Human Rights Council
Thirty-seventh session
26 February–23 March 2018
Agenda item 3
Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development


Note by the Secretariat

The report of the Independent Expert, which draws on the information she gathered during her visit, focuses on the challenges that must still be addressed to lower the number of reported attacks against persons with albinism in the United Republic of Tanzania. The Independent Expert also discusses other aspects of the situation, such as discrimination against persons with albinism, particularly in the areas of health and education, as well as the situation of persons with albinism living in designated schools. She highlights the important steps taken by the Government to address these issues and makes recommendations for strengthened efforts, including by addressing implementation gaps and removing barriers to the enjoyment of human rights by Tanzanians with albinism.
Report of the Independent Expert on the enjoyment of human rights by persons with albinism on her mission to the United Republic of Tanzania*

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* Circulated in the language of submission only.
I. Introduction

1. In accordance with the mandate set out in Human Rights Council resolution 28/6 and at the invitation of the Government of the United Republic of Tanzania, the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, conducted an official visit to the United Republic of Tanzania from 18 to 28 July 2017. The objective of the visit was to assess the human rights situation of persons with albinism throughout the country, with particular attention to be given to the relatively high number of reports of attacks against them.

2. During her visit, the Independent Expert travelled to the cities of Dodoma, Dar es Salaam, Mwanza, Shinyanga, Kigoma and Kasulu. She met with the Speaker of the National Assembly, the Attorney General, the Deputy Minister in the Office of the Prime Minister responsible for policy, parliamentary affairs and matters involving labour, employment, youth and persons with disabilities, the Chair of the Commission for Human Rights and Good Governance and representatives of the Ministry of Education, Science, Technology and Vocational Training, the Ministry of Health, Community Development, Gender and Children, the Ministry of Constitutional Affairs and Justice, the Ministry of Finance and Planning, the Ministry of Foreign Affairs and East African Cooperation, the President’s Office for Regional Administration and Local Government, the National Bureau of Statistics and the Tanzania Police Force, including community police. She also met with officials from the municipalities of Shinyanga and Kigoma and head teachers and staff members of schools designated as shelters, including Buhangija and Lake View — both in Mwanza — and Kabanga in Kasulu.

3. In addition, the Independent Expert met with academics and civil society organizations, particularly those representing persons with albinism, such as the Tanzania Albinism Society. Most importantly, she visited numerous persons with albinism, including victims of attacks, to hear from them about their enjoyment of their human rights. She also met with the United Nations country team and the heads of cooperation and foreign missions resident in the United Republic of Tanzania and active in the donor community. She observed the provision of health services to persons with albinism by civil society and government institutions in Mwanza and at Ocean Road Cancer Institute in Dar es Salaam.

4. The Independent Expert is grateful to the Government of the United Republic of Tanzania for its cooperation. In particular, she notes that her visit was the first official visit by a special procedure mandate holder that the country had agreed to in nine years. She is also grateful to all her interlocutors, especially persons with albinism, who shared their collective experience and individual perspectives with her. She looks forward to fruitful and continued dialogue with the Government and other stakeholders on the implementation of the recommendations contained in the present report.

5. The Independent Expert thanks the United Nations country team, particularly the Office of the Resident Coordinator and the United Nations Educational, Scientific and Cultural Organization (UNESCO), for their effective logistical, administrative and substantive support. She would also like to thank the Ministry of Foreign Affairs and East African Cooperation for coordinating all official meetings.

II. Background

A. General overview

6. The United Republic of Tanzania was formed as a sovereign State in 1964 through the union of the States of Tanganyika and Zanzibar. The country is composed of the Mainland — the vast majority of the territory — and Zanzibar, United Republic of Tanzania, which has autonomy over non-union matters in the archipelago. In 1974, Dodoma was designated the official capital of the country. However, it shares the seat of government and administrative offices with Dar es Salaam.
7. In October 2015, John Pombe Magufuli was elected the fifth President of the United Republic of Tanzania. The executive branch of the Government comprises the President, the Vice-President, the President of Zanzibar, the Prime Minister and the Cabinet.

