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**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Achievements, accomplishments, challenges and the way
forward: an overview of work on the mandate****Report of the Independent Expert on the enjoyment of human rights by
persons with albinism, Ikponwosa Ero***Summary*

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism provides a summary of the achievements and accomplishments of her tenure as mandate holder, from 2015 to 2021. These achievements are presented based on the vision set for the mandate in her first report to the Human Rights Council (A/HRC/31/63). The successes presented are key indicators of substantial progress in the realization of the initial vision of the mandate, particularly in the areas of mass awareness-raising, and concrete and specific measures to remove barriers to the enjoyment of human rights by persons with albinism. The Independent Expert also identifies continuing challenges and makes recommendations on ways to maintain the gains and address the gaps identified.



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I. Introduction

1. This is the final report of the Independent Expert on the enjoyment of human rights by persons with albinism to the Human Rights Council. It is submitted pursuant to Human Rights Council resolutions 28/6 and 37/5. In the report the Independent Expert provides an overview of selected achievements and accomplishments under the mandate during the six-year period of her tenure from 2015 to 2021. A thorough list of achievements and accomplishments can be found on the website for the mandate.¹ They are identified in accordance with the vision established in the first report the Independent Expert submitted to the Council (A/HRC/31/63). In the present report she also highlights the challenges to be addressed and makes recommendations.

2. The mandate of the Independent Expert on the enjoyment of human rights by persons with albinism was established by the Human Rights Council on 26 March 2015 in resolution 28/6 and extended in resolution 37/5. It is worth noting also that in resolution 69/170, the General Assembly adopted 13 June as International Albinism Awareness Day, to be commemorated from 2015 onwards.

3. In resolution 37/5 of 2018, the Human Rights Council welcomed the ongoing work of the Independent Expert in addressing harmful practices related to accusations of witchcraft and ritual attacks as one of the root causes of human rights violations and abuses perpetuated against persons with albinism, and encouraged the Independent Expert to engage with stakeholders and carry out analytical studies in order to enable States to take effective action. It also welcomed the Regional Action Plan on Albinism in Africa (2017–2021), and reiterated a call to Member States to ensure accountability through the conduct of impartial, speedy and effective investigations into attacks on persons with albinism, bringing perpetrators to justice and ensuring victims and family members have access to appropriate remedies.

II. Vision and priority areas

4. In her first report to the Human Rights Council (A/HRC/31/63), the Independent Expert defined her vision for the mandate under five main priority areas to be addressed:

- (a) Attacks, trafficking of body parts and related human rights violations;
- (b) Discrimination;
- (c) Disability;
- (d) Health;
- (e) The specific situation of women and children.

5. To address those priorities, four broad action points were identified:

- (a) Develop specific measures to address attacks and related human rights violations;
- (b) Define applicable legal frameworks;
- (c) Strengthen implementation efforts at international, regional and national levels;
- (d) Undertake awareness-raising, research and data collection.

These areas for action have framed the core activities of the Independent Expert. The present report provides an overview of her achievements and positive impact in relation to these four action points.

¹ See www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx.

III. Achievement and accomplishments pursuant to the vision of the mandate

A. Specific measures to end and prevent attacks

6. From the outset of the mandate, a critical area for targeted intervention was the combating of physical (often ritual) attacks on and killings of persons with albinism. Since 2006, close to 800 attacks have been recorded in 28 countries, mainly in Africa.² The most recent attack was reported in November 2020, during the writing of the present report. These are just the reported cases: civil society working on albinism believe the number of cases is much higher but that they remain unreported owing to, inter alia, the involvement of family members as perpetrators and rampant myths including the belief that persons with albinism do not die but disappear. Such attacks range from mutilation, maiming and murder to kidnapping, human trafficking and the desecration of graves to steal and traffic body parts from the corpses of persons with albinism. Reports indicate the existence of a black market for body parts of persons with albinism.³ To tackle these atrocities, in 2016 the Independent Expert brought stakeholders together to elaborate and adopt a regional action plan.

1. Regional action plan

7. In elaborating the regional action plan for the period 2017–2021, the Independent Expert consulted with States, civil society, international and regional bodies and agencies and other stakeholders. The exercise was based on the measures already identified by persons with albinism as necessary for intervention and on the relevant recommendations from resolutions adopted at the United Nations and the African Union, in particular resolutions of the African Commission on Human and Peoples' Rights, and recommendations of the African Committee of Experts on the Rights and Welfare of the Child, the United Nations treaty bodies, the universal periodic review mechanism, and resolutions and reports of the Human Rights Council.⁴ This was complemented by national best practices, such as the national action plans from Mozambique and Malawi and those drawn up by various national task forces in the United Republic of Tanzania. De facto and de jure national responses from other countries such as Kenya, Nigeria and South Africa were also considered.

8. The initial draft of the regional action plan was subsequently scrutinized at consultation workshops. They included a two-day forum entitled "Action on albinism in Africa" held in June 2016 in Dar-es-Salaam, United Republic of Tanzania, with over 150 participants from at least 26 countries in the region. In November 2016, a high-level meeting in Pretoria reviewed the proposed plan and made proposals for improvement. In the same month, a task force, whose members were elected at the end of the forum in Dar-es-Salaam and who had the mandate to collate, finalize and adopt the substantive text on behalf of all participants, met in Nairobi for two days to refine the proposed plan. Participants in the workshops included staff from various United Nations agencies, the African Committee of Experts on the Rights and Welfare of the Child and the African Commission on Human and Peoples' Rights, and representatives of civil society, including organizations representing persons with albinism, Governments, national human rights institutions and academia. The Independent Expert also solicited input during the whole of 2016 through regular correspondence with a wide range of stakeholders, including those who were unable to attend the workshops and consultations.

9. Through the consultation processes, a final version of the plan was completed by the task force. The Regional Action Plan on Albinism in Africa was translated from English into French, Arabic and Portuguese, three of the principal languages used by the African Union.

² See <https://actiononalbinism.org/page/sfj6gs7s8kjd5f6c6zyhw7b9>.

³ See International Federation of Red Cross and Red Crescent Societies, "Through albino eyes. The plight of albino people in Africa's Great Lakes region and a Red Cross response" (2009) and www.underthesamesun.com/content/issue#where-have-the-attacks-happened. The most recent attack in November 2020 indicated cross-border trafficking.

⁴ See, for example, Council resolutions 23/13 and 24/33. See also <https://actiononalbinism.org/en/page/s3e6cfhxqxie7v46ridjnstt9>.

The Plan was subsequently disseminated by the Independent Expert to all stakeholders who had been consulted and through her social media platforms, reaching thousands of persons, particularly in Africa. It was also posted on the webpage of the Independent Expert⁵ and presented to the Human Rights Council during its thirty-seventh session (see A/HRC/37/57/Add.3).

