Addendum: Achievements to date

Mandate of the Independent Expert on the enjoyment of human rights by persons with albinism

Ms. Ikponwosa Ero

August 2015 - July 2021

HIGHLIGHTS1:

2015 August	Mandate-holder begins work
	Achievements - main highlights
37 Reports	21 Reports to the HRC and the UNGA, 16 academic and non-academic papers and reports
7 official missions and 33 working visits	7 official missions (general practice of 2 missions per year). Mozambique, Malawi, Tanzania, Fiji, Kenya, South Africa, Brazil ²
	33 visits to various countries in Africa, Asia, North America, and the Pacific
Scores of Technical Support	Legislation support and advisory services to scores of government and non-governmental bodies
Hundreds of Advocacy & awareness	Hundreds of advocacy events, interviews, Op Eds, Advocacy campaigns and support to researchers across 4 continents including Africa
	Achievements - highlights in the context of the Vision of the Mandate
Attacks & related human rights violations	Developed Regional Action Plan to end attacks and related human rights violations against persons with albinism in Africa.
	Endorsement of the Regional Action Plan by the African Commission on Human and Peoples' Rights and the Pan African Parliament with the support of the Independent Expert.
	Developed multi-stakeholder online platform [www.actiononalbinism.org to monitor and co-ordinate global efforts in implementing the RAP.

 $^{^1}$ This document reflects selected activities by the Independent Expert and is an addendum to her main report A/HRC/46/32. We are unable to include all activities she carried out due to spatial limits.

1

² Missions of 2020 cancelled due to the COVID-19 pandemic

	Endorsement of the RAP by the Pan African Parliament (PAP_ with the support of the Expert). Establishment of a RAP taskforce, consisting of various stakeholders (including various UN agencies) and co-chaired by the
	Independent Expert and the International Bar Association. Endorsement by the African Union of the RAP to become a continent-wide policy. Decision by the African Union to establish a mandate for a Special Envoy on albinism for the region, who can also look into the measures covered in the RAP.
	The Expert supported the AU-led consultation on the Plan of Action to replace the RAP and to be adopted in 2021.
	Ground-breaking workshop on Witchcraft and Human Rights organised in September 2017.
Root causes	Co-developed workshop on Witchcraft and Human Rights in January 2019.
Noor sausse	Consultation with stakeholders throughout 2019 and 2020 on a proposed resolution on harmful practices related to the accusation of witchcraft and ritual attacks (HPWAR).
Research & data collection	Research on albinism and human rights multiplied over ten times the quantity published before the mandate.
	Launch of global inter-disciplinary research network and agenda on albinism to spur knowledge development on the issue.
Fundraising	Partnership with various organisations -over 20 UN and non-UN entities-, to co-organise and cover cost of activities not ordinarily covered by the budget of the mandate.
Capacity- building	Over 30 capacity-building workshops and strategic meetings with civil society, including ongoing capacity building initiatives with various civil society groups.

DETAILS

Presented according to the four core activities of the Expert as identified in the Vision she cast in her first report. $^{\rm 3}$

A. Develop and strengthen specific measures to end and prevent attacks

Status: Completed and Ongoing

Highlights:

	Led development of Regional Action Plan
2016 June Dar es Salaam	A two-day Consultative forum titled "Action on albinism in Africa" was held in June 2016 in Dar es Salaam, Tanzania, with over 150 participants from 26 countries in the region. This forum worked on first draft of Regional Action Plan
2016 November	A high-level meeting in Pretoria reviewed and made proposals to the draft regional action plan.
2016 November	Think Thank elected at the end of the forum in Dar es Salaam, and met in Nairobi for two days to refine the proposed plan.
2017 May	A Panel Discussion, followed by a side event, was organized during the 60th Ordinary Session of the African Commission on Human and People's Rights to promote implementation of the Regional Action Plan.
2017 May	Adoption of Resolution 373 by the African Commission on Human and Peoples' Rights, which, in addition to endorsing the Regional Action Plan, urges all States Parties to take all measures necessary for its adoption and implementation and invites relevant organs and bodies of the African Union to give due regard to adapting and implementing the Plan.
2018 March	A workshop with the Justice and Human Rights Commission of the Pan African Parliament on the Regional Action Plan.
2018 May	The Pan African Parliament adopted a resolution endorsing the Regional Plan of Action.
2019 - 2020	Draft of Pan African Parliament Guidelines on harmful practices related to the accusation of witchcraft and ritual attacks (HPWAR).
2020 - 2021	Preparation for the validation of the PAP Guidelines.