8. The United Republic of Tanzania is bordered by Kenya and Uganda to the north, Rwanda, Burundi and the Democratic Republic of the Congo to the west, Zambia, Malawi and Mozambique to the south and the Indian Ocean to the east. Attacks against persons with albinism have been reported in all countries bordering the United Republic of Tanzania.¹

9. Political stability has provided a solid foundation for growth (averaging 6 to 7 per cent a year) in the past decade, according to an overview of the country published by the World Bank.² Despite this growth, however, reducing poverty and maternal mortality is still a major challenge, as the social and economic dividends of the country’s growth have not reached the majority of the population. Key challenges identified in the United Nations Development Assistance Plan (2016–2021) included the need to improve the quality and scale of health care, education and other social services to cope with rapid population growth, the need to reach marginalized groups and the need to address a number of governance issues, including the protection of vulnerable groups.

10. Government efforts to increase tax receipts, including by eliminating exemptions, curbing evasion and combating corruption, have enabled ongoing public investment. According to the Tanzanian anti-corruption agency, however, corruption is still prevalent, and the efforts made to combat it are not entirely sufficient.³ A special court with jurisdiction over cases of alleged corruption (the Corruption and Economic Crimes Division of the High Court) was established in September 2016.

11. In addition, according to the Office of the United Nations High Commissioner for Refugees, there are 198,000 registered refugees, many from Burundi and the Democratic Republic of the Congo, residing in the United Republic of Tanzania.

B. Persons with albinism

12. Although there are people with albinism throughout the world, the impact of the condition on human rights and the way it is perceived by others, including its effect on social inclusion, vary from region to region. Albinism is non-contagious, genetically inherited and affects people regardless of race, ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in any part or all of the skin, hair and eyes. Persons with albinism therefore often appear pale in comparison to members of their family and their communities. Today, it is estimated that in Europe and North America there is one case of albinism for every 17,000 to 20,000 births. In sub-Saharan Africa, the reported frequency ranges from 1 in 5,000 to 1 in 15,000 births, with prevalence rates of 1 in 1,000 for selected populations. A higher frequency has been reported in parts of the Pacific (1 in 700) and among some indigenous peoples in North and South America (1 in 70 to 1 in 125).

13. There are different types of albinism. The best-known type is oculocutaneous albinism, which affects the skin, hair and eyes. Within this type are subtypes that may reflect varying degrees of melanin deficiency. A lack of melanin in the eyes results in high sensitivity to bright light and significant vision impairment, with the level of severity varying from one person to another. This vision impairment often cannot be completely corrected. In addition, one of the most serious health implications of albinism is vulnerability to skin cancer, which is still a life-threatening condition for most persons with albinism in certain regions. All violations of civil and political rights relating to albinism

¹ Information on those attacks is available from www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%20extended%20version.pdf.
reported to date have been linked to its oculocutaneous form, which is also the most visible form.

14. Under international human rights law, persons with albinism enjoy normative protection covering all their fundamental human rights, including the right to life, physical integrity, liberty and security, the right to the highest attainable standard of physical and mental health and the right to an adequate standard of living. Further protection is afforded by the Convention on the Rights of Persons with Disabilities and the International Convention on the Elimination of All Forms of Racial Discrimination, which proscribes “racial discrimination” on the basis of colour.

15. According to the National Bureau of Statistics, the population of the United Republic of Tanzania, as ascertained by the country’s most recent census, in 2012, was 44.9 million, including 16,477 people with albinism. In 2017, the population of persons with albinism was estimated to be around 18,000. However, both Tanzanians with albinism and the Government agree that those numbers are likely to be well under the reality, given the practical and methodological limitations of the census. The remotest areas could not be reached, and it was reported that some persons with albinism may have been hidden by their families when the census was conducted. In addition, a number of persons with albinism interviewed reported not being counted or interviewed at the time of the census. The Independent Expert also received information regarding the significant disparities between census figures for males with albinism (1 in 2,341 nationally and 1 in 2,558 for the group aged 0 to 19 years) and those for females with albinism (1 in 3,032 nationally and 1 in 3,900 for the group aged 0 to 19 years). Although the disparities could be linked to flaws in data collection, they merit further study.