10. In February 2018, the Independent Expert organized a consultation to develop targets for the Regional Action Plan. Participants included representatives of organizations of persons with albinism from at least 25 countries in Africa, national human rights institutions, international non-governmental and governmental organizations, and the Office of the United Nations High Commissioner for Human Rights (OHCHR). At the end of the consultation, 40 targets were adopted to realize the 15 measures identified in the Plan. Those targets were also linked to the Sustainable Development Goals to facilitate implementation by Member States and other key stakeholders.⁶

11. To promote awareness of the Regional Action Plan in Africa, a panel discussion, followed by a side event, was organized during the sixtieth ordinary session of the African Commission on Human and People's Rights in 2017. That led to the adoption of resolution 373 in which, in addition to endorsing the Plan, the Commission urged all States parties to take all measures necessary for its adoption and implementation and invited relevant organs and bodies of the African Union to give due regard to the Plan. Also in 2017, 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 rights of persons with albinism on the basis of non-discrimination and social inclusion by providing the necessary financial and technical assistance.

12. To further promote awareness of the Regional Action Plan and its implementation in Africa, on 9 March 2018 a meeting was organized with the members of the Committee on Justice and Human Rights of the Pan-African Parliament. The Chair of the Committee expressed grave concerns about the attacks on persons with albinism. In follow-up to that meeting, a panel was organized at the plenary session of the Parliament on 16 May 2018, at which the Independent Expert was invited to present the Plan. As a result of that discussion, the Parliament adopted a resolution on persons with albinism in Africa in which it, inter alia, condemned the attacks on persons with albinism and the violation of their human rights, endorsed the Plan and called on the member States of the African Union to take all measures to ensure the effective protection and promotion of the rights of persons with albinism and to promote regional cooperation to address cross-border crimes, notably the trafficking of persons and children and the body parts of persons with albinism.⁷

13. To give further impetus to both Governments and civil society to implement the measures set out in the Regional Action Plan, the Independent Expert continued to pursue high-level endorsement or adoption of the Plan at the apex body of the Commission of the African Union. In 2017 she presented the Plan to the African Union Specialized Technical Committee on Social Development, Labour and Employment. As a result, the Committee adopted a recommendation on the issue, requesting further work be done on the matter by the Department of Social Affairs.⁸

14. In July 2019, as a result of the continued engagement of the Independent Expert with the African Union, the Regional Action Plan was considered at the Executive Council of the African Union and was subsequently adopted as a continent-wide policy as the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031), which was incorporated into the larger disability architecture of the African Union, thereby giving further legitimacy to the need to implement the measures

⁵ See www.ohchr.org/EN/Issues/Albinism/Pages/AlbinismInAfrica.aspx.

⁶ See <https://actiononalbinism.org/en/page/172jn94zmm4p0owbwf088v9529>.

⁷ PAP.4/PLN/RES/05/MAY.18.

⁸ See “Investment in employment and social security for harnessing the demographic dividend”, report of the experts’ meeting (April 2017), available from www.ioe-emp.org/fileadmin/ioe_documents/publications/Working%20at%20Regional%20Level/Africa/EN/20170508_C1717_AU_2nd_Mtg_of_the_STC_on_Social_Dev_Lab_Emp_-_Report.pdf.

contained therein. The African Union also decided at the same session that a special envoy would be appointed to ensure the implementation of the Regional Action Plan, an important step towards having a dedicated high-level official to oversee and drive the necessary actions under the Plan. In November 2020, the Department of Social Affairs of the African Union presented the Plan of Action and a draft implementation strategy for the period 2021–2031 for consultation and validation at an online meeting with stakeholders. Participants included civil society organizations representing persons with albinism and representatives of national human rights institutions and United Nations agencies, including the United Nations Educational, Scientific and Cultural Organization (UNESCO) and OHCHR. The consultation and validation process of the Plan of Action and the implementation matrix is expected to continue with these stakeholders into 2021 with the support of the Independent Expert and the Department of Social Affairs. The process is expected to be completed before the end of 2021, at which time the Plan of Action with its implementation strategy is expected to replace the Regional Action Plan.

2. Implementation of the Regional Action Plan

15. To promote the implementation of the Regional Action Plan, the Independent Expert organized a regional meeting in Pretoria in November 2017 with representatives of international organizations. One of the objectives of the meeting was to discuss a coordination platform for mobilizing resources and unifying efforts by various organizations with a commitment to implementing the Plan.⁹

16. One of the points addressed in the meeting was the establishment of a user-friendly multi-stakeholder platform (actiononalbinism.org) which would measure implementation of the Plan with basic indices and serve as a resource base on the issue for national, regional and international stakeholders.

17. In addition, a multi-stakeholder task force consisting of various organizations present at the meeting was created.¹⁰ The task force has held regular meetings to progress a number of actions:

- (a) Develop outreach material to promote the implementation of the Regional Action Plan and advance its targets on albinism in Africa;
- (b) Support the content of the online coordination platform;
- (c) Coordinate activities on albinism on the continent and internationally;
- (d) Share experience, knowledge and best practices on albinism.

18. The Action on Albinism website remains operational with a full-time consultant assisting in its management and maintenance. The task force has also developed a curriculum for training civil society organizations of persons with albinism, focusing primarily on human rights skills for advocacy. To date, training sessions have been held in Mozambique, Senegal, South Africa and Uganda, as well as online to enhance participation across the region. The sessions have been conducted in English, French and Portuguese.

3. Guidelines on harmful practices related to accusations of witchcraft and ritual attacks

19. In collaboration with the Pan-African Parliament and the Centre for Human Rights at the University of Pretoria, the Independent Expert pioneered work to create guidelines aimed at ending harmful practices related to accusations of witchcraft and ritual attacks against

⁹ Participants included representatives from the nascent Pan-African Albinism Alliance, the World Bank, UNESCO (United Republic of Tanzania), the United Nations Malawi country team, represented by the United Nations Children's Fund (UNICEF), the Mozambique country team, represented by UNESCO, the International Organization for Migration (IOM) and non-governmental organizations, such as the Centre for Human Rights at the University of Pretoria, KiliSun, Standing Voice, Under the Same Sun and other major civil society stakeholders, such as the Open Society Foundations, Human Rights Watch and Amnesty International.

