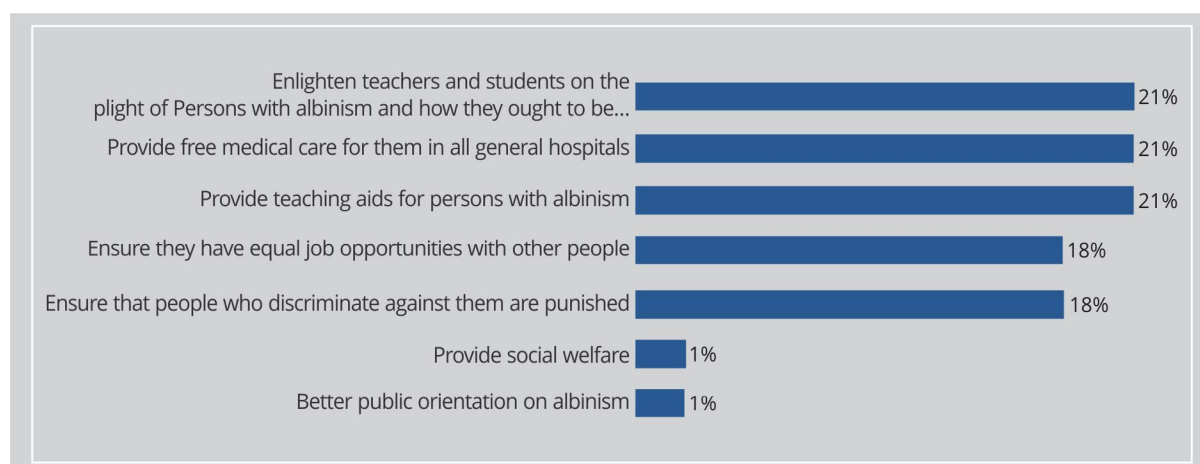
CRITICAL CONCERNS AND GOVERNMENTS ROLE IN IMPROVING THE PLIGHT OF PWA'S

Chart 20: Acute worries of those living with Albinism



- Among other important issues mentioned are inadequate funds required to access medical treatments or purchase assistive devices.
- A high number of PWA's also cite lack of funding for further education, especially at university level.
- Most are situated far from existing medical centres and cannot make the commute to the hospitals when necessary.
- Unemployment and discrimination faced are also key factors stated.

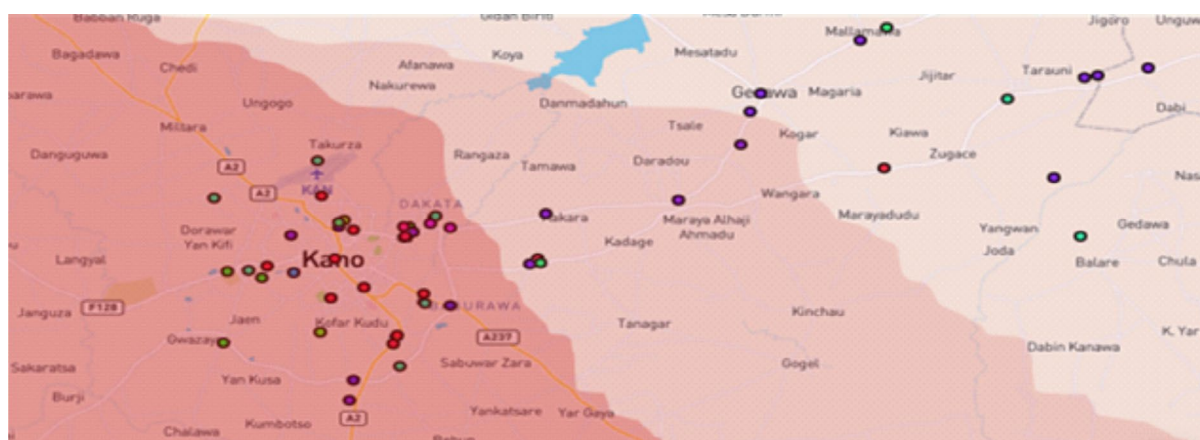
Chart 21: Suggestions to Government on ways to improve the plight of those living with Albinism



- They would like better enlightenment for teachers and students on how they should be treated in school.
- Many PWA's want access to free medical care in general hospitals as well as teaching aids in schools
- They want to see laws against the discrimination of people living with albinism passed by government and would like equal job opportunities when seeking employment.
- At a lesser degree, they also want to see better orientation to the general public on the plight of those living with albinism.

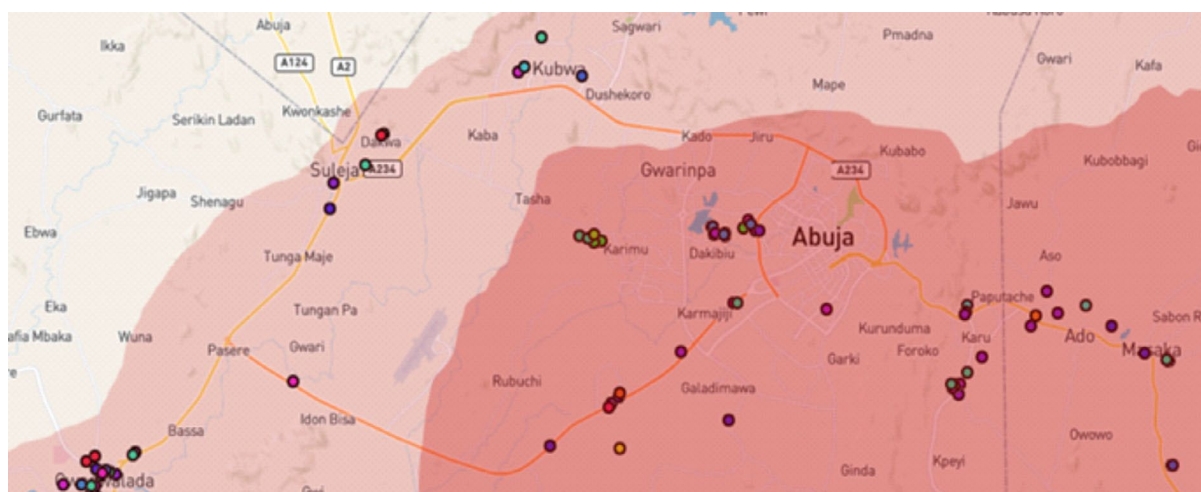
SECTION 5 – HEAT MAPS SHOWING PREVALENCE OF MEDICAL CONDITIONS ACROSS CITIES

Map 1: Heatmap showing locations with prevalence of medical conditions in Kano State



