**Action on Albinism in Africa**

**Consultative Forum**

17-19 June 2016

Dar es Salam (United Republic of Tanzania)

**OUTCOME REPORT**

The Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, is grateful to all partners (listed below) who made this historic forum a reality. In this outcome report, the Independent Expert presents specific measures identified by participants at the forum, most of whom have expertise on the issues faced by persons with albinism in the Africa region. Input has also been gathered and incorporated from a “Call for Input” sent out by the Independent Expert in the months leading up to the forum. In the months ahead, these measures will be further refined and consolidated to yield a brief and effective roadmap for immediate and long term action on albinism in Africa.

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# Background

1. According to information sent to the mandate of the Independent Expert by civil society, approximately 450 attacks have been reported in 25 countries of Africa. Most of these are from 2006 and consist of reported cases alone. It is widely believed that a majority of cases go unreported due to the secrecy of witchcraft and other harmful practices which serve as the context of most of these attacks. A pan African array of reports on deep discrimination and stigma against persons with albinism has also been reported in a majority of countries regardless of records of attacks.
2. Various bodies have adopted recommendations to address such attacks. These include those from OHCHR in 2013[[1]](#footnote-1), the Advisory Committee of the UN Human Rights Council in 2015[[2]](#footnote-2), the Organisation Internationale de la Francophonie[[3]](#footnote-3); resolutions of the African Commission on Human Peoples’ Rights,[[4]](#footnote-4) the Human Rights Council[[5]](#footnote-5); Treaty Bodies[[6]](#footnote-6); and from the universal Periodical Review Mechanism.
3. The objective of this Forum was to identify specific, concrete and achievable short, medium and long term measures to implement these recommendations.
4. The measures below were identified by the over 150 participants from 26 countries, in the region representing the civil society, government, National Human Rights Institution, regional and international governmental organisations and the academic sector. Discussions and development of specific measures took place in 6 working groups before being presented to and adopted by the plenary.
5. In addition, participants also expressed their commitment for the implementation of these measures. The commitments are also included in this outcome document.
6. The Forum was hosted by the UN Independent Expert on the enjoyment of human rights by persons with Albinism, the Government of Tanzania: Prime Minister`s Office, the UN Country Team in Tanzania, the Tanzania Commission on Human Rights and Good Governance (CHRAGG), The World Bank, The Office of the High Commissioner for Human Rights, Standing Voice, Under The Same Sun, the Embassies of Norway, Ireland and the USA in Tanzania, and the Canadian High Commission in Tanzania.
7. This document complements the outcome document of Day 1 seeking to identify the main challenges and priorities associated with the well-being and empowerment of persons with albinism[[7]](#footnote-7).

# Summary of Panel presentations

1. **Opening**
2. **Mr Alvaro Rodriguez**, UN Resident Coordinator in Tanzania, highlighted the importance of equality, dignity and justice for all. He recalled the important milestones in relation to ensuring the enjoyment of human rights by persons with albinism, including the UN resolution which established 13th June as the International Albinism Awareness Day and the creation of the mandate of the Independent Expert. He stressed that the roadmap formulated over this weekend is another important milestone and stressed the commitment of the UN country team in Tanzania to work on these issues alongside Government and civil society. Finally, he mentioned the importance of the UN Sustainable Development Goals as an avenue for advancing the human rights of persons with albinism since one of the main focus of these goals is “leaving no one behind”.
3. **Dr Abdalla Possi**, Deputy Minister, complemented this by stating that development is only sustainable when everyone is included. Thus, sustainable development goes hand in hand with equality, dignity and justice. He assured the participants of the commitment of the Government of Tanzania in this regard. He also highlighted the importance of changing social attitudes and ensuring accessibility to assistive devices which are necessary to enhance the vision impairment that is often part of albinism. Partnership between the Government and private sector are also key, as was done, for example, for antiretro-viral drugs in the fight against HIV/AIDs. Dr. Possi also listed some measures for consideration including data collection relating to persons with albinism, responsible reporting of attacks on the part of the media, the advancement of positive stories of persons with albinism in all forms of media and communication, and the establishment of a coordination and monitoring mechanism to ensure the implementation of the Convention on the Rights of Persons with Disabilities (CRPD).
4. **Panel discussion:** **Presentation on best practices on overcoming violence and discrimination against persons with albinism: Kenya**
5. **Mr Issaac Nwaura,** MP, stressed that the Albinism Society of Kenya was established in 2006. They have a programme which sponsors the education of over 40 children, provide eye-care services, protective clothing, support economic empowerment and do advocacy work. They also organise emergency missions to support victims of attacks and have provided legal support in cases involving persons with albinism. He stressed the importance of advocacy champions to push the issue, of ensuring that persons with albinism are included visibly, within the disability movement. He also pushes for engaging the media to ensure positive reporting in relation to persons with albinism. A petition was made, yet too late, to include people with albinism within the 2009 census, but they will ensure that it is included in the next census. Although the responsibility of ensuring the enjoyment of human rights by persons with albinism lies with the Government, partnership with the civil society is important.
6. **Mr Alex Munyere**, National Council for Persons with Disabilities, stressed the importance of having a person working specifically with persons with albinism within the Council. He briefly presented on Government programs to provide sunscreen lotion, sun protective lip balm and after sun lotion to persons with albinism through Government hospitals. Protective clothing is also provided and the Government will pay the medical bills for people with albinism who require cancer treatment as well as for comprehensive eye-care and free reading devices.
7. **Dr Bernard Mogesa**, Kenya National Commission on Human Rights, explained the role of the Commission in monitoring State compliance in relation to international and regional treaty obligations (including compliance with CRPD), in building partnerships (such as a training for journalists co-organised with the academia), and in mainstreaming human rights indicators. He also provided information on the electronic platform developed to present human rights complaints (the complaints are then channelled to the responsible entity and the system contains SMS features) and they work to build the capacity of the media and provide advice relating to existing legislation (including Disability Act 2003). Most complaints presented, regarding persons with albinism, relate to economic, social and cultural rights.
8. **Ms. Jayne Waithera**, Positive Exposure, presented the work of her organisation on economic empowerment, through seed projects (implemented both in Kenya and Tanzania), awareness raising including through photographic and art exhibitions, or dissemination of information on services available to persons with albinism. She stressed that the Government of Kenya has set aside a budget for awareness raising and healthcare relating to people with albinism but that despite these efforts, challenges remain such as the lack of accurate data, or the need to further increase security measures for persons with albinism.
9. **Panel discussion:** **Presentation on best practices on overcoming violence and discrimination against persons with albinism: Tanzania**
10. **Dr Abdallah Possi,** Deputy Minister, highlighted that violence can be physical or psychological, direct or indirect. The right to be protected from violence is enshrined in international human rights instruments as well as national legislation. Short-term measures such as prosecution of perpetrators may not tackle the root causes of violence. Long term measures include working towards inclusion, the provision of education and healthcare services. Challenges include the ongoing use of centres for children with albinism in which children are excluded from their families and communities. There are challenges in closing these centres as some children have been abandoned there by their families. The children will require appropriate rehabilitation as many of them have experienced trauma, schools will need to be identified for these children close to their community, and perceptions in the community must change before children are returned. **Mr.**
11. **Jon Beale**, Standing Voice, stated that social empowerment is the most effective measure to overcome violence and discrimination and stressed the importance of inclusion. Key practices include empowering community through income generating programmes and tackling ignorance through sensitization and education. He also stressed the relationship between economic empowerment and health and presented the Standing Voice mobile clinic model that could be replicated. A comment from the floor also stressed the importance of inserting the issue of albinism in the general school curricula.
12. **Mr. Nemes Temba**, Tanzania Albinism Society, stressed the importance of valorising persons with albinism in their societies, the need to work on healthcare, to use the media to convey positive examples of persons with albinism, as well as other means of awareness raising. Persons with albinism respected within their communities are less likely to be attacked. He also stressed the challenges or reunification between children with albinism in centres and their families.
13. **Ms.Vicky Ntetema**, Under the Same Sun, presented on the education program of UTSS which sponsors nearly three hundred persons with albinism from kindergarten to PhD level. She highlighted the importance of children with albinism gaining an education and becoming role models to others. UTSS has also developed a guide for teachers, care givers and parents on how to raise and teach children with albinism. It also has a rapid response team to support victims of attacks, gather in situ information, and work with the community. She also stressed the need to review legislations, including the Witchcraft Law of 1928 and the Traditional and Alternative Medicine Act which complicates investigations by authorising the use of animal parts in the practices of traditional healers although the law prohibits the possessions of human body parts for all except medical doctors.
14. All panellists stressed the need for cooperation and collaborative efforts. Comments from the floor also stressed the importance of investigation and prosecution to punish not just the person who carries out the attack but also those who demanded and paid for body parts. It was also stressed that stigma due to poverty and health issues can contribute to the lack of inclusion in communities and contribute to vulnerability and lack of protection in face of attacks.