16. The Independent Expert commends the fact that the census included a specific category for albinism, separate from other categories, such as visual impairments. The inclusion of that census category is a best practice in the region. The data from the 2012 population and housing census thus allowed the National Bureau of Statistics to draw conclusions on albinism in its Disability Monograph, published in 2016, which analyses and provides information on albinism and difficulties in such domains as seeing, hearing, walking, remembering and self-care.

17. Recognizing the need for comprehensive data, the Government, in cooperation with the Tanzania Albinism Society, is planning to collect data based on existing administrative records. Although it may not be possible to reach the remotest areas, and although many persons with albinism, given the stigma they must deal with and the poverty and exclusion that are often their lot, may not have administrative records, it is important to complement existing data and ensure that they are disaggregated to fully understand the situation of the human rights of persons with albinism.

18. The Independent Expert is acutely aware of the sensitive nature of information and data regarding persons with albinism, in particular where such information may reveal their whereabouts, and calls for high standards of data protection in this regard.

III. Legal and institutional framework

A. Legal framework and policies


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4 Population and housing census report of 2012.
20. The country has yet to ratify the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. In addition, the Independent Expert notes that, although the United Republic of Tanzania has ratified the Convention on the Rights of Persons with Disabilities, it has not yet submitted its initial report on its efforts to implement the Convention to the relevant Committee. The Attorney General’s Office has expressed its intention to finalize the report shortly.

**Attacks**

21. Although the country does not have specific legislation on attacks against persons with albinism, its legislative framework includes a number of relevant provisions.

22. The provisions of the Penal Code addressing murder, assault and grievous bodily harm, attempted murder, abduction, conspiracy to murder and kidnapping, for example, have been used to prosecute persons responsible for attacks against persons with albinism. Article 128 of the Code can also be invoked, as it criminalizes disinterring, dissecting or causing damage to the dead body of any person. The Attorney General’s Office has also prosecuted persons found in possession of body parts.

23. The Anti-Trafficking in Persons Act (2008) and its regulations adopted in July 2015 protect Tanzanians from any threat of violence and exploitation and seek to eliminate trafficking in persons, including for the purpose of organ removal. Article 3 of the Act states that “organs” include any part of the human body that can be removed and used to sustain life or for any purpose. The trafficking of body parts for muti or juju could thus be covered by the Act. However, although the provisions of the Act would apply in the event that a person was moved by abduction, coercion or deception for the end goal of organ removal, they would not apply to the trafficking of body parts that were harvested from a victim who was not moved, as is often the case with persons with albinism. In other words, persons caught with body parts from a person with albinism murdered but not moved could not be charged under the Act.

24. The Law of the Child Act (2009) is also important, as the majority of persons with albinism who are victims of attacks in the United Republic of Tanzania are reportedly children. The Act seeks to protect children by incorporating elements essential to the development of a protective environment, including a child-protection framework to prevent and respond to abuse, violence, exploitation and neglect. It also seeks to implement a child-friendly justice system.

25. The Witchcraft Act, although outdated, contains criminal provisions addressing the practice of witchcraft, which is a root cause of the attacks. The Act provides for the punishment of anyone who purports to have the power of witchcraft, makes, uses or has in his or her possession any instruments of witchcraft, supplies to any other person any instrument of witchcraft, advises any other person upon the use of witchcraft or any instrument of witchcraft or threatens to use or resorts to the use of witchcraft. “Instruments of witchcraft” are defined broadly and would probably include anything generally believed to contain witchcraft potencies, including charms and medicines. The definition is therefore likely to encompass the possession of body parts of persons with albinism.