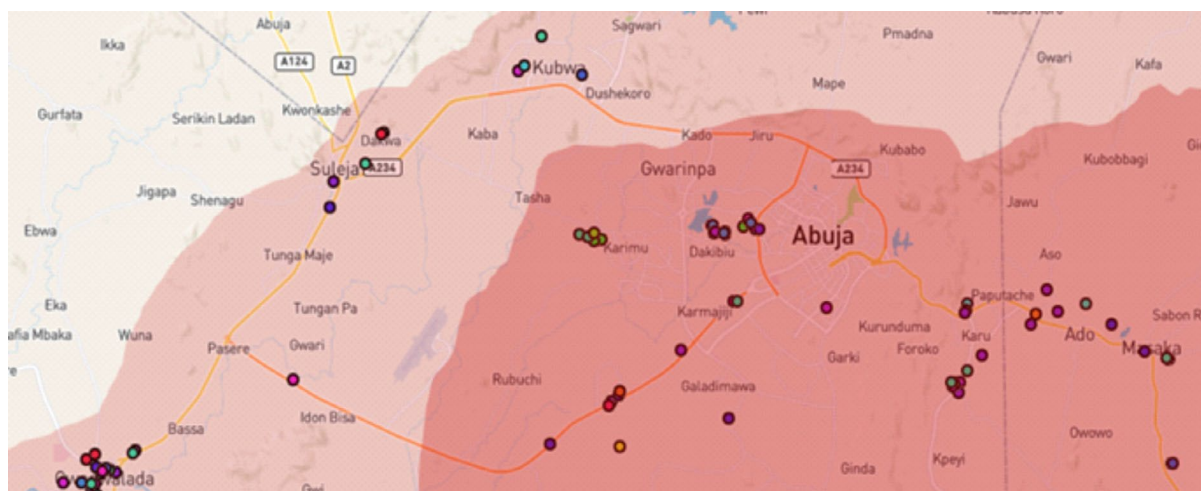
- Red indicators show frequency of occurrence of medical cases related to poor vision in cities such as Kofar Kudu, Dakatr and KAM;
- Areas with lower concentration of PAW's with visibility issues are in Tarauni, Mallamama and Balare

Map 2: Heatmap showing locations with prevalence of medical conditions in Abuja, FCT



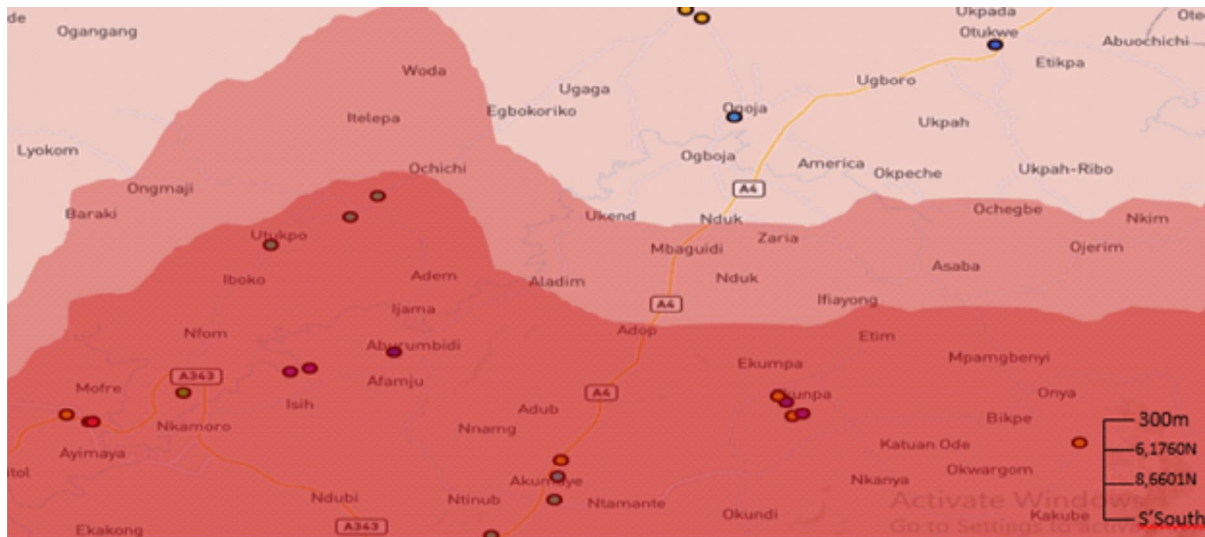
- With multiple clusters of PWA's existing across Abuja, we observe the dense population of those with medical concerns within Karimu, Ado, Papaduche and Dakibiu;
- While Gwagwalada has a large population of people affected with health concerns, only a few are eye defects related.

Map 3: Heatmap showing locations with prevalence of poor vision in Lagos State



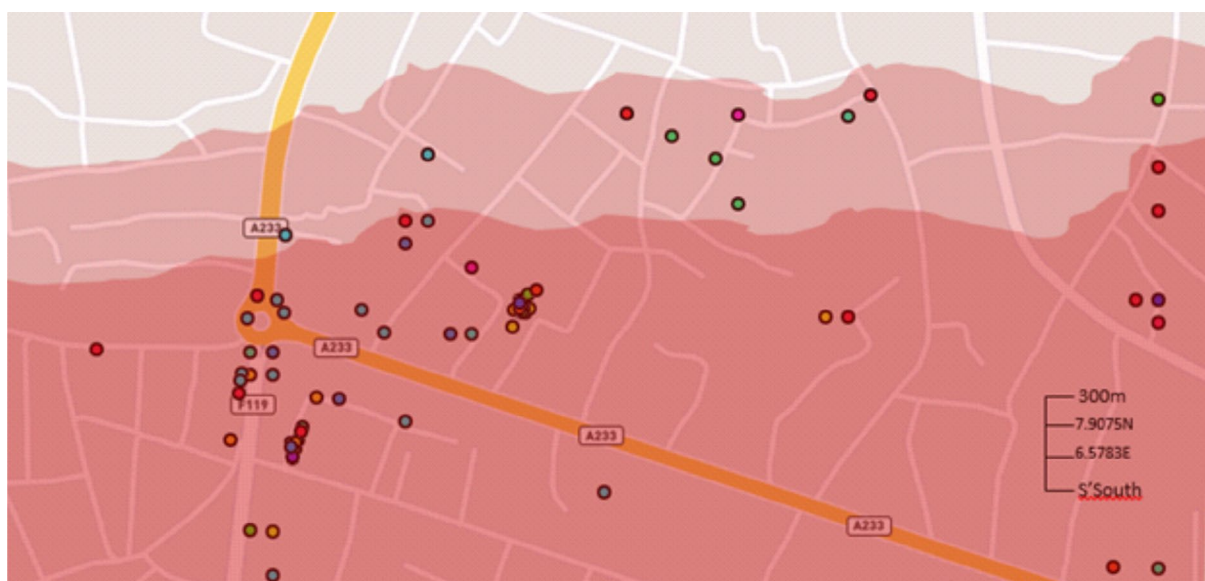
- Spatial representation of datasets in Lagos are dispersed, however, a high population of Albinos living within Lafia, Apapa and Ikorodu expressed health challenges including poor vision;

Map 4: Heatmap showing locations with prevalence of medical conditions in Cross River State



- In contrast with other locations, Cross River state has its PWA's afflicted with a wide range of skin and visibility problems across the state.
- Akumaye, Okunpa and Isih have the highest incidences of these conditions.

Map 5: Heatmap showing locations with prevalence of medical conditions in Kogi State



- Kogi state has the highest record of people living with albinism across the 7 cities surveyed. Most reported medical issues are thickening of skin, poor vision and dark spots;
- Access to health, job opportunities, education.