³ A/HRC/31/63

_

	Drive Implementation of the Regional Action Plan
2017 November Pretoria	Regional meeting with international organizations consisting of international development organizations as well as those with multinational capacity including organisations of persons with albinism to design an implementation strategy for the Action Plan.
2018 February Nairobi	Civil society regional meeting to develop targets to be achieved under the Plan at the "grassroots" by the end of the Plan in 2021
2018 March	Presentation of the Regional Action Plan to the Human Rights Council during the March 2018 session (A/HRC/37/57/Add.3)
2018 May	Development of platform by the Task Force to evaluate and publicise the activities to implement the Regional Action Plan.
2018(ongoing)	Regular meetings of the Task Force established after the Regional Meeting in November 2017 to follow up on the implementation of the Regional Action Plan.
2019 March	Workshop with the Pan African Parliament regarding modalities of work on the issue including Guidelines on Harmful Practices related to accusations of witchcraft and ritual attacks (HPAWR) supported by the Independent Expert with group of advocates attending the event.
2020	Validation of PAP Guidelines deferred to 2021. Background information and materials for validation have been drafted and are ready for finalisation. Inputs have been obtained from various stakeholders.
2020 November	Endorsement by the African Union of the RAP (officially referred to as the AU Plan of Action to end Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021-2031) to become a continent-wide policy. Decision by the African Union to establish a mandate for a Special Envoy on albinism for the region, to promote implementation of the Plan of Action. The Expert supported the AU-led consultation on the Plan of Action for the Implementation of the RAP, to be adopted in 2021.

B. Define applicable international legal frameworks

Status: Completed

2016-2017	Together with the International Bar Association, the Expert supported the development of the report on applicable legal standards in relation to albinism in Africa.
2017 March	The Expert contributed to the "Security Guidelines for People with Albinism" developed by the civil society organisation, CBM. ⁴
2017 October	Developed report on applicable international standards at the international level which was submitted to the UNGA.
2018 October	Developed report on albinism and the SDGs which was submitted to the UNGA.
2018 October	General Comment 36 on the Right to Life by the Human Rights Committee contains reference to persons with albinism, after submission by the Expert.
2019	Contributed to UNHCR's Need to Know Guidance: Working with Persons with Disabilities in Forced Displacement; publication of 2019, shedding much needed light on persons with albinism as refugees and Internally Displaced Persons. ⁵
2019, 2020	Discussion with stakeholders on a potential resolution on HPWAR

 $^{^{4}\,\}underline{\text{https://www.cbm.de/dam/jcr:}8252b21c-b36a-4f10-8b85-86f7fc7bfd90/security-guideline-for-people-with-albinism}\,cbm.pdf$

cbm.pdf

The Expert contributed to the "Security Guidelines for People with Albinism" developed by the civil society organisation, CBM, published in March 2017

C. Strengthen concerted implementation efforts

1. Regional and international agenda

Regional agenda:

Status: Completed and ongoing

2017 April	Presentation of the Regional Action Plan to Ministers of Social Affairs in Africa at the Specialised Technical Committee on Social Development, Labour and Employment of the African Union in Algiers.
2016 -2017	Participation of representatives of regional mechanisms at three regional meetings for the development of the regional action plan in Dar es Salaam, Niamey and Pretoria; as well as at the workshop on witchcraft and human rights in Geneva.
2017 May	Panel discussion on the Regional Action Plan during the 60th Ordinary Session of the African Commission on Human and People's Rights. This dialogue was continued during a side event on the margin of the same session organized by the Independent Expert.
2017	Joint Statements on the occasion of International Albinism Awareness day endorsed by the African Commission on Human and People's Rights as well as with various UN Special Procedures mandates were released.
2018	Workshop with the Justice and Human Rights Commission of the Pan African Parliament and presentation at the plenary of the Pan African Parliament.
October 2018	Panel and side-event organised with African Commission on Human and Peoples' rights, during the 63 rd ordinary session of the African Commission on Human and Peoples' Rights.
2019 February	Pan-African Parliament Draft Guidelines on Harmful Practices related to HPAWR.