¹⁰ Representatives from UNESCO, IOM Mozambique, Open Society Foundations regional offices, Regional Forum on Albinism, OHCHR, International Bar Association, Centre for Human Rights, University of Pretoria, see <https://actiononalbinism.org/page/g21dqw5v8x3cj5m0ulqc15rk9>.

persons with albinism. In May 2019, the Pan-African Parliament adopted a resolution on measures for the promotion and protection of the rights of persons with albinism in Africa and authorizing the drafting of guidelines.¹¹

20. It is important to note that even though the development of the guidelines was commissioned in the context of a resolution concerning persons with albinism in general, the guidelines will cover the problem of harmful practices related to accusations of witchcraft and ritual attacks in a holistic way. That is to say the guidelines will include all persons who are vulnerable to these harmful practices in Africa, including women, children, the elderly and persons with disabilities in general and, in particular, persons with albinism

21. At the time of the drafting of the present report, preparations were under way to hold a session with the Pan-African Parliament and other relevant organs of the African Union to validate the guidelines. The guidelines will be the first regionally developed document aimed at combating harmful practices related to accusations of witchcraft and ritual attacks.

4. Proposed resolution on harmful practices related to accusations of witchcraft and rituals attacks

22. Throughout 2019 and 2020, the Independent Expert held numerous consultations with Member States and civil society organizations, to advocate for a Human Rights Council resolution to condemn harmful practices related to accusations of witchcraft and ritual attacks. A resolution from the Council would significantly contribute to strengthening protection measures not only for persons with albinism, but also for other victims of such practices, including women, children, persons with disabilities and older persons. Substantial groundwork and preliminary data show the magnitude of the problem, with tens of thousands of persons being killed, maimed, tortured and stigmatized worldwide.¹² The Independent Expert hopes that this work will continue and that the Council will adopt a resolution on this phenomenon. She continues to engage with Member States and stakeholders in bringing this issue to the attention of the Human Rights Council.

B. Defining applicable international legal frameworks

23. In her report to the General Assembly at its seventy-second session (A/72/131), the Independent Expert provided a compilation of international human rights standards pertaining to the human rights violations faced by persons with albinism and the correlating obligations of States. She discussed the implications for persons with albinism, while considering the principle of the rights to equality and non-discrimination and how the intersectionality of colour and disability aggravates the experience of discrimination faced by persons with albinism.

24. The Independent Expert also discussed the rights to life and to freedom from torture, the importance of combating impunity and the efforts made to combat harmful practices and trafficking in body parts. She also looked at specific aspects of the rights to health, education, housing and work, and the situation of women and children impacted by albinism. The Independent Expert also considered how some aspects of international refugee law have been applied to persons with albinism. She also set out relevant international human rights treaties of general and specific applications and provided an interpretative aid on the jurisprudence emerging from a variety of treaty bodies and other international human rights mechanisms, including those dealing specifically with persons with albinism.

¹¹ Available from www.panafricanparliament.org/index.php/news-and-events/50-resolutions-of-the-second-ordinary-session-of-the-fifth-parliament.

¹² Preliminary data was gathered in collaboration with an independent advocacy and research group working with the mandate of the Independent Expert, namely, Miranda Forsyth and Ibolya Losoncz (Australian National University) Gary Foxcroft and Louise Meincke (Witchcraft and Human Rights Information Network), Kirsty Brimelow (Doughty Street Chambers), Charlotte Baker (University of Lancaster), Philip Gibbs (Divine Word University, Papua New Guinea), Leethen Bartholomew (National FGM Centre, United Kingdom of Great Britain and Northern Ireland). Many others have contributed indirectly to this project and will be listed in a forthcoming final report.

25. The Independent Expert also actively contributed to the work of the International Bar Association task force on the development of a report entitled “Waiting to disappear: international and regional standards for the protection and promotion of the human rights of persons with albinism”. In the report, regional human rights standards applicable to persons with albinism in Africa were identified. That report complemented the report of the Independent Expert on international standards relating to persons with albinism (A/72/131).

26. In 2018, the Human Rights Committee adopted general comment No. 36 on the right to life. The Independent Expert provided substantive inputs to the Committee in the lead-up to the adoption of the general comment and, as a result, specific reference was made to persons with albinism as requiring special measures of protection by the State, owing to their situation of vulnerability in certain contexts.

C. Strengthening concerted implementation efforts

27. The Independent Expert has engaged in a multitude of activities aimed at building and strengthening cooperation to discharge the priority activities of her mandate. Some of these activities are highlighted below.

1. International activities

28. The Independent Expert has driven implementation by multiplying the quantity and quality of evidence-based reports on albinism. Accordingly, she has addressed a myriad of critical issues in her thematic reports to the Human Rights Council and General Assembly as well as during official visits.¹³ She has also contributed to various United Nations and African Union resolutions and to relevant mandated reports, such as the first report of the Secretary-General on the social development challenges faced by persons with albinism (A/72/169).

29. Similarly, the Independent Expert has closely contributed, followed and in some cases participated in the work of the treaty bodies, including the Committee on the Rights of Persons with Disabilities, the Committee on the Elimination of Racial Discrimination and the Human Rights Committee (see para. 26 above). She presented the situation of persons with albinism to the Committee on the Elimination of Racial Discrimination and the Committee on the Rights of Persons with Disabilities and submitted a contribution to the Committee on the Rights of Persons with Disabilities in the context of the elaboration of its general comment No. 6 (2018) on equality and non-discrimination. She also encouraged and facilitated the contributions of civil society organizations to the treaty bodies at various stages of their work. As a result, albinism has been addressed by most of the Committees, including in multiple observations and recommendations made by the Committee on the Rights of Persons with Disabilities, the Committee on the Elimination of Racial Discrimination, the Committee on the Rights of the Child, the Committee on Economic, Social and Cultural Rights, the Human Rights Committee, the Committee against Torture and the Committee on the Elimination of Discrimination against Women. The issue of albinism has also been addressed in the context of the universal periodic review, as a result of various engagements by the Independent Expert. Over the past seven years, around 100 recommendations have been made under the universal periodic review mechanism in relation to albinism.

30. The Independent Expert has also collaborated with other special procedure mandate holders and senior United Nations representatives, including the Special Representative of the Secretary-General on Violence against Children, the Special Envoy of the Secretary-General on Disability and Accessibility, the Special Rapporteur on the rights of persons with disabilities, the Special Rapporteur on violence against women, its causes and consequences, the Special Rapporteur on extrajudicial, summary or arbitrary executions, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance. Such cooperation took the form of joint statements, joint communications, co-organization of events, joint research and fieldwork and joint reports, among others. Some examples are provided below.

¹³ See www.ohchr.org/EN/Issues/Albinism/Pages/Documents.aspx.