PART 2: ABSTRACT OF QUALITATIVE SURVEY SEGMENT

FOCUS GROUP DISCUSSIONS (FGDS)

1. Spontaneous Associations with Albinism

Persons living with albinism are seen as human beings that are different from other people and requiring special needs because of their skin and eye colour.

2. Prevalence of Albinism

The average number of children living with albinism that can be found in homes with incidence of albinism is 2 - 3

3. Caring for Persons Living with Albinism

People living with albinism are seen as requiring higher financial commitment to be cared for, being considered highly vulnerable to both human and environmental hazards if left without adequate care.

In view of the foregoing perceptions, the primary caregiver for the child living with albinism is the mother. In some homes, it is the joint effort of both parents.

4. Cause of Concern

Three main cause of concern for people living with albinism were identified as:

- Effect of sunlight/health
- Safety
- Accident

5. Stigmatization/Discrimination Issues

People living with albinism often have low self-esteem about themselves largely borne out of the various misconceptions associated with their skin, eyes and hair colour

6. Factors Promoting Stigmatization

Lack of information/inadequate information about the albinism condition

- Inadequate empowerment of people living with albinism
- Stereotype
- Inefficient Government Policy
- individual Orientation

7. Health Challenges

Skin related diseases, bleeding nose and poor eye sights are the main health challenges experienced by people living with albinism

8. Appropriate Treatment of People Living with Albinism

People living with albinism deserve to be treated specially largely because they are prone to health challenges;

Most stakeholders are of the view that PWAs deserve to be treated with particular attention to enable them adjust well into the society as well as enhance their chances of harnessing their potentials

IN-DEPTH INTERVIEWS WITH STAKEHOLDERS (MEDICAL, GOVERNMENT, EDUCATION)

1. Spontaneous Associations with Albinism

Though seen as normal human beings, people living with albinism are associated with having a congenital disorder affecting their skin and hair.

Considered less prevalent, the associated challenges experienced by people living with albinism make the condition a source of concern to them.

2. Discrimination / Challenges

Superstitious beliefs fuelled by inadequate information about the condition remain the main source of misunderstanding and discrimination experienced by people living with albinism

- Discrimination comes in the forms of:
- Child abandonment
- Use for ritual/spiritual purposes
- Less opportunity for education due to their poor eye sight
- Less employment opportunities leading to less financial empowerment

3. Caring for People Living

Given the associated health challenges people living with albinism are prone to, they are expected to be treated with care albeit with caution in order not to dampen their self-esteem or rouse feelings of unnecessary rivalry from the public

4. Care Giver

Care is given to PWAs primarily by their parents, followed by other family members

The government has a lot to do to ensure a better life for this category of people by providing conducive/enabling environment for their holistic wellbeing

5. Health Challenges

According to specialist, the prevalent health challenges noticed among people living with albinism are skin and eye related

6. Skin

- Allergies
- Sun burn
- Spots
- Cancer

7. Eyes

- Short sightedness
- Astigmatism

8. Addressing the Challenges

Public enlightenment aimed at sensitizing and educating the public as well as people living with albinism will help address identified issues. Some of the measures to take include the following:

- Education on the appropriate dress code for people living with albinism;
- Re-orientation of the mindset of the public in terms of beliefs about albinism;
- Promulgation and enforcement of laws protecting the rights of people living with albinism;
- Creating/promoting a viable forum for people living with albinism to meet;
- Provision of policy that ensure access to healthcare and education;
- Provision of government sponsored eye glasses;

9. Preferred Media

- Television, radio and social media are the main recommended vehicles of dissemination of information about albinism;
- Local languages should be adopted to ensure wider acceptance and reach

DETAILED REPORT OF FINDINGS: QUALITATIVE RESEARCH

GENERAL UNDERSTANDING OF ALBINISM

1. Spontaneous Associations

Various associations are given to albinism. The general consensus among discussion panellists is that although they are normal human beings they have special needs that require more dedicated attention.

In all, people living with albinism are often regarded as different from other people largely because of their skin colour and their eyes.

Words and phrases associated with albinism include the following:

- Oyinbo
- Ayari
- White person
- Lack of pigmentation
- Different from other people
- Having genetic issues
- Persons with light skin problem
- Having significantly different colour
- Having neither white nor red skin colour

With this mindset, albinos are often looked upon with pity or with feelings of empathy.

“The first thing that comes to my mind when I see a person with albinism is pity, because they are really being discriminated in the society because of their skin pigmentation and even some children are afraid of people and don't like to get close to them; so that social discrimination is why I feel pity for them”

IDI, Adamawa

When I see people living with albinism, I feel empathy for them because I know that at any moment, they might develop some form of blindness and other skin diseases because they are prone to it

IDI, Cross River

I feel they would need extra support because of the issues they might have in life arising from the little knowledge I have about them. Persons living with albinism have some health challenges that they need support with on a regular basis

IDI; Kano

Similarly, parents of children living with albinism see them as being different from other children, and as such require more attention to be taken care of.

“Yes, I usually pay attention to them because of their skin because the sun affects their skin a lot so I usually pay attention to them “

“Yes, I pay attention to mainly that very one, this special one because he is different. He’s an albino and needs special care”

Parents, FGD; Abuja

“I have to be extra careful because of how their system and skin is, it’s very sensitive and whatever thing that touches them could harm them. He could fall into places that are not okay for him, that’s why I pay more attention to him.”

“They are special people, so everything about them is special”

Parents, FGD; Cross River

Within professionals across different fields, albinism is further described as an inherited disorder that affects the skin colour, eyes and hair of people born with it.

“Albinism is generally a deficiency in melanin pigmentation. Basically, what happens is that the pigment that makes the skin black in a lay man’s term is not there. Everybody is supposed to have this pigment in their skin. But for one reason or the other, in a congenital abnormally this pigment is deficient, the child could come out with this general fair complexion without the general tint of the black we have in the melanin.”

IDI; Cross River

“Albinism is a condition in which someone lacks the melanin pigmentation and so they have a white skin colour, with white hair and eyes.”

IDI; Enugu

“Albinism is just like any other sickness you can pass on to a child, albinos are normal human beings like you and I, it’s just that their skin colour is not like yours and mine”

IDI, Kano

Albinism is an autoimmune condition in which the individual is lacking the melanin pigment and so the melanin pigment is not being produced in the gene of the individual and most times, it is inherited from the parents or forefathers of the individual

IDI, Lagos

PREVALENCE OF ALBINISM

Currently, in homes with the incidence of albinism, the average number of albinos per household is 2 – 3.