# Foundational Measures

1. The following measures have proved to be effective catalysts in the successful execution of specific measures

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| Actor | Measure | Role(s) | Time frame |
| **Government** | **Immediately set up a dedicated mechanism on albinism with its own budget**  Best practices include:  (i) a full time paid officer (Kenyan model)  (ii) a multi-sectorial task force with a coordinating ministry (modelled in Malawi, Mozambique) | * **Execute government programs** * **Coordinate all efforts on albinism** | Immediate |
| **CSOs**  **And**  **NHRI** | **Identify and use** **champions of the cause who are knowledgeable, effective and unifying**  (modelled in Kenya, and Malawi) | * **Lobby government to set up dedicated mechanism** * **Hold government accountable** * **Cooperate with government on all relevant initiatives** | Immediate |

# Specific Measures

1. Specific measures (tabulated) are based on general recommendations made by the UN and AU to date. These general measures are grouped into 4 categories namely preventive measures, protection measures, accountability measures and discrimination. Participants developed specific and concrete measures under each of these categories based on what has worked (best practices) in the African context and what could work based on expert experience and what has worked with analogous groups

## Prevention Measures

1. **Address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating prejudice, superstition and stigma vis-à-vis albinism to achieve social change.**

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| **Actors Responsible** | **Measures[[8]](#footnote-8)** |
| Government, NGO,  Academia,Media | **Short term:**   * **Research in situ, involving** local, traditional and religious leaders on albinism; as well as training with them on root causes * Continuous **research** on the root causes of attacksat all levels, including academic * **Continuous advocacy and sensitization** on the scientific aspects of albinism * **Combat witchcraft practice**; a rootcause of attacks**:** * Legislation should not validate or give legal character to the phenomena of witchcraft * Laws banning witchcraft accusations should be upheld in this intent * Criminal Law should expand provisions of murder, abduction, kidnapping, grave robberies and other relevant crimes to include built-in aggravating factors such as the intent to use a victim’s body parts for witchcraft purposes where the facts support such intent * Traditional medicine should be delineated and regulated under separate legislative instrument. Practitioners should be registered and oversight by government activated through monitoring mechanisms such as revocable licenses, periodic inspection of work and self-regulation boards accountable to national law. * Thorough and sustained awareness raising on the social harm caused by witchcraft should be undertaken * Research on the use of body parts of persons with albinism should be conducted, including understanding of the underlying myths or reasons, the regions where such myths are widespread, and the origin and spreading pattern of such myths. * Undertake investigative research to find root causes of attacks, locate markets for body parts including cross-border trade as well as perpetrators and end-users of body parts of persons with albinism * **Address poverty** by ensuring access to services for communities at local level. |
| Government, NGO | **Medium term:**   * **Continuous advocacy** and sensitization; * **Sensitization of traditional and religious leaders** on the impact of certain beliefs and practices * **Legal support** for persons with albinism * **Address poverty** using the principles of the UN sustainable development goals (SDGs) which aims to “end poverty in all its forms everywhere” by the year 2030. |
| Government | **Long term:**   * Insert information on **albinism in the school curricula** from the very early stages e.g. primary school * **Address poverty** by ensuring access to services for communities at local level. |

1. **Demystify albinism: educate the public on the medical condition of albinism**