31. Between 2018 and 2019, the Independent Expert actively contributed to the global thematic report of the Special Representative of the Secretary-General on Violence against Children, which was presented at the high-level political forum on sustainable development in July 2019. She also joined the Special Representative in a side event in the margins of the fortieth session of the Human Rights Council, at which she gave a presentation on emerging forms of violence against children, particularly harmful practices related to accusations of witchcraft and ritual attacks and how they affect children with albinism worldwide. She was also invited to participate in various events organized by other mandate holders.

32. On 29 October 2020, the Independent Expert engaged with the Special Envoy on Disability and Accessibility to discuss the impact of the coronavirus disease (COVID-19) pandemic on persons with disabilities in Africa. She provided information on the situation of persons with albinism, which has been largely underreported during the pandemic.

33. In addition, through numerous dialogues with Member States during and in the margin of sessions of the General Assembly and the Human Rights Council, the Independent Expert has ensured the continued inclusion of albinism in the international debate. She has cooperated with OHCHR in the organization of events to promote the implementation of the Regional Action Plan; with the Office of the United Nations High Commissioner for Refugees to develop guidelines to ensure the well-being and safety of persons with albinism who are refugees or in a situation of displacement; and with the United Nations Interregional Crime and Justice Research Institute to address the criminal aspects of attacks against persons with albinism.¹⁴ She has also held regular and ongoing engagements regarding the implementation of the Regional Action Plan with representatives of UNESCO, UNICEF, the United Nations Population Fund, IOM, the United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women), the United Nations Development Programme, OHCHR and several others, forming part of various United Nations country teams. Countless other engagements have been held with civil society organizations, academia and non-traditional partners, including film producers, radio and television media and other stakeholders.

2. Best practices

34. In accordance with Human Rights Council resolution 28/6 and the specific request therein to promote good practices, in 2020 the Independent Expert presented her report to the General Assembly (A/75/170) with an accompanying addendum of best practices in the protection of human rights of persons with albinism.¹⁵ The compilation of best practices is a tool for States and other stakeholders to learn about and replicate measures that will ensure the effective protection of persons with albinism.

3. Global alliance on albinism

35. In January 2020, the Independent Expert, together with partner organizations, created the first global alliance on albinism in Paris.¹⁶ The alliance brings together representatives of organizations of persons with albinism from all the regions of the world to address some of the priority issues identified in the Independent Expert's report on albinism worldwide (A/74/190 and Corr. 1.)

4. Regional activities

36. In line with her priorities, the Independent Expert has also focused on cooperation with various regional actors. Her engagement in Africa has been significant, owing to the attacks reported in the region.

¹⁴ See www.unicri.it/situation-analysis-human-rights-and-protection-persons-albinism-mozambique-special-focus-human-trafficking.

¹⁵ Available from www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx.

¹⁶ In collaboration with Genespoir association française des albinismes and the National Organization for Albinism and Hypopigmentation, United States of America, and with the support of Open Society Foundations and Under the Same Sun.

37. The Independent Expert initiated, supported, co-organized and led several events and activities to drive the implementation of the Regional Action Plan. They included deep bilateral and multilateral engagement with the African Union Commission, the African Commission on Human and People's Rights, the African Committee of Experts on the Rights and Welfare of the Child, the Pan-African Parliament, Governments, national human rights institutions and non-governmental actors, including academia and organizations representing persons with albinism. She has also engaged with subregional economic communities such as the Southern African Development Community and the East African Community. These engagements have resulted in resolutions, reports and advocacy, often for the first time, on the protection of persons with albinism.

38. The Independent Expert has also provided technical support and capacity-building for the nascent Pan-African Albinism Alliance. This initiative started in 2015 during the Pan-African albinism conference held in Dar-es-Salaam. Its general objectives are, inter alia, to strengthen organizations of persons with albinism across Africa and to build a platform for advocacy and the exchange of information.

5. National activities

39. The Independent Expert has facilitated the replication of the "Kenya" model across the continent. The model ensures a national plan on albinism with a multi-year budget. The Independent Expert has promoted the establishment of national task forces to drive the creation of national action plans on albinism, using the Regional Action Plan as a guide. The task forces are multisectoral, involving organizations representing persons with albinism, government agencies, national human rights institutions and representatives from the relevant sectors, such as disability, health, education and the private sector. The national task forces advocate for a specific budget for their work and for the implementation of the national action plan. The budgetary support for such action plans on albinism may be for the medium or long term, depending on the situation of each country. The budget disbursed for such measures may be dispensed to the department in charge of disabilities, specifically a disabilities council or commission, which in turn dispenses the funds. This ensures that the issue of albinism is mainstreamed from the human rights perspective into the sector on the human rights of persons with disabilities, whose standards are set by the Committee on the Rights of Persons with Disabilities. It also provides an opportunity for the appointment of a specific programme officer on the rights of persons with albinism, who is located at the disabilities commission or council and who may oversee the funding with internal oversight from the commission or council, while being accountable and accessible to the constituency of persons with albinism. The Independent Expert has supported the development and functioning of this model through direct engagement and technical and advisory support in Malawi, Mozambique, South Africa and Uganda. To date, aside from Kenya, only Malawi has successfully adopted the model, while others in the region are in the process of doing so or have yet to begin (South Africa and Uganda). It is worthy of note that the African Union policy on albinism, which will take over from the Regional Action Plan in 2021, is scheduled to run for 10 years, in parallel with the timeline of the Sustainable Development Goals, which have at their core the pledge to leave no one behind.

40. The principal tool to orient and weigh in on the national agenda have been country visits. The Independent Expert visited Malawi and Mozambique in 2016, Fiji and the United Republic of Tanzania in 2017, Kenya in 2018 and Brazil and South Africa in 2019. These visits provided crucial opportunities for her to raise awareness and to seek information in situ on the situation of persons with albinism in those countries. In addition, the Independent Expert delved into issues around accessibility and reasonable accommodation concerning persons with albinism in the framework of standards established by the Committee on the Rights of Persons with Disabilities, particularly in the education and employment sectors. She also assessed the framework concerning health, given that skin cancer is one of the main causes of deaths for persons with albinism in countries with warm or tropical climates. Finally, she assessed criminal laws for their adequacy in the light of physical and verbal attacks and threats, the desecration of graves, trafficking in body parts and harmful practices related to accusations of witchcraft and ritual attacks. In countries without a record of attacks, the Independent Expert has highlighted priority areas for intervention in the enjoyment of the right to health and non-discrimination for persons with albinism.

41. The visits of the Independent Expert, in particular to Malawi, Mozambique and the United Republic of Tanzania, have highlighted regional trends and the correlating need to reinforce regional or subregional cooperation. That has been taken into account by international organizations which, for example, organized in Mozambique a two-day regional forum to address trafficking related to persons with albinism in Malawi, Mozambique and the United Republic of Tanzania.