"I have two, one is 8 years and the other is 2 years"

"I have four children and two are albinos"

"I have five children and three albinos, the three of them are 15, 13 and 8 years old"

FGD, Abuja

"I have 4 of them: 22 years, 15 years, 10 years and 6 years"

"I have 2, they are 3 and 1 years"

"I also have 2, they are 9 and 5 years"

"I have 3: 14, 11 and 6 years"

"I have 2, they are 11 and 9 years"

FGD; Kano

"I have 2: a boy and a girl aged 11 and 8 years"

"I have 1 albino, he's 20 years"

"I also have one, aged 10 years"

"I have just one, a 9-year old"

- I have one, he's 34 years old now

FGD; Lagos

CARING FOR PEOPLE LIVING WITH ALBINISM

- Across board, people living with albinism are believed to require special and concerted effort to ensure they survive as well as have a fulfilling life;
- Albinos are seen as vulnerable to both human and environmental hazards if left poorly unattended to;
- Observably, the care of children with albinism is hardly entrusted to house helps or other care givers, but is the primary responsibility of the parents;
- To most of the professionals involved in the study, albinism is a source of concern largely due to the higher health-related challenges believed to be prevalent amongst people living with albinism;

"I think it's a problem, a very serious one because they don't look like the rest of us"

IDI; Enugu

“To me it’s a problem because although they have the same functionality as a normal person, they are prone to certain dysfunction or malfunction in their system. I think it’s a problem”

IDI; Cross River

I think it’s not a big problem as long as the person meets with his physicians, the optometrist and their dermatologists as much as possible, especially when it involves the eyes or skin

IDI; Kano

Well, it’s a skin condition and so should be seen as a serious problem and precautions should be taken to protect the skin of a person living with albinism because the skin is already at risk of some skin diseases

IDI; Lagos

Among the parents, the primary caregiver for children living with albinism remains the mother followed by a combination of the father and mother as mentioned by few of the participants.

Children with albinism are treated differently from other children in terms of food, clothing and playtime.

- Food – Most of the parents drastically reduce the salt and sugar content in the meals they prepare for their albino children;
- Clothing – Effort is usually made to ensure that they are clothed in long sleeve tops on long trousers with the aim of ensuring that as little part of their body as possible is exposed to the environment
- Play time – Almost all the participants regulate the type of play, time of play and where to play for their children living with albinism. The time of play is usually pegged at morning and evening when is it less likely that they will be bitten by insects or beaten by the sun

“Yes, I usually pay attention to them because of their skin because the sun affects their skin a lot so I usually pay attention to them”

“Yes, I pay attention to mainly that very one, this special one because he is different.

“When he was small, at age 2, we never knew about his albinism and people would be telling me not to give him salt and some other different things but then we found this foundation and I can see that the teaching here is different”

FGD; Abuja

Yes, we pay extra and special attention to our children living with albinism because we don't want any fly or mosquito to touch their body, so we provide them with mosquito's net, we spray the house with insecticide

FGD; Adamawa

*"Because of their complexion, to make their skin safe, I try to keep him from the sun"
"I have to be extra careful because of how their system and skin are, their case is very sensitive and whatever thing that touches them could harm them. He could fall into places that are not okay for him, that's why I pay more attention to him"
"Being that they have special needs, we have to treat them specially also. Like the sun and the rain, we have to keep them away from such environments*

FGD; Cross River

"I always make sure that they wear trousers to school and other places, every class she enters I must meet the class teacher with doctor's report from Parklane or from the Albino Foundation so that they will treat her well"

FGD; Enugu

GREATEST CONCERNS

Three main areas of concern about people living with albinism were identified as:

- Effect of sunlight and health
- Safety
- Accident

1. Effect of Sunlight

Awareness for the negative effect of sunlight on people with albinism was high. Most of the parents of children living with albinism endeavour to keep the children away from the sun due to the understanding that they are prone to skin cancer and other dermatological issues.

Two measures adopted to prevent the effect are:

- Hardly sending such children on errand under the sun but instead, sending the other children;
- Applying sunscreen creams to protect their skins

"My greatest concern about him is the effect of the sun. So, my greatest fear is the sun so that others would not drag him to the sun especially from 12noon to 3pm when the sun is high"

FGD; Abuja

"My greatest concern is sunshine, when they are in school it gives me much concern."

FGD; Enugu

2. Safety

People living with albinism as well as their caregivers are concerned about their safety in the face of the belief that people living with albinism are 'sprit' hence suitable for rituals

"To some people, albinos are seen as spirits. They are usually used for rituals believing that their blood is very efficacious"

FGD; Enugu

"Some consider them to be spirits; some people use them for rituals"

IDI; Adamawa

3. Accident

Believed to be prone to accidents, a perception borne out of the concern for their poor eyesight and sensitive skin

"You know, children when you tell them not to go out and play, they would not listen. Like yesterday when I got home I discovered something has cut her leg. They said she was running around and playing football with the brother, then she fell down. So that is the only thing, so that they don't go to where they are not supposed to go when I'm not around".

FGD; Kogi

*"My greatest concern is crossing the road, most time they don't see very well"
- Rough play in the school, my son is very stubborn and that gives me the most concern. I even tell the teacher to make sure he does not go out like that to play. Sometimes when I go to their school he will be at the back but I will tell the teacher to make him be in the front because of his sight problem"*

FGD; Lagos

They are discriminated because some people believe they have magical powers or they have been cursed and that they bring bad luck

IDI; Kogi

STIGMATIZATION/DISCRIMINATION ISSUES

People living with albinism often have low self-esteem about themselves largely borne out of the various misconceptions associated with their skin, eyes and hair colour

Reasons for the discrimination include:

- Skin: often times people living with albinism have spots / wrinkled skin. This often puts people off them;
- Eyes: the seemingly uncontrollable movement of the eyes, of people living with albinism, known as nystagmus, is another dislike by people. Some describe it as scary:

“Yes, they are discriminated against because they don’t see very well and because of the way their eyes move, so they call them derogatory names”

IDI; Enugu

“They are discriminated especially because of the way they look especially when they are in the sun, if you see some of them in the sun the way they look and the way their skin is spotted, it’s irritating and people like to avoid them because of that”

IDI; Adamawa

“Some people avoid associating with them because of their skin colour and the colour of their hair and eyes”

IDI; Kano

Some of the aspects where PWAs experience discrimination include the area of:

- In the area of education
- When accessing healthcare
- At social gatherings
- When seeking employment
- When seeking spouses for marriage

i. Education

Due to their poor eye sight they often fall behind in academic performance with the resultant effect of class mates teasing/mocking them. This in turn further leads to low self-esteem.

Furthermore, there is a belief that people living with albinism are less intelligent vis-à-vis their counterparts. Bearing both challenges, some people living with albinism would rather stay out school, a situation which further worsens their challenges

“the girls that always look sad when she comes back from school, she doesn’t have strong heart any little insult will get to her.

FGD; Lagos

There are many ways they are being discriminated against, like during marriages, in friendships and even in schools

IDI; Adamawa

....and probably in school, he might be set aside because they feel that he is deficient in knowledge, that is just the stigma that goes along with it, especially in the school, work place, along the street, in public places

IDI; Cross River

ii. Accessing Healthcare

Though all Government and privately-owned hospitals willingly offer health care to all classes of people, those living with albinism report discrimination from fellow patients, more often than not, people tend to avoid sitting next to them

"There used to be one albino that comes to this clinic. Often, he arrives very early, well ahead of other people, but by the time they start consultation, I'd be surprised that he will be among the last to be attended to. The other people will push him aside so he will have to wait till others are gone before coming forward"

IDI; Enugu

iii. Social gatherings

Most people living with albinism shy away from social gatherings because of the way people react to them.

They are often not given attention like their counterparts.