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| **Actors** | **Measures** |
| Government,  NGOs, Academics, Intergovernmental Organizations and International Community | **Short term:**   * **Education of persons with albinism, their family**, parents and the community to understand and accept the condition * **Develop information**, education and communication material to educate the public at large on albinism, spread biological and scientific information on the genetic origins of albinism * **Showcase successful persons with albinism** as role models, involve champions including celebrities and successful people with albinism * **Educate and use traditional** leaders and local practitioners to transmit information on albinism * **Specific education and information on health aspects** (including on the appearance that can be the result of skin cancer) * **Counselling of parents of persons with albinism** and dissemination of simple information on the genetic and medical condition of albinism (such as a ten points fact sheet) * **Continuing and clear information** on the results of research **on the root causes of the attacks** * Importance of **using language easy to understand** and channel the message through persons of the community (peer to peer education) * **Mobilisation of resources** at all level, including local level * Debunk myths and misbeliefs on the condition through **innovative yet accessible means** that work in all communities particularly the rural including radio **and community theatre and arts** * Use **television advertisements** to educate * Ensure that explanations and material also address the **gender dimension** of attacks * **Represent/ensure the participation people of albinism** in all methods of awareness-raising * All activities should **target family members of** people with albinism, rural communities and other **communities on the border** * **Engage successful business persons** and trade associations in public awareness campaigns * **Encourage continuous symbolic gestures from public officials**: statements, press releases and other forms of mass media * **Government should** **consider the appointment of a person** **with albinism** to a senior and visible position in government. * **Regulate Nollywood** more effectively to avoid the spreading of detrimental stereotypes regarding witchcraft and persons with albinism |
| Government and NGO | **Medium term:**   * **Decentralisation of celebrations of International Albinism Awareness Day** so that it reaches all parts of the country. * **Use of faith Based Organisations**, local leaders as well as traditional healers |
|  | **Long term:**   * Develop **curriculum** to be used in education system to educate on the condition of albinism * Using prominent leaders and **successful persons with albinism** as role models * **Adapt the curriculum of nurses and midwifes** to educate the parents of children with albinism |

1. **Strengthen awareness raising campaigns**

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| **Actors** | **Measures** |
| Journalists, police, Ministry of Health, nursing schools, hospital administration, medical schools, ministry of education, teacher training, local human rights associations | **Short term:**   * Sustain awareness-raising **campaigns for a minimum of 2 years with no gaps** between programs * Develop strategies to work with persons with albinism, their families, and communities and **ensure engagement of community members at all levels** * **Use creative awareness methodologies** and new ways of presenting information including **through drama, novels**, pop stars songs, **M**r **and Ms Albinism** contests etc * **Use social media and technology**: Facebook, Whatsapp, as well as other applications, features and SMS to promote awareness. * **Use radio and TV programs** popular at community level to promote awareness * **Work closely with the Ministry of Education** to develop new creative ways of presenting albinism and to **review the curricula to insert concrete information on albinism** for teachers, nurses, hospital administration, health care professions, lawyers, journalism. Similarly, specific booklets should be developed for each of these professionals * **Ensure that specific material is developed**. Such material developed **should have a strong human rights based approach** * **Appoint special needs educators (trained on albinism)** to mainstream inclusive education in primary and secondary schools progressively * **Ensure that the community is an actor of the awareness raising, not just the recipient**, promote peer education throughout the country * **Ensure that persons with albinism are familiar with their rights** and are empowered and have the means to demand for their human rights (including regarding healthcare). Persons with albinism should be at the heart of all these measures * **Provide counselling to** persons with albinism to **boost self-esteem and psychological support** as needed * **Ensure accessibility of health treatment** by allocating resources and ensure free quality health services to persons with albinism * **Promote networks of volunteers** to come to school **to deliver speeches in schools (**motivational speakers) * **Avoid stereotypes in media**, including television programs and reporting on persons with albinism * **Involve faith based organisation**s |

1. **Promote community involvement and the creative use of the media**

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| **Actors** | **Measures** |
| Government, NGO,  Media | **Short term:**   * **Identify the information already exists, and what should be stressed/enhanced**, and select specific and adequate information to send using: * Radio, Drama * Social media * Moonlight story telling sessions * Text messages, mobile networks * Town crier, village speaker (identified through traditional leaders) * Community champions * Leaders, etc. * **Encourage Media to publish articles that are balanced**: including attacks and at the same time showcasing humanized persons with albinism * **Train media on investigative reporting** to avoid inadvertent fuelling of attacks * **Train media on accurate reporting on albinism** (including the right use of terms, scientific information on albinism, etc) * **Stop negative reporting alone**: Celebrate positives as well / humanize PWA, avoiding mentioning amounts body parts are related to. * Objective and responsible reporting of the media on attacks in a way that deters attacks (no reference to amount or value of body parts) |
| Government, community and civil society | **Medium term:**   * Mainstreaming all the issues identified, using the Government and CSO, and ensure that communities, leaders at local, regional, and national level, take ownership |
| Government, NGO, UN, AU | **Long term:**   * Impact study * Continental reach |

1. **Evaluate and address the needs of persons with albinism**

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| **Actors** | **Measures** |
| Government | **Short term:**   * **Needs assessment and studies** regarding the situation of people with albinism in the country should inform policies. * **Consultation and close cooperation** – on an ongoing basis - with people with albinism is necessary throughout the process. * **Strengthen civil society**, in particular victim and women groups and other stakeholders through engagement and consultations * Allocate **funds to this issue** * **Health programs** through local hospitals and dispensaries to provide sunscreen and protective clothing * **Need for data to** develop new programs and if needed legislation * **Education of persons with albinism** and mothers of children with albinism on self-care, etc. * Promote essential health packages to be included as an essential drug * Access to **education and literacy** classes for persons with albinism * Ensure that persons with albinism are included in State led **welfare programs** |
| Government, civil society | **Medium term:**   * Importance **of allocating funds to this issue** |
|  | **Long term:**   * **Train dermatologists** and ensure proper allocations to institutions to meet the needs of persons with albinism * **Conduct national census** which gathers **data on persons with albinism** |