42. One example of the impact on the national agenda of the country visits undertaken by the Independent Expert is the case of Malawi, where many of the recommendations she made were implemented by the Government and other actors. For instance, both the Penal Code and the Anatomy Act were amended after her visit to address concerns raised during the visit. Furthermore, a practice direction on sentencing guidelines was issued in May 2016 by the Chief Justice.

43. Furthermore, in follow-up to the recommendation of the Independent Expert for the appointment of stronger leadership on the issue, a National Technical Committee on Albinism was established in Malawi, chaired by the Chief Presidential Adviser, Dr. Ntaba, with the Committee secretariat located in the Department of Disability. In 2020, the new Government of Malawi also appointed a person with albinism as a close adviser to the President and another was appointed as a Commissioner on the National Commission on Human Rights. These appointments are welcomed by the Independent Expert because cases of physical attacks, the desecration of graves and trafficking continue to be reported in Malawi (see A/HRC/34/59/Add.1).

44. In addition, following the Independent Expert's visit to Malawi, the "human rights window" of the United Nations in the country supported the establishment of community-based protection systems in various provinces, together with psychosocial support. The window was also used to support the implementation of the country's 2015 response plan to end attacks and to implement the recommendations of the Independent Expert. In addition, 148 police prosecutors, investigators and magistrates were trained, a handbook for prosecutors on cases of attacks against persons with albinism was developed, community police forums were strengthened and basic protection devices (including torches and whistles) were given to persons with albinism.

45. A partnership for the local production of sunscreen is being contemplated between the Government of Malawi and Kilisun, which produces a sunscreen adapted to the needs of persons with albinism. This process has been facilitated by the United Nations country team in the light of specific recommendations made by the Independent Expert regarding access to health care. As of 2018, the pilot project to produce sunscreen was completed and production with the support of the Government is anticipated. The Independent Expert has facilitated similar processes in several countries, including Angola, Malawi and Mozambique.

46. With the technical and advisory support of the Independent Expert, after her official mission to Kenya and in collaboration with OHCHR and civil society representing persons with albinism, Kenya included a specific indicator on persons with albinism in the 2019 national census, a process which disclosed that government efforts on albinism were reaching less than half the population of persons with albinism in the country. The Independent Expert has also provided similar technical and advisory services, including through communications sent to Member States and in collaboration with United Nations country teams in Kenya, Mozambique, South Africa and Uganda. She has also provided, upon request, comments on draft legislation, for example to national and subnational governments, including in Argentina, Brazil, Fiji and Malawi.

47. During her visit to Brazil in November 2019, the Independent Expert focused on the challenges of persons with albinism, including in indigenous communities and those who are persons of African descent. Shortly after the visit, the Ministry of Health agreed to implement one of the recommendations she had made on the right to health by directly supporting and expanding the only comprehensive health programme serving persons with albinism from the State of São Paulo to the rest of the country.

48. During her visit to South Africa in September 2019, the Independent Expert not only completed a successful fact-finding mission but also held a national consultation with over 40 civil society organizations representing persons with albinism from six provinces, nearly

all with albinism themselves (see A/HRC/43/42/Add.1). The consultation led to the establishment of a national task force on albinism comprised of those civil society participants. She also featured in various television and radio broadcasts to share the preliminary findings from her visit. Several episodes of her visit were also launched on YouTube by the OHCHR communications department and incorporated into awareness-raising programmes by the BBC and an online campaign for international awareness of albinism.¹⁷

D. Awareness-raising

49. Significant awareness-raising events on albinism have taken place globally, including around International Albinism Awareness Day. In that context, the Independent Expert has participated in and supported scores of activities. She has also collaborated with the African Commission on Human and People's Rights and various United Nations entities, including special procedure mandate holders and the OHCHR communications department, Governments and non-governmental entities to develop and execute various communication strategies during and beyond International Albinism Awareness Day, including on human rights in general.

50. The Independent Expert celebrated International Albinism Awareness Day in 2016 in Dar-es-Salaam with high-level government officials and representatives of embassies and civil society. In 2017 she attended an event organized by the Liliane Foundation in the Netherlands and an international symposium organized by the Josephat Torner Foundation in the United Kingdom.

51. In 2018, the Independent Expert co-organized a photographic exhibition in Geneva on the subject of witchcraft and human rights at the Palais des Nations. That year she also co-organized with the Permanent Mission of Sierra Leone, a photographic exhibition, including for the first week of the June session of the Human Rights Council.

52. In 2019, the Independent Expert participated in the session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, during which she held side events and consultations with various actors to spread awareness of the situation of persons with albinism as part of the constituency of persons with disabilities.

53. In June 2020, during the lockdowns imposed around the world owing to the COVID-19 pandemic, the Independent Expert led and co-organized with other partners the first online concert for International Albinism Awareness Day featuring several musicians with albinism. The concert was part of a larger campaign led by the Independent Expert and OHCHR, which engaged almost 1 million people.

54. In order to increase awareness and share information with relevant civil society organizations and other stakeholders, the Independent Expert has sent regular (often quarterly) updates on the work of the mandate, on the ways to interact with United Nations mechanisms, including the treaty bodies and special procedures, on relevant developments in international law, reports, guidelines and other documents, statements and resolutions. This regular sharing of information has been fundamental to ensuring that all organizations working on the issue remain up to date and that their work is coordinated and mutually strengthened.

55. The Independent Expert took part in and was featured multiple times in numerous interviews in community, national and international media, including the BBC, CNN, Al-Jazeera, NPR and Reuters. In addition, she participated in numerous public engagements, including interventions in a multiplicity of conferences and expert meetings, which were occasions used to raise awareness among diverse audiences, share information and promote good practices with regard to the enjoyment of human rights by persons with albinism.

56. Those engagements included participation in and carrying out of awareness-raising activities at the sixteenth national conference of the National Organization for Albinism and Hypopigmentation of the United States of America; the European Days of Albinism; a regional expert meeting on support services for persons with disabilities held in Addis Ababa;

¹⁷ See www.youtube.com/watch?v=ulkTID8uGD4 and www.bbc.co.uk/programmes/w3cszj3q.

and the fourth annual conference on disability rights in Africa, organized by the Centre for Human Rights of the University of Pretoria. The Independent Expert also took part in an event organized by the International Bar Association for the launch of its report on the international and regional legal framework on albinism. In Africa, she led, or developed alone or in collaboration with others, numerous activities to drive implementation of the Regional Action Plan, carried out awareness-raising activities, such as the symposium entitled “Action on albinism in Africa: time for implementation”, and participated in a high-level expert meeting of the Specialised Technical Committee on Social Development, Labour and Employment of the African Union in Algiers. Elsewhere, she attended two conferences in Japan and the annual conference of the Attorney General in Fiji, among many other events that are too numerous to list here.