"At times, in any group or meetings, some people will be scared, maybe we are sitting at the same desk, some will try to move away from me. At times, I used to ask: do I have body odour or am I smelling? I used to ask people and they would say No. I wonder why others when we sit together, they won't want our arms to touch, that is what I face at times"

FGD; Kogi

"Like I said earlier you can be going with your child and some children will start saying 'oyinbo pepper' even up to wherever you are going. Those children will follow you, sometimes they touch your skin and run away, they will come back and touch it again as if it is strange to them, some will say 'afin', 'he cannot see'"

FGD; Lagos

"They are discriminated against in employment and also at social gatherings, some people don't like to associate with them"

IDI; Cross River

iv. When Seeking Employment

There were reports of discrimination at work places and during job interviews. It was perceived and alleged that most employers would rather employ a non-albino largely because of the belief that albinos have less stamina and are less intelligent:

"the major thing I would say is that the albino is jobless, he is not empowered"

FGD; Abuja

"Yes, first and foremost at the work places. If an albino goes for a job interview, no matter how intelligent he is, they might find him wanting thinking he might not be able to take charge of the job"

IDI; Cross River

"Most albinos are not accepted in the society and they are seen as not normal human beings, some people don't want to employ them because of their skin colour and some people insult them and avoid associating with them, some don't want to give them jobs and even when looking for accommodation, some people discriminate against them and won't give them houses"

IDI; Kano

v. Marital Matters

In the course of the study, it was also reported that some people living with albinism were denied the opportunity of marrying the person of their choice because of this albinism

"The society or community don't have the knowledge of albinism. People also don't want to marry albinos, they fear that if they marry albinos they will have albino offsprings too"

IDI; Kogi

FACTORS THAT CAUSE STIGMATIZATION

i. Lack of information / inadequate information

The public is poorly informed about the issue of albinism. The information about albinism is mostly limited to word of mouth with little or no scientific enlightenment to boot.

... also, the lack of information, it's because that's what they were taught in schools by their peers. It was in the school that I learnt about albinism

FGD; Abuja

People get their orientation in schools with their peers, from their peers, they call you names, it's because that's what they were taught in schools. It was in the school that I learnt about albinism

"Well I would say it is lack of awareness and they should be educated about albinos and what it takes to be an albino and how persons living with albinism should be treated"

FGD; Adamawa

"People have such attitude to them because they are not well informed about albinism"

FGD; Cross River

"I think people have these misconceptions and beliefs based on their level of literacy. Some illiterates call them derogatory names just because they are not informed to know that they are normal human beings like you and me, it's just their skin colour that makes them different and it's inherited, they didn't have a choice in it"

IDI; Lagos

ii. Stereotyping

Some cultural beliefs foster the negative reaction from the public towards people living with albinism

Albinos are seen as 'objects' for spiritual atonement or curative purposes

Some of these beliefs include that:

- The parents committed abomination hence are cursed or serving punishment
- Albinos are evil hence their blood is suitable for rituals
- Having sexual interaction with an albino is curative for diseases like HIV/AIDS
- Albinos are prone to giving birth to albino babies

"They do not believe that they are the same and should be doing things together. Even they can do things better than we that are black."

FGD; Enugu

“People see them as products of mistake; they believe that if the parents are blacks how come white came as whites? They see them as products of accident, not knowing that their forefathers may be white. Before in the ‘80s we had only one albino in my community but now they are many”

FGD; Enugu

“Some of the beliefs and misconceptions I know about albinism are that it’s a curse, a bad omen or a punishment and sexual intercourse with an albino is a cure for some kinds of diseases like HIV/AIDS and that albinism is contagious and that albinos bring bad luck and albinos cannot have normal children and that albinos are sterile and cannot have children, which are all very wrong, some people even think that a mother to an albino is a witch”

“The belief I know of is that people think they are evil and they are always used for rituals because some people believe that if you use their body parts for rituals, you can get money from it and some other things, which is very wrong”

IDI; Adamawa

“Some people will tell you that somebody that is an albino has some spiritual something whatever, depending on where you come from, they believe them”

FGD; Kogi

iii. Inadequate empowerment of people living with albinism

Inadequate empowerment of people living with albinism make them vulnerable to discrimination and neglect.

Some of the identified areas of inadequate empowerment include:

- Information on caring for/taking care of themselves
- Educational level needed to secure high-end jobs
- Finances – to be independent

“If you have money. Because money answers all things. There is nothing money [cannot] do. So, when albinos have money or the parents of albinos have money, they don’t need someone to take care of them, even right now, some people are talking about creating special schools for albinos”

FGD; Abuja

“Illiteracy, lack of education can affect persons with albinism from having adequate care, especially when the parent doesn’t know how to take care of their albino child.”

FGD; Enugu

“Lack of awareness can also limit them too, for example if you don't even know how to take care of an albino and you have one, you wouldn't know what to do even if you have the money to spend for them.”

IDI; Lagos

iv. Inadequate Government Policy

Little or nothing is known about policies protecting the rights of people living with albinism.

“Government policies and programmes will help to keep albinos safe, if governments have policies that recognize albinos in the country. There should be provision in the policy for adequate care and if the public will be enlightened, especially the children in the school, if the teachers are enlightened about the status of children with albinism, I believe that the children will have adequate care. So, enlightenment and government policies should be some of the major tools for adequate care of persons with albinism.”

IDI; Kogi

v. Individual Orientation

This is closely tied to being insensitive to the feelings of others. Most members of the public fail to see and accept people living with albinism as normal people. Rather, people living with albinism are looked down on largely because of the challenges they have with their skin and eyes:

“I'll say it depends on the nature of this person and lack of regards for the feelings of these people”

FGD; Lagos

HEALTH CHALLENGES

Some health-related challenges were identified. However, parents of children living with albinism, people living with albinism and experts involved in the study agreed that the skin and eyes are the two main areas prone to health challenges.

Another identified health challenge is nose-bleeding which often occurs following prolonged exposure to the sun;

“Low vision and skin problems”

“Let me talk about their skin problem first. There is something that grows on their skin and their body, it comes and goes and that it is in season. When they stay in the sun for too long they have will it and when they stop going out into the sun, it goes, it's like rashes and sometimes it's like boil, that's one skin problem I've noticed”

FGD; Abuja

“For me, the one I gave birth to with this one that is at home, they all have different abilities, because the one that died, her eyes were okay, but this one at home, her eyes are always shaking, so she cannot see clearly in school or while reading, until she brings the book closer to her eyes. I still gave birth to a set of twins black and white, the white one has the same eyes like the first one, her eyes don’t shake, her eyes are just fine, but I know it’s poor vision.”