1. **Data collection on the people and the issues**

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| **Actors** | **Measures** |
| All users of data on albinism, all 'owners' of data collection systems,  data researchers and trainers  from both government and NGO, community groups. | **Short term:**   * **Review and learn lessons from previous national censuses** and make recommendations to promote effective and accurate collection of data on albinism in future national censuses across Africa. * **Review and learn lessons from other data collections** and data collection methodologies relevant to albinism held/conducted by government and non-governmental agencies. * **Analyse existing data**; make recommendations for future data collection. * **Establish national and international mechanisms** for coordinating albinism data collection, analysis and dissemination. |
| **Medium term:**   * **Develop a comprehensive and sustainable mechanism for collecting a wide range of albinism data** which is independent from and complements national censuses. This mechanism should to be conducted locally, and the use of digital data collection technologies. * **Build capacity within institutions** and society for collecting, understanding and using data on albinism. * **Conduct research into the data that is needed to better understand and guide interventions** in areas such as vision, dermatology, security, social acceptance, etc. develop specific data collection tools for these areas. * **Conduct confidential census** of people with albinism including amassing disaggregated data based on sex, age, status, location, amongst others * **Data must be stored securely** and not easily availed or accessible to prevent misuse by potential perpetrators |
| **Long term:**   * **Develop a holistic data reporting and publishing system** that includes individual, systemic and media aspects. * **Collect data on specific aspects** including vision, health, education, employment in the public sector, poverty or other social aspects * **Promote the integration of albinism data collection**, analysis and use into all appropriate official routine data collection systems. |

## Protection Measures

1. Adopt specific measures, strategies and actions plans promoting the rights to life, to security of person and not to be subject to torture or ill-treatment

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| **Actors** | **Measures** |
| Government, NGOs | **Short term:**  **Protection measures**:   * Actualisation and accessibility (including language used) of all attack **reports** (including building networks to gather the information) * Visible policing and other measures to ensure the security and protection of persons with albinism * Conduct safety and **security assessments** of the child taking into account home security, community support, and family support structure and on that basis take measures to ensure secure accommodations for PWA and their families, and in extreme cases consider moving child or family with their consent to a safer area within their community * Establish **community task forces** and watch committees at community level to ensure the protection of persons with albinism * Build strong graves, and ensure that houses of PWA are equipped with doors, locks, iron bars on windows, etc. * **Hotline** toll free, and broadcast knowledge on albinism through an accessible mobile phone hotline * Appoint **early intervention focal point** at clinics, hospitals, midwives, community nurses and traditional leaders. * Carryout **periodic visits** to assess the situation child and their family (social services)   **Schools**   * Build **fences** around school parameters. * Increased **watch** over children with albinism. * Train teachers on the **special needs** of children with albinism, including for protection measures. * Encourage pupils and students to have friends with albinism and training on **peer support** and protection   **Policing**   * Enhance and facilitate **mechanism to report** case * Sharing **best practices** systematically * **Hotline toll free** to report suspected criminal activity (with witness protection measures) * **Training and deployment of police** officers in criminal investigation and use of modern technology for information gathering * **Improve public perception** of the police to increase cooperation   Cross border strategies   * Immigration department to work with police and **systematic check of passengers travelling with PWA** * **Train border patrol** on the issue and how to use existing structures such as roadblocks and questioning as a protection measure * **Put alert systems** and response plans in place across borders * **Develop a cross-border cooperation** to ensure collaboration among governments across borders. * **Work closely with Interpol** * **Enhance mutual legal assistance** in the broadest terms regarding investigations, prosecutions and judicial proceedings regarding attacks against persons with albinism * **Develop strategy of integrated border management** including through basic Memoranda of Agreement on the issue between national police to facilitate investigation. * Involve organisations of persons with albinism throughout the protection process |
| Government, NGOs, UN, AU, International community | **Medium term:**   * Establish **community watch centres** (at village level) * Provide **adequate schooling** for children with albinism (with necessary protection measures) and improve school security * **Educate staff** of schools, border forces, police and other relevant actors on albinism and safety and security of children * Systematic use **Interpol** mechanism throughout the region |
|  | **Long term:**   * Include the needs of persons with albinism in the action plan of **social services** (as there is a direct link between poverty and protection) * Involve UN actors, as well as NGO, including with regards to health programs |

1. Adopt specific measures to end trafficking in body parts

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| **Actors** | **Measures** |
| Government, NGO, UN, AU, International community | **Short term:**   * Identify national, regional and international **legislation applicable** * **Review existing legislations** on organised crime, trafficking, organ trafficking, to ensure there areno loopholes * **Train** police, and border guards * **Strengthen investigation** to gather proof, including regarding organised crime * Ensure the **specific sentences** for body parts trafficking are enacted * Involve **Interpol** and facilitate police cooperation at local level |
| Government, NGO, UN, AU, International community | **Medium term:**   * **Develop regional instruments** targeting specifically these practices * Establish a **database** to understand with certainty where the body parts are found * Train law enforcement and analysts in the use DNA to **enhance investigation** and evidence gathering * On the basis of elements collected, **study the routes and tendencies** in body parts trafficking, as well as networks involved |
|  | **Long term:** |

1. Adopt specific measures aimed at protecting women and children

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| **Actors** | **Measures** |
| Government, Civil society, international community | **Short term:**   * **Acceptance-based security strategy**, ensuring that persons with albinism are welcome in their communities, well embedded, understood and that the community trusts them and understands the risk they face * **Localised training** for communities * **Risk assessment** carried out at local level twice a year * Ensure that **peer support** is organised, for example to ensure that children with albinism do not travel alone if the risk is high, to avoid quiet roads, to establish a “buddy system” for school, inform people on their whereabouts, etc. As children with albinism cannot be watched by their parents all the time, such peer support needs to be planned and coordinated * **Community vigilance** with clear **alert systems**, including whistles for persons with albinism, mobile phones and emergency lines (with number on speed dial), as perpetrators often relatives or members of the local communities * Importance of strengthening and working closely with **community police**, mobilising community support, including all members (community elders for examples could help as gatekeepers) * Ensure that the community, schools, etc. **understand the unique vulnerability of persons with albinism** |
| Government, Civil society, international community | **Medium term:**   * **Strengthen women’s groups** in the community to share concerns and support each other * Ensure the **promotion of women’s rights** in the communities and empower women with albinism |
|  | **Long term:** |