57. In addition, the Independent Expert organized a side event, together with the United Nations Interregional Crime and Justice Research Institute, in the margins of the thirty-first session of the Human Rights Council on the root causes of attacks against persons with albinism and took part in other side events, including in the margins of the seventy-first session of the General Assembly, to mark the tenth anniversary of the Convention on the Rights of Persons with Disabilities. In March 2017, she co-organized a side event in the margins of the thirty-fourth session of the Human Rights Council on the situation of persons with albinism in Malawi, together with the Permanent Mission of Malawi to the United Nations Office and other international organizations in Geneva and Amnesty International, and participated in a side event with the Special Rapporteur on the rights of persons with disabilities and the International Disability Alliance on article 5 of the Convention on the Rights of Persons with Disabilities. In May 2017, the Independent Expert organized a panel and side event at the sixtieth session of the African Commission on Human and People’s Rights. In October 2018, during the sixty-third session of the African Commission on Human and People’s Rights, she co-organized with OHCHR a photographic exhibition on persons with albinism to promote implementation of the Regional Action Plan and highlight the issue of skin cancer, which is the primary killer of persons with albinism in Africa.

58. During the seventy-third session of the General Assembly, the Independent Expert’s presentation was filmed by David Darg, an Oscar-nominated film-maker covering various human rights topics whose work includes a recent production on Nobel Peace Prize winner Nadia Murad. The film featuring the Independent Expert, entitled Lazarus, has won awards and was featured at the Tribeca Film Festival, reaching tens of thousands of people.¹⁸

59. In 2018, the Independent Expert supported and participated in the first conference on albinism to be held in the Asian region. The conference, which she co-organized with the Nippon Foundation, was held in Tokyo and brought together various persons with albinism from Africa, North America and Asia. It was a catalyst for the engagement of the Government with civil society organizations representing persons with albinism in Japan.

60. 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.¹⁹ 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.

61. In the light of all her efforts in raising awareness of the situation of persons with albinism, the Independent Expert has received several awards in the context of her work on the mandate. In April 2020 she was the recipient of the prestigious international advocate award from the United States International Council on Disabilities. In July 2020, she was also named to the Diversability inaugural D-30 Disability Impact List, which acknowledges persons who have had a significant impact on the disability community worldwide. At the

¹⁸ See a video clip at www.youtube.com/watch?v=9_7sp8ouv1w.

¹⁹ See <http://albinism.ohchr.org>.

mid-term of her mandate in December 2017, the Independent Expert was named by *New African* in its list of 100 of the most influential Africans of the year. She was also recognized in the list of 70 women speakers globally selected in celebration of the seventieth anniversary of UNESCO.

E. Research and data collection

62. To advance the collection of data, increase the quality and quantity of research and promote evidence-based advocacy on albinism, the Independent Expert has, in close collaboration with academics from a number of universities,²⁰ initiated an international, interdisciplinary research policy network, including civil society, which has developed a prioritized agenda at the intersection of albinism, spiritual and cultural practices and human rights. This collaboration has identified gaps and will guide further work on the issue in order to inform policy, advocacy and other human rights-centred initiatives.

63. In the context of research and data collection, the Independent Expert co-organized a round table on human rights and albinism in Geneva in September 2018. The meeting brought together a large number of participants from diverse sectors, including scholars, policymakers and civil society organizations, with the aim of building and consolidating priorities for research, advocacy and policy at the juncture of albinism, spiritual and cultural practices and human rights (see A/HRC/40/62/Add.2).

64. The Independent Expert works closely with the Centre for Human Rights at the University of Pretoria to conduct research on topics of particular importance for persons with albinism, including access to justice. The Independent Expert has also engaged in research to gather information on the putative correlation between attacks against persons with albinism and political elections. She has also supervised preliminary research on other relevant topics, including on the trafficking of body parts of persons with albinism and on human rights defenders who are persons with albinism. These have been completed in collaboration with a number of academic institutions in Africa, North America and Europe.²¹

65. The Independent Expert has also expanded research and the availability of data on albinism directly through her mandated reports. In that regard, she has produced over 37 reports, academic papers and articles, of which 23 have been presented to the Human Rights Council and the General Assembly. Those reports have contributed to key themes, including the right to health, and included a detailed report on the importance of driving specific measures for the protection of persons with albinism in the 2030 Agenda for Sustainable Development and its fundamental pledge to leave no one behind. She has also submitted a preliminary report on some of the root causes of attacks against persons with albinism, such as poverty and ignorance of the condition of albinism (A/HRC/34/59). Of all the root causes identified, harmful practices that are related to accusations of witchcraft and ritual attacks are some of the most challenging to conceptualize and to tackle. The Independent Expert has also provided and continues to provide technical and advisory services and support to several key research programmes in South America, Europe and Africa.

66. To further the discussion on harmful practices, in Geneva in September 2017 the Independent Expert organized the first-ever workshop to discuss witchcraft and human rights in a systematic manner. The two-day workshop brought together over 100 United Nations experts, academics and members of civil society to discuss the violence associated with such beliefs and practices and their impact on groups in vulnerable situations, including persons with albinism. The workshop concluded with the identification of best practices, recommendations and suggestions for the way forward (see A/HRC/37/57/Add.2). Following

²⁰ Sheryl Reimer-Kirkham, Barbara Astle, and Emma Strobell (Trinity Western University, Canada), Lori Beaman (University of Ottawa), Wisdom Tettey (University of Toronto, Canada), Bonny Ibhawoh (McMaster University, Canada) and Kristi Panchuk (University of British Columbia, Canada). The collaborators were Duncan Dixon and Rick Sawatzky (Trinity Western University). Funding was provided by the Social Sciences and Humanities Research Council of Canada and the Under the Same Sun Fund.

²¹ The Universities of Pretoria and Toronto, the Geneva Academy, Trinity Western University and Kwantlen University Polytechnic.

up on the workshop, a side event on the theme of “Violence against children: witchcraft beliefs and practices” was co-organized by the Independent Expert and the Special Representative of the Secretary-General on Violence against Children in the margins of the thirty-seventh session of the Human Rights Council.

67. In January 2019, the Independent Expert supported a follow-up workshop in the United Kingdom, at which a historical and interdisciplinary perspective on the issue of witchcraft and human rights was emphasized, along with the human rights and sociological implications. The Independent Expert subsequently formed an independent research and advocacy group on witchcraft and human rights with several academic and advocacy groups (see para. 22 above), through which research and data on the issue are being gathered, consolidated and inserted into relevant processes, such as the drafting of regional guidelines on harmful practices related to accusations of witchcraft and ritual attacks and under the Human Rights Council.