FGD; Adamawa

“Nose bleeding; for my son, whenever he exposes himself to the sun his nose starts bleeding”

FGD; Kano

“The first thing you notice is their skin, you would see that most of them have black spots on their skin, and their skin would be peeling, the outer layer especially and most of them can’t see far distances because of their shaky eyes”

IDI; Adamawa

“They are prone to skin cancer and have poor eyesight which could lead to blindness”

IDI; Cross River

“I know that because of their lack of melanin pigmentation, they are prone to skin cancer and they suffer from poor eyesight; for the skin cancer prevention, they have to avoid going out in the sun and avoid being in places that are very hot, as it’s not good for their skin and if they have to be out in the sun, they need to wear clothes that cover them very well and also they should make use of their sunscreen regularly”

IDI; Enugu

APPROPRIATE TREATMENT OF PEOPLE LIVING WITH ALBINISM

While most of the participants do not look forward to giving birth to a child living with albinism, they will however resign to the will of God should they give birth to one

One of the main reason for the above reaction is the believe that people living with albinism require care (which often than not is seen as financially and physically demanding to the parents of such children)

It was a general consensus that people living with albinism deserve to be treated specially. Being prone to earlier mentioned health challenges, they deserve to be treated differently to enable them adjust well into the society as well as enhance their chances of harnessing their potentials

It is expected that children living with albinism should be:

- Given front seats in classes to help them have clearer view of the board
- Given extra time during class tests and examinations, bearing in mind their sight challenges which put them at a disadvantage vis-à-vis their classmates
- Encouraged to take leadership roles
- Protected from verbal, physical and other types of assaults form classmates
- Monitored in terms of their participation in outdoor activities

For the adults, it is expected that they:

- Should be protected against assault and threat to their physical bodies
- Are financially empowered to ensure independence
- Equipped with adequate information on proper healthy practices that enhance healthy living and less health issues
- Given equal employment opportunity
- Posted to duties that ensure that they are protected from the sun

“Yes, they do because they are prone to skin cancer and eye disorder as well and so they deserve proper care and treatment”

“Of course, they do deserve special care to complement their deficiencies”

IDI; Adamawa

“They should be treated with special care, they should be allowed to sit at the front in class for them to see well. And during exams, extra time should be given to them because of their problem of poor vision.”

FGD; Enugu

“They should not be allowed to go out like others. In the schools, they should not be allowed to go out, i.e. during playtime they should be guided because of the sunshine. Also, they should not be allowed to participate in any school labour because of their sensitive skin”

FGD; Kano

"We should be treated as one, they should see us as same thing not discriminating, getting a job as an albino is very difficult, when they see you they believe you cannot do the job, we should be treated as one, they need to give persons with albinism more attentions because of their sight"

FGD; Lagos

"Yes. They deserve special care and why I said so is that we are trying to bring them out of that point where they feel neglected or disadvantaged to where they can feel acceptable by the society"

IDI; Cross River

"They are prone to skin cancer and have poor eyesight which could lead to blindness"

IDI; Cross River

"I know that because of their lack of melanin pigmentation, they are prone to skin cancer and they suffer from poor eyesight. For the skin cancer prevention, they have to avoid going out in the sun and avoid being in places that are very hot as it's not good for their skin, and if they have to be out in the sun, they need to wear clothes that cover their bodies very well and they should also make use of their sunscreen regularly"

IDI; Enugu

"The first thing you notice is their skin, you would see that most of them would have black spots on their skin, and their skin would be peeling, the outer layer especially and most of them can't see far distances because of their shaky eyes"

IDI; Adamawa

PERCEPTION OF GOVERNMENT'S INTERVENTION TOWARDS IMPROVING THE LIVES OF PEOPLE LIVING WITH ALBINISM

Currently the federal government is seen as less responsive to the plight of people living with albinism but is seen as being championed by individuals and by NGOs.

Government's effort in terms of intervention in the challenges facing people with albinism is seen as very low.

Specific variables considered in this review include:

- Prevention of cancer
- Counselling services to parents with albinism
- Counselling services for community members and peers
- Medical services
- Creating awareness about managing the conditions among members of the public.

Currently government is seen as falling short of the expectations of PWAs, in that little or nothing has been done in terms of the above-mentioned variables. The key interventions in this regard are largely attributed to individuals and non-governmental organizations like the Foundation for Albinism.

"I think creating awareness on albinism is in place where the Ministry of Health officials move around communities educating people on albinism in the society, it will help"

IDI; Lagos

"...what should be done to the persons living with albinism, let the government pass a law in the house on persons with disability. Albino is not a disability but the government should pass a law that will help them, and the killing of the albinos for ritual should be stopped - it has happened in Benue, it is a belief among the people so it has to be stopped"

FGD; Adamawa

"Yes, I know an NGO for albinos, it's called the Albino Support Group"

IDI; Adamawa

"Yes, I've noticed about 3 different media channels that help create awareness about albinism, also some teachers in our schools also help and also some clergymen in our places of worship also try to make some efforts"

FGD; Kano

"I have not heard of any and I don't know if there is any"

FGD; Kano

"For now, nothing has been done in any of these areas"

IDI; Cross River

"I know some dermatologists try to create some awareness about skin cancer, they write articles on it and I know that the Albino Foundation also helps. I also advise my patients when I see them on what to do especially for their poor eyesight. I know the IPPA, DFID and some others also help in providing free medical services as well for albinos in Enugu here, they give free eye check-ups and provide eyeglasses for them to help"

IDI; Enugu

"I think the Federal Ministry of Health to some extent has helped in the eradication of skin cancer and the Albino Foundation has also helped with counselling people living with albinism, and there are some international NGOs that do help out especially in their vision problems, they donate glasses for free to some albinos, that's all I know"

IDI; Enugu

SOME NAMED ALBINO FOUNDATIONS

Awareness for the foundations working towards protecting people living with albinism includes:

- NITAP
- Albino Foundation
- Social inclusion group

“There is NITAP”

- Also, The Albino Foundation, they are doing their best by going to the media on discrimination issue, telling people not to discriminate albinos”

“And also, another group called Social Inclusion, they are trying too”

FGD; Kano

“Very recently I became aware about LASODA, they recognize albinos as people who live with disability and give them some preference, at times there will be grants, provided employment for them and they are working towards creating grants for albinos. They ensure that people living with albinism will be given 1 or 2 hours in National exams WAEC & JAMB, so they are working toward all of those things that are right for the people living with albinism”.

FGD; Lagos

Some perceived achievements of the various foundations include:

- Creating awareness about the plight of people with albinism
- Enlightenment programmes for people living with albinism
- Granting of scholarships to PWAs

“Albino Foundation has paid school fees for my daughter twice in a year before. It’s a way of encouraging them”

IDI; Enugu

“In most missionary schools they give them extra attention. Even our parish priest often takes them home after service to show them more care and love”

“Also, there’s the provision of sunscreen and providing them with sunshade eyeglasses”

FGD; Enugu

“I just remembered some doctors in Aminu Kano Teaching Hospital that are assisting us. The skin doctors sometimes call the albinos, treat their skins and check their eyes for free and they give awareness on covering the body by wearing long sleeves, using umbrella and using sunscreen, I believe that will help in preventing skin cancer”

“In terms of counselling I think the media are trying by advocating and telling people that, unlike before, if you have an albino child you will be afraid to bring him outside, but now since they are always talking about it on air, people are hearing and the parents now know what to do with such children”

FGD; Kano

“Apart from The Albino Foundation that has been trying their best in creating awareness, there isn’t much awareness from the government”

FGD; Kogi

“The effort is still among albinos, the outreach programmes are not enough yet, but The Albino Foundation is really trying; it is a non-governmental organization; they enlighten people living with albinism, they encourage and let us know the causes of albinism, they educate and care for the albinos. They always tell us to clothe our children with long sleeve clothes because of the sun. Government needs to set out policies that will be favourable towards albinos”

FGD; Lagos

PREFERRED MEDIA

- Television is the most preferred channel of communicating information on enlightening the public, due to its dual benefits of audio-visual attributes;

Other media target audience are exposed to include:

- Radio – has the advantage of being handy and readily accessed even on mobile phones, with no electricity;
- Social media – for the benefit of accessibility and speed of dissemination of information, although there is the concern about credibility of information via the platform;
- Specific social media platform commonly used is Facebook.