International agenda

Status: Completed and ongoing

2016-2017	Input to resolutions posited at the GA and the AU by Member States.
2016-2017	Provided inputs to the drafting of the first Report of the Secretary-General on the social development challenges faced by persons with albinism as mandated by GA resolution (A/72/169).
	Submissions and presentations to Treaty Bodies
2016 -2017	 Committee on the Rights of Persons with Disabilities Committee on the Elimination of Racial Discrimination Human Rights Committee
	Support to Civil Society to participate in the work of Treaty Bodies
2015-2018	Regular guidance to CSOs to support submissions to the following Treaty Bodies:
	Mandates and Mechanisms at the UN
2015-2020	Collaborations with the Special Rapporteur (SR) on the rights of persons with disabilities, on violence against women, its causes and consequences, on extrajudicial, summary or arbitrary executions, on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, on contemporary forms of racism, racial discrimination, xenophobia and related intolerance.
2015-2020	Close and active collaboration with the Special Representative of the Secretary-General on Violence Against Children, particularly on the issue of the violence emanating from witchcraft related harmful practices.
2020 November	Led training in Mozambique for CSOs serving persons with albinism – in partnership with UNESCO, OHCHR and the SRSG-VAC. The training focused on Lusophone CSOs from the region.
2016-2017	Co-developed draft guidelines with the office of the UN High Commissioner for Refugees to ensure the well-being and safety of persons with albinism in situation of displacement.

2016-2017	Worked with UNICRI (United Nations Interregional Crime and Justice Research Institute) on the criminal aspects of attacks
	against persons with albinism.
2016-2021	Regular and ongoing discussion and collaborations with representatives of UNESCO, UNWOMEN, UNFPA, UNICEF, IOM, UNDP and the OHCHR including in at least 15 events and workshops such as the Action on Albinism forum in Dar es Salaam in 2016.

2. National agenda

Status: Completed and ongoing

	Country Visits:6
2016	Malawi and Mozambique
2017	Tanzania and Fiji
2018	Kenya
2019	Brazil and South Africa South Africa: during her visit in September 2019, the UNIE held a two-day consultation with stakeholders which led to the establishment of a national task force to take forward the protection
	of human rights of persons with albinism. Brazil: As a result of her visit in November 2019, the Government of Brazil provided necessary support to civil society serving persons with albinism. This support will assist in the provision of essential resources including sunscreen for persons with albinism. An ordinance supporting the population of persons with albinism will be officially launched by the Government.
2017	Signed on 14 March at Lilongwe by all political parties in Malawi. Commitment to stop attacks and promote and protect rights of all persons with albinism including through funding of the Malawi Action Plan. Signed by MCP, DPP, UDF, PP, UTM, AFORD, CMD.
	The European Parliament adopted resolution 2017/2868 on the situation of persons with albinism in Africa, notably in Malawi, in which it also endorsed the Plan and called upon the European Union and its member States to, inter alia, support efforts to address the

 $^{^6}$ In 2020 the COVID-19 pandemic forced cancellation of scheduled visits.

	rights of persons with albinism on the basis of non-discrimination and social inclusion by providing the necessary financial and technical assistance.
2015-2020	Communications transmitted to various States regarding particular cases of alleged human rights violations against persons with albinism.

D. Increase awareness and understanding of albinism and the situation of persons with albinism

1. Awareness-raising

Status: Completed and ongoing

2015-2021	Regular (often quarterly) comprehensive updates are made to civil society on developments regarding the human rights of persons with albinism.
	Media – traditional and social
2015-2021	Numerous media interviews, features and conferences including on the BBC, CNN, Guardian, Al Jazeera, among others.
December 2017	New African Magazine announced its 100 most influential Africans for 2017 which included the UNIE due to her work as an advocate on the human rights of persons with albinism.
2015-2021	Active and regular presence on social media including Facebook, Instagram and Twitter
2015-2021	The Independent Expert took part in numerous local and international media interviews including with the BBC, Al Jazeera, NPR, Reuters and various awareness events across the world. In addition, the Independent Expert participated in numerous public engagements, including interventions in multiple of conferences and expert meetings, which permitted her to raise awareness among an extensive and diverse audience, share information and promote good practices with regard to the enjoyment of human rights by persons with albinism.