68. The collection of statistical data is a recommendation that has been reiterated by the Independent Expert in her country visit and thematic reports. She has repeatedly highlighted the good practice of inserting into the national census and survey a specific indicator for persons with albinism. In February 2019, in consultation with the Independent Expert, the Washington Group on Disability Statistics published a comment on how States might achieve this in their data collection.²² The Independent Expert has subsequently successfully supported this process in Kenya in collaboration with the OHCHR Human Rights Adviser. Other countries are following suit.²³

69. The creation of the mandate by the Human Rights Council and the work of the Independent Expert appear to have had a significant impact on the increase in research and scholarship on albinism from a human rights perspective. In January 2018, a search of academic articles under this category, going back in time indefinitely, yielded around 83 articles, of which 46 per cent used the phrase “human rights” and 45 per cent were written by an African, an important indicator given the extreme human rights violations reported in that region. During the writing of the present report, a search using the same keywords was rerun, covering the period from January 2018 to October 2020. Forty-six articles were found with over 70 per cent using human rights terminology and 59 per cent written by Africans. That represents a significant increase in just over two years.

IV. Challenges and limitations

Resource constraints

70. 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.²⁴ That is an important point

²² See www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/.

²³ Malawi included persons with albinism in its most recent census, with the support of the United Nations country team. Other countries, including Nigeria and Uganda, have conducted baseline studies. For more best practices in data collection, see the addendum to A/75/170 on best practices in the protection of human rights of persons with albinism, available from www.ohchr.org/EN/Issues/Albinism/Pages/Reports.aspx.

²⁴ The Independent Expert would like to thank the Open Society Foundations and their regional offices across Africa, Under the Same Sun, the Ford Foundation, the international human rights programme at the University of Toronto, the Centre for Human Rights at the University of Pretoria and the Social Sciences and Humanities Research Council of Canada for contributing human and financial resources and providing in-kind support to the mandate on a large scale or multiyear basis. She is also grateful to the Africa Group, in particular the Permanent Mission of Somalia, the Permanent Mission of Sierra

in terms of management of expectations as to what might be achievable in the absence of such significant extrabudgetary 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.

71. On a regional and national level, civil society organizations working on issues related to albinism have reported dire financial situations. A recent human rights training session for civil society organizations in Africa revealed that the COVID-19 pandemic had exacerbated the situation and programmes and workplans in the region had been hampered.

72. The Independent Expert is concerned about the short- to medium-term effects of the COVID-19 pandemic on future resource mobilization efforts, should the mandate be continued. Resources are needed to continue the important work of implementation of the Regional Action Plan among other concrete changes in the lives of persons with albinism. Given the minority status of persons with albinism in terms of population, every effort should be made to improve the financial and other resources allocated to this work, particularly in the area of protection from attacks and skin cancer, as outlined in particular measures of the Regional Action Plan, and to facilitate the implementation of recommendations made concerning persons with albinism in other regions such as South America and Asia (see A/74/190).

Capacity of civil society working on the issue

73. Civil society organizations working on the promotion and protection of human rights of persons with albinism not only face a shrinkage in resources but also tend to grapple with relatively weak capacity in human rights advocacy related to albinism. That is due to several factors, including an absence of coordination in the constituency, the relatively small number of persons with albinism and their dispersion, which requires deliberate efforts (often weak or absent) to include them in discourses that concern them. Thankfully, over the last two decades, well over 200 organizations of persons with albinism have been formed worldwide, creating loci and entry points to include them. In the light of a global reduction in the allocation of resources to human rights initiatives worldwide, it is likely that there will be a lesser allocation of resources to support issues related to persons with albinism, not only at the United Nations but also generally. The Independent Expert reiterates the central and complementary role of civil society organizations, particularly non-governmental organizations and academia, health and faith-based actors, in promoting the rights of persons with albinism, particularly in concretely advocating for and implementing specific measures and appeals for targeted efforts to involve them in capacity-building, including training on advocacy and human rights.

Tackling root causes and impunity

74. The Independent Expert underscores the need to continue to tackle the root causes of human rights violations against persons with albinism, particularly the attacks and related human rights violations which have continued to date. In addition, she notes that unless impunity is eliminated and perpetrators, including the masterminds, are prosecuted swiftly, such violations will be likely to continue. The need to adopt guidelines on harmful practices related to accusations of witchcraft and ritual attacks and the proposed resolution on the subject for consideration by the Human Rights Council is now more crucial than ever because COVID-19 protection measures have tended to fuel further attacks during lockdowns and in the context of similar restrictions.

75. Further, in the context of protection and accountability measures, the Independent Expert proposes that attacks on and violations of the human rights of persons with albinism should be considered a hate crime on the basis of colour. That is an area that the Committee

Leone, and to the Permanent Missions of Canada, Israel, Kenya, Nigeria and Portugal and the European Union delegation for their moral support over the past six years. She is particularly grateful to OHCHR for their support in building this work from the ground up.

on the Elimination of Racial Discrimination can support through a commentary or guidance in the context of persons with albinism. The Special Rapporteur on extrajudicial, arbitrary or summary executions has noted that the killings of persons with albinism should be treated as hate crimes and States should adopt a range of measures, including legal, investigatory, sentencing and protection, as safeguards (A/HRC/37/57/Add.2, para. 28). Aggravating factors that should be considered when determining hate crimes should include the harm to victims, their extreme vulnerability and the motivations of the attackers. As such, States must do everything in their power to prevent killings related to witchcraft, including harmful stereotyping and discrimination.

Need for stronger political will

76. The political will of stakeholders, particularly States, is crucial to ensuring that the multifaceted, multisectoral approach and the partnerships that have been built throughout the existence of the mandate continue to be effective in protecting and promoting the enjoyment of human rights by persons with albinism. States that the Independent Expert has visited on official visits must ensure the implementation of the recommendations made to ensure persons with albinism are protected and included in decisions affecting them. The relatively low cost of intervention needed to produce a positive transformation in the lives of persons with albinism, in addition to the global pledge to leave no one behind, should suffice to motivate States to support this issue, including by carrying out the recommendations set out below.