1. Support the protective role of the family

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| **Actors** | **Measures** |
| Parents, family, community, care givers, social welfare, educators, religious leaders, COB, Health | **Short term:**   * **Empowerment of health care workers and midwives** to pass the right messages to the family from the birth of a child with albinism onwards, including relevant information on health, information and other protection information * **Legal/social aid** for persons with albinism and their families to understand the reporting procedures and to access welfare programs etc. * **Economic empowerment programmes** for persons with albinism and family members * **Strengthening the social workers involvement** * Involve **traditional leaders** to support the families of persons with albinism (ensure that education and information is provided) * **Adequate care accessible** for the families close to the community can take care of the victims and their families * Importance of ensuring that both **fathers and mothers** are involved in the process * Consider **adoption, foster care or guardians** if the parents reject their child with albinism * Ensure access to **social services and welfare programs** for families of persons with albinism to ensure that they are not seen as a burden by their families |
| Same as short term | **Medium term:**   * **Empowerment of health care workers** (ensuring that they are aware of the specific situation of persons with albinism, and the implication it has on their situation at all levels, including economic) * **Inclusive education** for persons with albinism throughout the country (so that children with albinism can stay with their families) |
| Same as short term | **Long term:**   * **Review** the policies adopted and processes and gather best practices to adapt the measures taken |

1. Empower people with albinism to prevent and address incidents of violence

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| **Actors** | **Measures** |
| Government, NGO | **Short term:**   * Better **information on existing frameworks** and legislation (such as the disability act) to access services. * Provide **mobile phones** to people with albinism and their families containing contacts for police among others * **Reinforce weak housing structures**, build secure doors, windows, fences and cement gravesites * Develop **programs** consisting of ring of protection consisting of trusted relatives and friends who can walk a persons with albinism when there is a risk, who can take care of the crops/business of a persons with albinism if an urgent measure is necessary at a time where the person with albinism cannot leave his house safely, etc * Permit **employees to have schedules** that avoid their walking to work in the dark * Equip persons with albinism, including children with albinism with **toolkits** of torches and whistles to ensure their safety * Develop **affirmative action program** in the public sector to advance employment prospects and inclusiveness * Recognise the link between poverty and vulnerability and link protection to welfare processes and economic empowerment |
| Government, CSO, NHRI, Media | **Medium term:**   * **Legal framework awareness**, training of judges and law enforcement agencies, health workers as well as of persons with albinism * Ensure legal assistance for cases of attacks to **involve persons with albinism in the whole legal process** * **Strengthen legal framework**, and standardize laws relating to albinism to ensure that they are clear, that the adequately protect persons with albinism, * **Dissemination of information on legal framework** by media |
| UN, AU, NHRI, Government, CSO | **Long term:**   * **Awareness for persons with albinism on processes**, and ensure they are involved in the evaluation process and report on the implementation of measures. * Create a strong framework and **platform for information sharing** between key actors * Work on a regional level with NHRI and organisations of persons with albinism to influence **regional regulatory framework** |

1. Increase monitoring and reporting of attacks against persons with albinism

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| **Actors** | **Measures** |
| Community leaders and communities | **Short term:**   * **Community leaders** should be empowered to report any incident, threat or attack against persons with albinism in their communities * **Information sheet on reporting** available at all levels * **Visible policing** in all communities * Work closely with **migration officers** to ensure they are aware of the possible traffic in persons with albinism * Considering the use of **plea bargaining** to get information on where the demand comes from * **Training police** on collection of evidence, including through DNA and advanced techniques * Increase **community awareness** on legal processes (including the importance of witnesses and evidence) * **Continuously monitor** and evaluate the impact of the implementation (or lack thereof) of the specific measures to ensure the protection of persons with albinism * **Clear indicators** should be used in order to guide the process of monitoring and evaluation in tracking progress in short, medium and long-terms as follows: * Number of reported cases of attacks Number of cases appealed and got proper sentencing; * Number of cases that have been handled by courts vis-à-vis cases at hand; * Number of arrests of perpetrators made; * Number studies undertaken on the situation; * Number of trainings and sensitization meetings and campaigns undertaken; * Number of people, communities and districts reached; * Number of community policing structures strengthened and working; * Number and types of information, education and communication materials produced and disseminated. |
| Government, police, community | **Medium term:**   * **Education to law enforcement agencies** on albinism issues to ensure they properly handle reports and attacks against persons with albinism * **Resource allocation** by the Government to promptly coordinate and prosecute and follow up on reports of incidents of attacks |
| Government, media | **Long term:** |

## Accountability measures

1. There is a need for a comprehensive strategy to guarantee the protection of persons with albinism and address discrimination against persons with albinism

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| **Actors** | **Measures** |
| Local authorities | **Short term:**   * Treat the issue of attacks and violence against persons with albinism as an **urgency** * Adopting a **multi-sectorial approach** consisting of all relevant sectors including health, education, disability, justice, social affairs, police, DPP, and groups including religious leaders, traditional authorities, traditional healers, organisations serving persons with albinism * **Use of existing structures** and mechanisms at local, community, regional and national levels in carrying out specific measures against these attacks and for the provision of health care * **Translate** protection measures for persons with albinism in all national languages and use accessible language * Create **vigilance cells/focal points** in all communities * Ensure the **systematic prosecution** of all cases of attacks and discrimination against persons with albinism |
| Government and international organisations | **Medium term:**   * Adopting a multi-sectorial action plan/strategy involving all relevant sectors including health, education, disability, justice, social affairs, police, DPP, and groups including religious leaders, traditional authorities, traditional healers, organisations serving persons with albinism , |
| Government and international organisations | **Long term:**   * Create a **position of representative of persons with albinism at the regional leve**l to oversee the establishment of a regional strategy |

1. Take the necessary legislative measures to criminalize harmful practices

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| **Actors** | **Measures** |
| Government, | **Short term:**   * **Analyse current legislation** to see whether existing provisions cover adequately the specificities of crimes against persons with albinism * Consider **reviewing criminal legislation** to to define and properly address these types of crimes and harmful practices. Consider expanding relevant provisions on murder, abduction and other relevant crimes with built-in aggravating factors in the provision such as * The victim who is a child * The intended harvest of body parts * The intended use of body parts for witchcraft for “witchcraft" (muti and juju) where the facts support such intent * Amendment of **witchcraft laws** and traditional healers legislations to regulate the profession and ensure an oversight |
| Department of Public prosecution | **Medium term:**   * **Empowerment of persons with albinism** and their families to establish and understand these legislations and the steps necessary to implement them * African countries to **coordinate and promote mechanisms** and guidelines at regional level |
|  | **Long term:**   * Legal framework protecting specifically the rights of persons with albinism inserted in Constitution |