“Television I will recommend TV also, like Channels TV

“There is this radio station that children in Enugu like to listen to, Urban Radio. They should consider it. Like my children they don’t play with Urban Radio”

FGD; Enugu

“They can use TV and Radio

“I feel here in Kano, radio is better”.

FGD; Kano

“I would suggest TV and radio”

IDI; Cross River

PREFERRED MEDIA CHANNELS

Locations	Radio station	Television station
Cross River	Hit FM Voice of Nigeria	Al Jazeera Channels TV CRBC
Enugu	Urban radio Dream FM Radio Nigeria	NTA
Adamawa	Radio Pulaaku Radio Nigeria Radio ABC	ATV TV Gotel
Kano (Various respondents)	Radio is most effective in this part than TV; Radio is more important for creating a wider awareness in the society. Even if you don't have a radio, you can still have access to it on your mobile phone; I will use radio because it has a wider reach; Radio is best	
Kogi	Radio and social media. They can also try using roadshows to create public awareness on the plight of persons with albinism; I recommend radio because it reaches urban and rural areas	Television I will suggest NTA because of its wide network and national coverage TV stations too
Lagos	The radio of course, has a wider reach and many people tend to listen to radios on their mobile phones these days; There are many private radio stations that can be used as partner media to create these awareness programmes	TV stations, especially NTA, TV Continental and Channels Television
Abuja	Radio and social media will be very useful in this case; Radio stations have a wide reach. They are received in remote villages. Such messages should be broadcast in Hausa and other local dialects so that the people will follow	TV stations. NTA is very strong in Abuja and environs. They should use NTA TV will be good too

- For television and radio channels, both government and private owned stations enjoy high viewership/listenership;
- In terms of language, it is expected that regional local languages should be adopted to ensure effective reach.

Some specific effective channels of disseminating information that were mentioned are:

SUMMARY

This survey has been able to address the key objectives for which it set out to explore. The outcomes are summarised along the objects of the survey as detailed below:

1. The demographic distribution of persons with albinism in Nigeria;

- From the study, there is a higher representation of women living with albinism than men (55% versus 45%). Further stratified, 65% practice Christianity while 33% are Muslims. A very minute minority practices other forms of religion (2%);
- A majority of the people with albinism are single (63%) and is reflected in all geographic locations where surveys took place. Married individuals (32%) occupy the next highest level of concentration and to a lesser degree, Separated and Divorced spouses account for just 2% and 1%) of respondents;

2. The geographical spread of persons with albinism in Nigeria;

- The first impression arising from this survey is the geographic concentration of persons with albinism in Nigeria's middle belt region, extending to the Federal Capital Territory, Abuja and farther to the northern part of the country;
- The population spread of PWAs is less likely to be found in the southern part of Nigeria;

3. The nature and extent of albinism among persons with albinism in Nigeria;

Several factors conspire to affect PWAs adversely. They include poor vision, unemployment, limited access to healthcare facilities and skin care solutions, as well as discrimination and low literacy level;

4. The requirements or special needs of persons with albinism in terms of health, education, information, employment opportunities, financial assistance and assistive devices, as well as accommodation of the interests of their dependents in Nigeria;

- Some of the common assistive devices used by PWAs to manage their condition include sunglasses, face caps or bowler hats, sun screen creams and umbrellas;

5. The measures in place for taking care of the needs of persons with albinism;

- There is currently no known government welfare programme to cater to the health and education needs of persons with albinism;
- Parents of children with albinism particularly mothers, are the primary caregivers for their albino children in all manner and form;

- However, to some extent, NGOs such as The Albino Foundation, NITAP, Albino Support Group and Social Inclusion Group are helping to fill the knowledge, educational and awareness gaps on the plight of and ways to manage albinism in various parts of the country.

6. The level of educational and health facilities that are accessible to persons with albinism;

- Generally, neither the federal government of Nigeria nor state governments have a distinct policy footprint to cater for the welfare of PWAs, however, some general hospitals render free treatment of PWAs with skin infections, eye tests and medications.
- The only organs that are providing necessary access to information on the causal factors of albinism and its management are NGOs, notable amongst which are: The albino Foundation, NITAP, Albino Support Group and Social Inclusion Group.

7. The various types and forms of discrimination against persons with albinism in the various states of the federation;

- Discrimination is widely experienced by persons living with albinism across the country, regardless of the background or gender (96%). Females report higher levels of societal discrimination (54%) within family and friends' circles than men (46%);
- Common places of discrimination are public buses (23%), schools (23%) and villages or town squares (20%). Other places with lower reported cases of discrimination are religious centres (5%) and financial institutions (4%). A small category of them (2%) say they have never experienced discrimination at any of these locations before;

8. Such other factors and variables that will enable the formulation and implementation of policies, which will assist in the mainstreaming and empowerment of persons with albinism in Nigeria.

- It was a general consensus that people living with albinism deserve to be treated specially. Being prone to earlier mentioned health challenges, they deserve to be treated differently to enable them adjust well into the society as well as enhance their chances of harnessing their potentials

It is expected that children living with albinism should be:

- Given front seat in class to help them have clearer viewing of the blackboard
- Given extra time during class test and examination bearing in mind their sight challenges which put them at a disadvantage vis-à-vis their classmates
- Encouraged to take leadership roles
- Protected from verbal, physical and other types of assaults from classmates
- Monitored in terms of their participation in outdoor activities

For the adults, it is expected that they:

- Should be protected against assaults and threat to their physical bodies
- Are financially empowered to ensure independence
- Equipped with adequate information on proper healthy practices that enhance healthy living and less health issues
- Given equal employment opportunity
- Posted to duties that ensure that they are protected from the sun

PHOTO GALLERY OF FOCUS GROUP PARTICIPANTS

KANO STATE



ENUGU STATE



CROSS RIVER STATE



LAGOS STATE



ADAMAWA STATE



KOGI STATE



ABUJA, FCT



ABOUT THE ALBINO FOUNDATION (TAF)

Established in 2006, the Albino Foundation (TAF) is principally an organisation established for persons with albinism and other vulnerable groups such as persons with disabilities. The foundation is an independent non-governmental organization registered in Nigeria with the Corporate Affairs Commission. TAF is a special focus organization advocating for the recognition and respect of the rights and socio-economic inclusion of people living with albinism.

The Foundation works to create awareness of the social challenges that Persons with albinism face in Nigeria and the world, by working with governments, development institutions in Programme areas that improve the health, education and social wellbeing of persons with albinism in Nigeria; as well as assist and empower them to find their rightful place in society. The Foundation now bears national spread cut across the 36 states of the federation and FCT-Abuja. The foundation equally partners with some disability organisations and institutions in Nigeria to ensure that persons with albinism and other vulnerable groups are socially and economically empowered.

MEMBERSHIP

Membership is open globally to anyone who shares the ideas of TAF and not unlimited to persons with Albinism alone. Membership is also derived from Government and non-governmental organisations, National Associations and corporate bodies who submit to the guidelines of TAF.