	Other
2015-2021	Organization of several Side Events on the margins of sessions of the UN and AU as well as participation at various others.
2015-2021	Contributions to UN campaign site on albinism. Participated in OHCHR's StandUpForHumanRights Campaign.
2017- 2019	Technical support and capacity building for the budding Pan African Albinism Alliance.
	Directly organized and participated in 16 activities to commemorate International Albinism Day. Highlights:
2015-2021	Side-event organized by the UNIE was launched at the Conference of State Parties for the CRPD in New York. The event was also in commemoration of IAAD. Panellists included States, civil society organization and a renowned model with albinism. Over 100 participants attended. With the support of the NYDG foundation and in collaboration with the Expert, billboards of models with albinism were erected at Times Square in a campaign titled #colourfull.
	Malimbe, an in-flight magazine for four Nigerian airlines (Arik, Aero, Dana, Bristow) featured persons with albinism on its cover to commemorate IAAD. The featuring of persons with albinism was done in close consultation with the UNIE.
2018 December	On 10 December 2018, OHCHR commemorated the seventieth anniversary of the Universal Declaration of Human Rights and Roben X, a musician with albinism who has featured in the OHCHR campaign on albinism, which the Independent Expert supports, was made an OHCHR Champion of Human Rights by the High Commissioner during the event. The event was attended by 400 youths and representatives from the United Nations, Member States and civil society. The High Commissioner also held a panel discussion that included Roben X and the issue of persons with albinism was a focus. The Independent Expert continues to engage with Champions for Human Rights around the world who are partners in the cause of albinism.
2019 April	Screening of the movie Lazarus which also included the Independent Expert – at the Tribeca Film Festival in New York. The movie was produced by Oscar-nominee David Darg and the musician Madonna.
2020 June	OHCHR with the UNIE ran a campaign for IAAD called #MadeToShine. Over 25 posts went out in English, Spanish and French on our social media platforms engaging nearly one million persons.

⁷ http://albinism.ohchr.org.

2. Research and data collection

Status: Completed and ongoing

	Reports
2015-2021	 Thematic reports to the UN include the following themes: Root causes of Attacks Right to Health International Human Rights and other Legal Frameworks Applicable Witchcraft and Human Rights of persons with albinism Sustainable Development Goals Access to Justice Women and Children with Albinism Albinism Worldwide Protection of Persons with albinism Best Practices on protection on persons with albinism (compilation) Progress, achievements, challenges and the way forward: an overview of work on the mandate on albinism
	Research
2016-2021	Co-developed an international, interdisciplinary research policy network, and developing a prioritized research agenda pertaining to the intersection of albinism, spiritual and cultural practices, and human rights in collaboration with Trinity Western University, Canada, and other academics
2015-2021	Provided input into various research projects and theses to spur development of information and knowledge in this area of work, for example with the Centre for Human Rights of the Pretoria University

3. Resource Mobilizations

Status: Completed and ongoing

	Fundraising and Resource Mobilization
2015-2021	The significant quantity and quality of the achievements made under the mandate in the previous six years, have been due to the financial support of the regular budget allocation of OHCHR and ad hoc support from United Nations agencies in the field. However, a significant number of those achievements were made possible through the fundraising and resource mobilization efforts undertaken by the Independent Expert. She is particularly grateful for the multi-year support from private and other entities, which together often matched or exceeded the contribution from the regular budget. That is an important point in terms of management of expectations as to what might be achievable in the absence of such significant extra-budgetary support. It is also worth noting that obtaining such support is demanding of both the time and resources of the mandate holder in significant ways that must be emphasized. Overall, the achievements set out in the present report are undoubtedly correlated to the time invested by the Independent Expert, which amounted to the equivalent of full-time employment.
	Resource Mobilization for organizations representing persons with albinism
2015-2021	The Independent Expert has also facilitated the grant-seeking processes of civil society groups through support letters and networking, all of which have generated financial and in-kind support to the tune of over 2.5 million US dollars in this time period (names of recipient organizations available upon request)

3. Conclusion and the way forward

Highlights:

Activities

Regional Action Plan - Implementation

Promote implementation of the AU Plan of Action to end attacks and other human rights violations targeting persons with albinism in Africa (2021-2031).

Complete guidance to States on the issue of harmful practices related to accusations of witchcraft and ritual attacks.

Strengthen concerted implementation efforts

Continue to work with other international human rights mechanisms, including to produce joint statements and carry out joint activities at the UN and AU.

Continue to follow up on recommendations made after country visits.

Strengthen the cooperation with regional mechanisms and international organizations in the region.

Carry out country visits, issue communications and provide technical assistance on legislation, policy and other areas upon request.

Advocacy and Awareness Raising

Continue to carry out public education and awareness-raising activities in countries where attacks continue to occur, as well is in countries where little attention has been brought to the issue.

Continue to use media – both traditional and social – to raise awareness. These include the UN campaign platforms available.

Reports

Topics for future reports could look at the enjoyment of the right to education by persons with albinism and take an in-depth look at attitudinal barriers to the enjoyment of human rights by persons with albinism.

Other:

Continue to seek support: financial and human resource – for the mandate's activities.

Continue to build the capacity of civil society and provide assistance on engaging with the UN and AU systems. Continue to explore the possibility of collaborations with various actors (traditional and non-traditional) to enhance education and heighten awareness of issues related to the human rights of persons with albinism.