1. Adopt measures to fight impunity for attacks against persons with albinism, including investigation and prosecution

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| **Actors** | **Measures** |
| Police, community, Justice, NGO, Media, DPP | **Short term:**   * Build **capacity of human rights organisations and organisations of persons with albinism** at local level to monitor violations * In depth investigations, including through **special investigation techniques** to establish the whole chain that led to the attack, including those at the origin of the demand * Ensure the implementation of **witnesses protection programs** in cases of attacks * **Increase the capacity of law enforcement**, and prosecution providing them with the right kind of tools/equipment to complete the investigation (including with regards to DNA, etc) * Immediately investigate, prosecute and take other necessary action where **bribery or corruption** is suspected * **Train law enforcement on using law effectively** e.g. multiple charges to compensate for weak sentencing of single charge * Strengthen **Community policing** initiatives * prioritisation of cases against persons with albinism * Ensure that **measures are taken at regional level to facilitate extradition and law enforcement cooperation** initiatives. Ratify extradition protocols and mutual legal assistance agreements * Appointment of **Special Prosecutors** specifically for attacks against PWA, who should be: * well-resourced * focussed exclusively on cases of attacks (with a team if necessary to support him or her) * **Fair trial** principles must be applied for all parties – accused and defence * **Provide regularly information** to the family on the investigation * Keep **complete and accurate records** of cases of attacks against people with albinism and corollary crimes * Ratification of relevant treaties, conventions and protocols including on human rights, international organised crimes, corruption, trafficking * Ensure access to forensic medicine (both training and means) to be able to have enough evidence, including through DNA analysis |
| NGO, Government | **Medium term:**   * States should develop in consultation with the civil society and international agencies appropriate **long-term protection policies**, programs and mechanisms to ensure the safety and security of persons with albinism * **Children with albinism protection register,** database with information on offenders (taking into account the human rights of all parties) * Monitor media and challenge **hate speech** and derogative terms against persons with albinism |
| NGO, Government | **Long term:**   * **Educate and empower persons with albinism on their rights and the relevant laws** |

1. Strengthening the legal response to crimes affecting persons with albinism

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| **Actors** | **Measures** |
| Community,  Police, DPP,  Parliament, Judiciary | **Short term:**   * Enforcement of DNA Acts (where relevant) * Community legal education to explain evidence gathering processes as well as different stages of a trial * Legal counselling for victims * Witness protection laws and adoption of witness protection programs at community levels * Transfer of technology to facilitate investigations, and enhance the police investigation skills * Prioritise investigation of cases of attacks against persons with albinism * **Sensitize legal enforcement agencies**, the judiciary and human rights of persons with albinism * Issue **Sentencing Guidelines** to the judiciary to clarify context and recommend factors to consider |
| Police, DPP | **Medium term:**   * Establish **capacity at the police** and DPP to work on cases of persons with albinism (e.g.specific units for Gender and Vulnerable groups) |
|  | **Long term:** |

1. Ensure redress and the reintegration of victims

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| **Actors** | **Measures** |
| Government, families, NGO | **Short term:**   * **Centres for victims** and displaced should only welcome them for a maximum of 6 months, and only on an emergency basis * **Engage families** through counselling of families and reunion programs in preparation for their members in the centres (involve organisations such as red cross in these programs) * Undertake **follow up visits** with families and children that have been reunited with their families * **Psychological support** to persons with albinism who would request it (victims of attacks or others), for redress but also to increase their self esteem * Cover all **cost of medical** treatment including surgery both immediately after attack and over life time. * Cover costs for functioning **prostheses** and associated physiotherapy over life time * Ensure that the victim has **access to legal support** to be adequately represented in Court * Establish appropriate procedures to provide **access to compensation and restitution** for victims * **Enable views and concerns of victims to be presented** and considered at appropriate stages of criminal proceedings against offenders in a manner not prejudicial to the rights of the defence. * Establish **victims support Funds** to cover the eventual costs of medical, psychological assistance as well as relocation of the victim if necessary * Ensure **economical tools and programs** to empower persons with albinism, including after attacks |
|  | **Medium term:**   * Put in place **transitional mechanism or exit strategies in centres** such as: * Vocational skills training programs in the centres * Psychosocial support to victims in the centres * Foster parenting programs * Tracing the families and communities of the children at the centre to promote family reunification * Economic empowerment of victims and their families * Incentivize teachers to reduce staff turnover rates * Frequently **provide reports** on the situation of centres in terms of staffing and enrolment * Formalise **measures of tracking the children** in the centres * **Strengthening legal provisions** to ensure that they address issues of persons with albinism |
|  | **Long term:**   * **Abolish the centres** for the displaced (only keep them as an emergency measures where PWA would stay for a maximum of 6 months) * Countries to use and report on the use of relevant **regional and international instruments** * Consider having an **African Decade of Persons with Albinism** |

## Discrimination

1. Address the all forms of discrimination and social stigma affecting persons with albinism, including by ensuring they have adequate access to health care, social services, employment and education (encouraging inclusive education)

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| **Actors** | **Measures** |
| Government, NGO | **Short term:**   * Awareness and **training at all levels on the rights of persons with albinism** * **Adapt the educational system** to be fully inclusive * Include basic **information on albinism** in the primary school curricula, as well as more advanced information for health care services, social welfare services, teachers, etc. * Ensure access of PWA to **social services** (recognising the link between poverty, discrimination and vulnerability to attacks) * Ensure **access to employmen**t including through affirmative action measures * Ensure the full inclusion of persons with albinism in **persons with disabilities** policies * States and stakeholders should conduct **needs assessment** of albinism as a lesser known disability and integrate findings in its disability initiatives and inclusive education policies * **Quotas** in public service and promotion of employment of persons with albinism * **Public appointments** and promotion for political positions of persons with albinism * **Train health professionals** on cancer intervention and especially equip hospitals with equipment for cancer intervention |
| Government  NGO | **Medium term:**   * Include albinism in all sectorial policies (**transversal** measures) * Ensure **free and accessible health and social care** for persons with albinism close to their communities * Ensure access of persons with albinism to **social programs** (including social housing) * **Review legislation on social protection** as well as criteria used to ensure that social protection and disability polices include specifically the needs of persons with albinism * Develop **scholarship programs** for children with albinism * **Strengthen the organisations of persons with albinism** including the Pan-African Albinism organisation * Mentorship for persons with albinism Parental empowerment |
| Government, NGO | **Long term:**   * Adopt and implement national **legislations and national action plans** to protect persons with albinism from discrimination * Ensure that **organisations of persons with albinism can take part as third parties to legal proceeding** sin case of attacks   Equip government hospitals to provide adequate **ophthalmologic and dermatologic services** to persons with albinism |