V. Conclusion and recommendations

77. Numerous and high-quality achievements have been accomplished since the establishment of the mandate. That is indicated by the significant progress on all elements of the vision set out for the mandate six years ago. Specific measures are now in place in Africa, as developed by the Independent Expert with other stakeholders under the rubric of the Regional Action Plan on Albinism in Africa (2017–2021), which is to be replaced by the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031). Hundreds of mass awareness-raising events and activities led by or involving the Independent Expert through traditional and social media, official country visits and numerous cultural events she has initiated or supported have reached millions of persons globally and in Africa in particular. The Independent Expert has also effectively drawn in a wide array of partners from various public, private, governmental and non-governmental sectors to drive the implementation of the Regional Action Plan and the recommendations made in her reports to support persons with albinism, particularly in South America and Asia. Research and data on the situation of persons with albinism across six continents incorporating a human rights perspective have also improved and increased remarkably over the period of the mandate. Data, particularly from census and surveys, as well as qualitative data on albinism around the world are now available in a manner that was lacking prior to the establishment of the mandate. Training of persons with albinism through multi-level engagement with their representative organizations has amplified their voices and equipped them to participate in discourses pertaining to them. Extensive pioneering work has also been undertaken to tackle harmful practices related to accusations of witchcraft and ritual attacks as a root cause of attacks on and violations of the human rights of persons with albinism.

78. However, significant challenges remain. The full implementation of the Regional Action Plan is still to take place and the adoption of long-term measures to address harmful practices in this context are necessary. Recommendations made by the Independent Expert to States and stakeholders in her previous reports are largely still to be implemented. Furthermore, discrimination against and stigmatization of persons with albinism continue. Resource constraints hamper efforts to improve the participation and advocacy of persons with albinism in processes that affect them. The Independent Expert hopes that continued efforts will be made to carry out these recommendations, particularly efforts to integrate the situation of persons with

albinism into relevant sectors including, but not limited to, disability, health, education, racial discrimination, rare conditions, criminal law, including on hate crimes, trafficking in persons and other harmful practices. That often means the adoption of laws, policies and specific measures, including those set out below.

79. The Independent Expert recommends that Member States:

(a) Undertake data collection and situational analysis and support participatory research to better understand the human rights situation of persons with albinism;

(b) Support sustained multi-year efforts in public education on albinism, including through International Albinism Awareness Day and particularly in rural and remote areas, as well as border communities, to provide relevant information about albinism, including the scientific reasons concerning albinism and the human rights of persons with albinism;

(c) Ensure that any act of discrimination against persons with albinism is adequately and proportionally sanctioned, including by considering “colour” as a ground of discrimination under domestic legislation and considering attacks on and killings of persons with albinism as a hate crime;

(d) Address resource shortages by establishing a fund aimed at leaving no one behind, supporting the participation of groups recognized among those “left behind” and “furthest behind” in the framework of the Sustainable Development Goals. That can ensure that the pledge to leave no one behind is truly fulfilled. The fund could also support capacity-building of civil society groups representing persons with albinism so that the vicious cycle of their marginalization is addressed;

(e) Implement measures to address the situation of women and children impacted by albinism as laid out in the thematic report by the Independent Expert (A/HRC/43/42) and those highlighted in her other thematic reports to the Human Rights Council and the General Assembly;

(f) Ensure the full implementation of recommendations made by the Independent Expert to Member States where official country visits were undertaken;

(g) Ensure reasonable accommodation measures and the full enjoyment by persons with albinism of their rights to the highest standards of physical and mental health, education, adequate housing and decent work;

(h) Ensure the full and meaningful participation of persons with albinism in the elaboration and implementation of all measures and initiatives concerning them, in particular national plans and legislation, and appoint them to senior public posts;

(i) Consider adopting a draft resolution on harmful practices related to accusation of witchcraft and ritual attacks to strengthen the protection of persons who are vulnerable to such forms of violence, including persons with albinism;

(j) Continue to support States and civil society organizations working on albinism where attacks have been reported, including through capacity-building, data gathering and, as needed, law enforcement, including investigative techniques and forensic analysis;

(k) Continue to monitor and report on the rights of persons with albinism in international human rights mechanisms, including treaty bodies and the universal periodic review;

(l) Support the replication of policies based on best practices, including those elaborated in the addendum to the report being submitted by the Independent Expert to the General Assembly at its seventy-fifth session;

(m) Support efforts for the effective realization of reasonable accommodation for vision impairment and the right to an adequate standard of health of persons with albinism in order to eliminate deaths due to skin cancer;

(n) Ensure that all actions taken in regard to albinism are carried out with a human rights approach and in cognizance of the intersecting character of applicable rights and the correlating need to bring multisectoral stakeholders, who are among those who are the furthest behind, into the process to guarantee both issue integration and specific programming.

80. The Independent Expert recommends that States with records of attacks:

(a) Domesticate and implement the Regional Action Plan (and the African Union version once it is validated in 2021) and provide a specific budget for implementation;

(b) Support the mandate of the Special Envoy on albinism of the African Union once a mandate holder is appointed;

(c) Ensure prompt investigation and prosecution of cases of attacks on and crimes against persons with albinism, including desecration of graves and exploitation in all forms, including trafficking in persons and in body parts;

(d) Adopt the guidelines on harmful practices related to accusations of witchcraft and ritual attacks once they are adopted by the Pan-African Parliament or a relevant African Union body;

(e) Ensure that any act of discrimination against persons with albinism is adequately and proportionally sanctioned under domestic legislation and treat attacks and killings of persons with albinism as a hate crime;

(f) Develop and implement long-term awareness-raising campaigns as these are critical for addressing harmful practices related to accusations of witchcraft and ritual attacks and all forms of violations of the rights of persons with albinism.

81. The Independent Expert recommends that civil society organizations:

(a) Incorporate and prioritize the human rights approach in advocacy, public education, research and all other domains of work to mitigate the negative consequences of the medical or charity approach to persons with disabilities, who include persons with albinism;

(b) Collaborate with key actors, advocates, experts and researchers in relevant domains, including disability, health, education, racial discrimination, rare conditions, criminal law, including on hate crimes, trafficking in persons and other harmful practices;

(c) Develop national, regional and global collaboration platforms to promote national, regional and global action plans on albinism and promote and replicate best practices;

(d) Include the human rights situation of persons with albinism in national, regional and international human rights and development forums and initiatives in a coherent, strategic and effective manner.

82. The Independent Expert recommends that international organizations, donors and businesses:

(a) Support the work of civil society groups representing persons with albinism with technical and financial assistance to strengthen and develop their capacity to enable their transition from volunteer-driven organizations to robust organizations with dedicated personnel. That will help such organizations undertake human rights work and advocacy effectively in relevant human rights forums, particularly in countries where human rights violations are extreme and need to be monitored and reported;

(b) Seek out and include organizations representing persons with albinism in capacity-building and training activities relating to human rights generally and in specific domains such as disability, health, education, racial discrimination, rare conditions, criminal law, including on hate crimes, trafficking in persons and other harmful practices;

(c) **Deliberately seek out and include persons with albinism in all public discussions on human rights, including relevant national and international mechanisms and processes, as well as in regional forums tasked by the United Nations to follow up on the implementation of the Sustainable Development Goals.**