The Foundation presently has 42 chapters cut across all the 36 states of the federation and Federal Capital Territory, Abuja. The Foundation from inception have created an established platform that provides an enabling forum where the chapters meet monthly to share information, exchange ideas, deliberate on projects, build support network and carry out advocacy at various levels.

The Foundation has been working with each chapter from the date of their inception based on the thematic programme that fits the chapter's geographical location. Chapters are free to initiate and embark on programmes. In such instance, TAF Headquarters plays a support role by mobilising human and material resources to support the chapter to carry out a given project at any given time. However, whenever TAF is embarking on a national or international programme, the chapter organisations participate actively by mobilising human and material resource as the case may be.

VISION

The Albino Foundation envisions a society with equal opportunity for persons with albinism

MISSION STATEMENT

We are an advocacy organisation that empowers persons with albinism and educates the society on issues of albinism in Nigeria and the world.

OUR VALUES

Accountability:	We are responsible and answerable for our actions
Commitment:	We are devoted to our cause
Stewardship:	We are caring and continuously improving our service delivery
Passion:	We are excited about what we do
Inclusiveness:	We embrace and collaborate with all who share our vision

BOARD OF TRUSTEES

The Foundation has a seven-member board of trustees comprising highly esteemed individuals who have made their mark in their various fields of career and life endeavours. The board is responsible for the governance, organizational direction, policy and strategy formulation of the Foundation.

Alhaji Shehu Shagari, GCFR	Grand Patron
Chief Olusegun Obasanjo, GCFR	Patron
Dr Ndi Okereke	Chairman
Dr Douglas Anele	Vice Chairman
Jake Epelle	Founder/Chief Executive Officer
Barr. Gabriel Arewele	Secretary
Prof. Mercy Olumide	Member

ORGANISATIONAL FOCUS

With a view to impacting all persons with albinism in Nigeria, Africa and the world, our focus as an organisation is categorised into six major areas:

Healthcare: The aim of the albinism healthcare project is to reduce and mitigate health related challenges associated with albinism such as sunburn, skin cancer and eye related problems;

Legislation and policy advocacy: The aim of the Legislation and policy advocacy on Albinism is to ensure total mainstreaming of albinism into government programmes and policies in Nigeria and to ensure that there are necessary laws to protect their rights

Social Awareness: The aim of the Albinism Social Awareness project is to properly educate and orientate Nigerians and the world about the true state of albinism and to help promote understanding, acceptance and socio-economic inclusion of PWAs into mainstream society.

Learning and Education: The aim of the project is to ensure that persons with albinism especially children with albinism have access to qualitative education

Economic Empowerment: The aim of the project is to enhance the operational capability of the Foundation and ensure that PWA live independent lives

Albinism Rights: The albinism rights project is aimed to protect, promote and defend the fundamental human rights of persons with albinism in Nigeria

For further information and enquiries:



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ABOUT THE EUROPEAN UNION DELEGATION TO NIGERIA

The EU Delegation to the Federal Republic of Nigeria and ECOWAS is a full diplomatic mission representing the European Union in Nigeria, with concurrent accreditation to the regional economic body, ECOWAS, headquartered in Abuja.

The Delegation of the European Union to Nigeria and to ECOWAS is part of the European Union External Service and is one of the 140 Delegations throughout the world.

The European Union is made up of 28 Member States, has a population of around 500 million and is the largest trading bloc in the world. Nigeria is a key strategic partner of the European Union, being Africa's most populous nation and its biggest economy. It is the biggest EU diplomatic hub in the continent.

The activities of the Delegation of the European Union in Nigeria are developed in close coordination with the Member States of the European Union with diplomatic representation in the country. 20 out of the current 28 Member States are accredited in Nigeria: Belgium, Bulgaria, Czech Republic, Denmark, Germany, Ireland, Greece, Spain, France, Italy, Hungary, the Netherlands, Austria, Poland, Portugal, Romania, Slovakia, Finland, Sweden and United Kingdom.

The Delegation's mandate includes the following:

To actively promote the values and policies of the European Union, in an open and equal partnership with the Government and people of Nigeria;

To deepen the political dialogue on all issues of mutual interest and to strengthen the partnership both with Nigeria and ECOWAS;

To implement the EU Common Foreign and Security Policy, the development and trade policies focusing on poverty alleviation and on the promotion of democracy, Human Rights and the Rule of Law as well as the smooth and gradual integration of developing countries into the world economy;

To inform Nigeria and ECOWAS about the policies and programmes of the European Union, as well as its institutions and values;

To support regional integration in the Economic Community of West African States as well as the planned development of Pan-African policies, programmes and institutions.

Presently, the Delegation to Nigeria support albinism cause in two areas vis-à-vis: Promoting Access to social services for persons with albinism, which ensures that persons with albinism have access to health, education and economic empowerment. Is also supports in enhancing the civic and political participation of persons with disabilities in electoral processes in two states (Ekiti and Osun) and FCT-

Abuja, which do not only ensure that persons with albinism come out to vote during elections but also contest and be voted for in elective and political positions in Nigeria.

The Ambassador/Head of the Delegation, Ketil Karlsen, who arrived Nigeria in August 2017. As the Head of EU Delegation to Nigeria and to ECOWAS, Ambassador Karlsen represents the EU in its diplomatic engagements and multi-faceted bilateral cooperation with both Nigeria and the regional body. He regularly engages with government officials, development partners, the civil society, the business and the diplomatic communities and the media to explain the policies, programmes and values of the European Union.

The EU Head of Delegation provides the lead in the regular political dialogue with Nigerian authorities; oversees the implementation of development aids and negotiates trade deals. Ambassador Karlsen is passionate about the EU-West Africa Economic Partnership Agreement, which he believes will help the region's competitiveness, enhance its trade and unleash its economic potentials.



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His Excellency
Ketil Karlsen.
The EU Ambassador to Nigeria
and ECOWAS

ABOUT PRL RESEARCH

PRL Research is a leading market research company in Nigeria, and an acronym for Polls & Ratings Limited. It is incorporated in Nigeria as a full-service marketing research, social research, monitoring, evaluation and business consulting firm.

PRL Research combines market research and consulting services to help businesses develop and implement innovative, workable solutions to complex business problems.

We treat each situation individually, tailoring solutions and strategies to our clients' needs to help them identify, develop, and execute investment and marketing strategies aimed at retention, acquisition and penetration of high-value customers.

PRL Research uses rigorous and advanced analytical techniques to interpret the components of customer and human behaviour that lead to the greatest value creation for all our stakeholders who have relied on our skills for more than 20 years to provide them with speedy and accurate data in their decision-making processes.

We translate our understanding and knowledge into strategic and tactical recommendations for marketing, sales, new and existing product development, and customer-centric initiatives. We focus on improving revenue performance and increasing profitability – both today and in the future.

Our time-tested team of research analysts bring a unique combination of industry expertise and hands-on experience with tactical and strategic initiatives based on market research and analytics.

Our services are driven by a superior edge built on new technology and global best practices that give us leverage in the market research industry.

We maintain a pan-African presence in the West African sub-region, particularly in Niger, Ghana, Togo, Liberia and Gambia, where we represent several clients' interests on a consultancy basis.

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