1. Address intersecting forms of discrimination faced by women and children with albinism

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| **Actors** | **Measures** |
| Government, NGO | **Short term:**   * **Education** for persons with albinism on their rights, and on Gender equality * Ensuring the **participation of women with albinism** in all processes * Particularly for women with albinism and mothers of children with albinism measures to increase scceptance in the community and family and **fight against self-discrimination, family discrimination**, discrimination in the framework of marriage, school , workplace, community, etc * **Parents** are key to build the self-confidence of children * **Recognise** multiple forms of discrimination for persons with albinism and take adequate measures * Take measure to address **child bullying** * **Educate teachers and care givers** about persons with albinism |
| Government, NGO | **Medium term:**   * **Modifying cultural beliefs** and ensure that they are positively encompassing the rights of persons with albinism including women with albinism * **Participation in community** gathering to understand, include and protect persons with albinism * **Empower women** to ensure independent living * Create **support groups for women and children** with albinism * **Social programs** and socio-economicprotection programs should include specific needs of women with albinism * Ensure **representation of women** at policy level * Involving traditional leaders and **faith based organisations** in this process * **Dialogue** between institutions |
| Government, NGO | **Long term:**   * **Enhance child care systems** at all levels |

1. Integrate the situation of persons with albinism into human rights national action plans or action plans to combat discrimination.

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| **Actors** | **Measures** |
| Government, NGO | **Short term:**   * **Mainstream albinism** throughout national human rights action plans (reviewing national action plans if necessary) * **Engage National Human Rights Institutions** to address explicitly and directly issues of persons with albinism (including through specific programs) and to monitor the specific actions of the government (including budget allocation) in this regards * **Reintroducing albinism** to the community working on the rights of persons with disabilities * Adopt a **rights based approach** * Ensure that there is a **specific focal point** for persons with albinism in National Human Rights Institutions to follow up on the issue * Analysis of existing legislations and policies to **mainstream** rights of persons with albinism |
| Government, NGO | **Medium term:**   * **Civic education** to increase respect for persons with albinism * albinism * **Document best practices** to ensure the full integration of persons with albinism in various countries * Ensure that **albinism is seen as a cross cutting issue** and insert it in existing framework * Continuing **monitoring and evaluation** of work done to ensure the full integration of persons with albinism |
| Government, NGO | **Long term:** |

# Way Forward

1. **Representatives elected**
2. The following 23 participants were elected to be present at 2 subsequent smaller stakeholder meeting (subject to funding) to refine the above measures and transform them into a brief and effective roadmap for action on albinism in Africa: Tapiwa Gwenlisa Marange(Mozambiuqe), Isaac Mwaura (Kenya), Jake Epelle(Nigeria), Bamba Diop(Senegal), Khadijatou Moumouni(Niger), Sissoko Mamadou(Mali), Patricia Logan(Liberia), Nemes Temba(Tanzania), Nancy Ngula(Tanzania), Josephat Torner(Tanzania), Ruusa Ntinda(Namibia), Alex Munyere(Kenya), Jon Beale(UK/Tanzania), Nomasonto Mazibuko(South Africa), Mary Kessi(Tanzania), Gamariel Mboya(Tanzania), Abdallah Possi(Tanzania), Jayne Waithera(Kenya), Sam Clarke(UK/Tanzania), Joshua Mkwehiwa(Malawi), Tumeriwa Mphepo(Malawi), Alshaymaa Kweygir(Malawi), Nassirou Boukari(Togo).
3. An additional 12 participants will be added by the Independent Expert taking into account – in addition to knowledge and expertise – gender balance, linguistic balance and sub-regional balance:
4. **Commitments**
5. Participants publically declared the following commitments to specific measures for advancing issues related to persons with albinism at the national level
6. **States**

Namibia (Chief Legal Officer in Law Reform Commission)

* Review of all laws that impede development and assess which laws are no longer applicable or relevant
* Formulating a Disability Act
* Training of relevant stakeholders including Parliamentarians

Malawi (Ministry of Justice, DPP)

* Comprehensive legal framework for traditional healers
* Amendments to existing laws including specific grounds to assist prosecution in case of crimes against persons with albinism

Malawi (Asst. Commissioner of Police, Interpol)

* Create special team to investigate cases relating to albinism, will have information regarding this by August
* Working through community policing on sensitizing communities
* Recruitment of officers trained in criminal investigation
* Equip officers in terms of preventative policing

Malawi (Ministry of Gender, Disabilities Dept.)

* Train magistrates in relation to persons with albinism, only professional magistrates should deal with cases relating to persons with albinism
* Training of media
* Training of police, investigators and prosecutors on offences relating to persons with albinism

South Africa (Dept of Social Development)

* Continued support of people with albinism
* Have arranged a conference regarding persons with albinism
* Continued legal support to assist people with albinism (amicus curiae)

Kenya

* Include people with albinism within the next census
* Mainstream albinism issues within programmes

Kenya (Isaac Mwaaura, MP)

* Commit to prioritising legislation and representation of persons with albinism in Kenya
* Prioritise allocation of resources for persons with albinism
* Continue providing leadership and motivation through public engagement and advocacy
* Build capacity of national albinism organisations

1. **National Human Rights Institutions**

Mozambique (National Human Rights Commission of Mozambique)

* Raising awareness
* Research on understanding reasons for attacks
* Developing National Action Plan for the Commission by the end of the year

Malawi

* Continuing awareness campaigns
* Include persons with albinism in Human Rights Action Plan which is being finalized
* Will monitor Government in relation to measures relating to persons with albinism, as well as with regards to budget allocation

Tanzania

* Continue coordinating stakeholders including Government including organizing stakeholders meetings
* Committed to using existing structures and working with multiple partners to carry out activities at community level

1. **Civil Society Organisations and Academia**

Tanganyika Law society

* Training advocates in relation to the Human DNA Act
* Coordinating and training paralegals in relation to issues regarding people with albinism

Tanzanian Women Lawyers Association

* Continue partnership with Tanganyika in order to facilitate access to justice for women and children
* Tracking budget regarding gender issues relating to persons with albinism

ALBIMOZ (Mozambique)

* Continue to work on promotion and protection of people with albinism
* Continue to work with Ministry of education in relation to inclusive education
* Continue to work with ministry of health in relation to protection from and treatment of skin diseases
* Continue to work with social services for those in vulnerable situations

New Light Children Centre Tanzania

* Continue awareness raising sessions to communities by using influential people to create community mind-shift
* Continue to lobby Government to prioritise cases relating to people with albinism
* Provide psychosocial counselling and re integration to traumatized children in collaboration with Social Welfare Office and TAS Tanzania
* Provide legal assistance by working with communities to provide evidence and testimonies for cases

Under the Same Sun

* Prioritise bringing parents and children together
* Work at local level to gather information on people with albinism
* Continue to work CHRAGG and Independent expert
* Build capacity of APAM in Malawi in next year and will possibly do the same in Mozambique the following year
* Work on Directive for Care Givers

APRODEPA (DRC)

* Work with the Independent National Electoral Commission to promote a census of adults with albinism
* Follow up on the implementation of the strategic plan for persons with disability adopted in June 2016, including with regards to persons with albinism
* Continue to carry out advocacy activities
* Cooperate with the Cinquantenaire Hospital and other partners to ensure access to adequate health care for persons with albinism

SCOSP (Uganda)

* Continue to work in relation to raising awareness relating to people with albinism including through TV
* Promote inclusive education
* Provision of sunscreen, sun protective clothing and education relating to skincare

Albino Foundation Nigeria

* Offered personal services in relation to building capacity of other organizations

Albinism Society of South Africa

* Continue to advocate and raise awareness in relation to the issue
* Lobby for a comprehensive educational policy including at SADC level
* Organise conference on issue of albinism

Tanzanian Albinism Society

* Advocating for rights and dignity of persons with albinism
* Collaborate with other organization

Association Burkinabe pour l’intégration des personnes albinos (Burkino Faso)

* Encourage families and communities to protect people with albinism

Association Nationale des Albinos du Togo

* Will continue working for the rights of persons with albinism

Association Nationale des Albinos du Senegal

* Mainstream albinism issues within Government and UN presence in Senegal activities
* Put together action plan involving all stakeholders

Alive Albinism Initiative Trust (Zimbabwe)

* Continue to raise awareness in school
* Continue partnerships with relevant ministries

National Albinism Initiative Networking of Zambia

* Advocate with Government to adopt a policy on albinism and to ensure that the rights of people with albinism are protected

Patricia Lund (Coventry University) and Standing Voice

* Produce an evidence-based analysis of the facilitators and factors that influence transition at key points in the life of a person with albinism in Tanzania to inform and influence policy and interventions by both governmental and non-governmental agencies.
* Implement a campaign to tackle ignorance about the genetics of albinism, which unites creative artists and scientists to create innovative public engagement techniques that can be replicated across Africa.

African Institute of Mathematical Sciences

* Catalogue and review current albinism data collection programmes
* Analyze existing albinism data collections
* Develop training for albinism data providers and users.

Disability Rights Promotion International

* Commit to disseminating 7 modules regarding monitoring of rights of persons with disabilities

Hospital Cinquantairenaire (DRC)

* Continue to provide commit free treatment

Astane Mariamu (USA)

* Transform their awareness raising efforts from an education campaign to a social interaction programme
* Expand skincare programme to Uganda

KCMC

* Continue to train dermatologists in sub-Saharan Africa, provide sunscreen and advocate to have this model adopted by Government

Tshimologo Association (Botswana)

* To train teachers relating to people with albinism

Association Mondiale pour la Défense des Intérêts et la Solidarité des Albinos (Cameroun)

* Continue advocacy and awareness raising through information, education and communication

Association Ivoirienne pour la promotion des femmes albinos (Cote d’Ivoire)

* Awareness raising for women on protective clothing
* Income generating activities for women with albinism

Peacemakers for Albinism & Community

* Begin to track and use data in all programs
* Expand the community education program

Standing Voice

* Launch our Skin Cancer Prevention Programme in Malawi and continue to expand the programme into new regions across Tanzania
* Expand our Vision Programme to reach 4,000 people with albinism across Tanzania over the next 4 years.
* Train teachers to become Vision Ambassadors for pupils with albinism in schools across Tanzania
* Enable PWA who have been denied formal education to gain new skills training at the Umoja Training Centre
* Continue to build capacity and facilitate partnerships within the albinism community

1. Office of the High Commissioner for Human Rights, First report on albinism. Persons with albinism, 12 September 2013, A/HRC/24/57 [↑](#footnote-ref-1)
2. Albinism Report by the Advisory Committee of the UN Human Rights Council 2015, Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism, 10 February 2015, A/HRC/28/75 [↑](#footnote-ref-2)
3. Albinism Expert Meeting by the Organisation Internationale de la Francophonie and the Office of the High Commissioner for Human Rights 2014, Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward, 24 September 2014, unpublished [↑](#footnote-ref-3)
4. African Commission on Human Peoples’ Rights. Resolution 263: Resolution on the prevention of attacks and discrimination against persons with albinism, Done in Banjul, The Gambia, 5 November 2013 [↑](#footnote-ref-4)
5. Human Rights Council, Resolution 23/13, Attacks and Discrimination Against Persons with Albinism, 13 June 2013, A/HRC/RES/23/13 [↑](#footnote-ref-5)
6. Including CERD, CEDAW, CRC, CRPD, CESR, HRC, CAT, CRPD, [↑](#footnote-ref-6)
7. This consultation day was organised by Standing Voice with the support of the World Bank to explore the challenges and needs of people with albinism from different angles in an open setting, creating a fuller understanding of this issue and realistic avenues for constructive action. [↑](#footnote-ref-7)
8. Short term is current to 2 years. Medium : 2 to 5 years and long is 5 or more years. [↑](#footnote-ref-8)