26. However, the Witchcraft Act raises many concerns, including in respect of the definition of “witchcraft”, which remains elusive in the Act. It also poses challenges as to what is admissible as evidence of such practices in judicial procedures. In 1992, a presidential commission observed that the Act remained entrenched in colonial jurisprudence and should be repealed.\(^5\)

27. As in many other countries in the region, it is very difficult to differentiate the work of witchcraft practitioners or witch doctors from that of traditional healers. In response to the problem, the Government adopted the Traditional and Alternative Medicines Act (2002). One of the purposes of the Act was to regulate practitioners of alternative medicine who had formal training and healers who provided traditional remedies using plants, animal and mineral substances and the like. The Act, under which the Traditional and Alternative

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Health Practice Council, a regulatory body, was established, prohibits the practice of unregistered persons and establishes the duties of practitioners towards their patients.

28. This approach is to be commended, as it involves oversight of the practices of traditional healers and distinguishes between registered practices and illegal ones. However, the Independent Expert notes that full implementation of this Act requires ongoing efforts and resources for regular checks and permanent oversight. According to information received from a number of sources, only a minority of traditional and alternative health practitioners are registered, and in remote areas in particular, including where attacks against persons with albinism have been reported, there is still confusion about what is a legitimate practice and what is not.

29. A review of the Witchcraft Act and the Traditional and Alternative Medicines Act was to be carried out as part of the National Human Rights Action Plan (2013–2017), which is coming to an end. As the review has yet to be conducted, the Attorney General’s Office stressed that it would be included in the second National Human Rights Action Plan (2018–2022).

Persons with disabilities

30. The Persons with Disabilities Act (2010) was adopted to give legal effect to the National Policy on Disability (2004) and implement the provisions of the Convention on the Rights of Persons with Disabilities. The Act requires the Government to take appropriate steps to ensure that persons with disabilities have full enjoyment of their rights and freedoms, without discrimination. It addresses health care, education, rehabilitation, employment, accessibility, participation, integration, non-discrimination and other relevant matters.

31. The division of the Prime Minister’s Office responsible for, inter alia, disability affairs has indicated that it intends to review both the National Policy on Disability (2004) and the Persons with Disabilities Act (2010) and develop a national action plan on the promotion of the rights of persons with disabilities.

32. Furthermore, the Ministry of Health, Community Development, Gender and Children is in the process of developing the national guidelines on health-care fee waivers for persons with disabilities to facilitate access to health care for such persons, including persons with albinism.

33. In addition, in follow-up to its inclusive education policy, the United Republic of Tanzania developed the National Strategy on Inclusive Education (2009–2017) and formulated guidelines on support services for children with albinism and visual impairments. Although these are excellent steps towards the full realization of the right to education of persons with albinism, further measures are necessary to implement this policy throughout the country.

B. Institutional framework

Albinism

34. The Deputy Minister responsible for labour, youth, employment and disability affairs, who works from the Prime Minister’s Office, has a mandate to ensure the realization of the human rights of persons with albinism.

35. The 2015 appointment of a person with albinism to this position was widely applauded. It led to the necessary prioritization of the issue and fruitful initiatives advancing the promotion and protection of the rights of persons with albinism. Of particular note were the Deputy Minister’s efforts to begin reintegrating those who had been displaced by attacks.

36. Unfortunately, the prioritization of the human rights of persons with albinism seems to have been linked more closely to the Deputy Minister’s personal experience than to the pursuit of any long-term policy by the Prime Minister’s Office. Moreover, with the recent reassignment of the former Deputy Minister to other functions abroad, it appears that
matters related to albinism, now dealt with mainly by the Directorate responsible for disability affairs, are not a priority of the current Deputy Minister. The Independent Expert is of the view that this change has affected the visibility and prioritization of the issue.

37. In response to the violence and inherent criminality of attacks against persons with albinism, committees were established at the ministerial level — at the Ministry of Home Affairs, for example — with a view to ensuring the protection of persons with albinism.

38. In November 2016, the Deputy Prime Minister’s Office convened a task force, thereby leading to the de facto replacement of those committees. The task force, which seeks to take a coordinated approach to issues relating to persons with albinism, comprises representatives of the Government, civil society organizations and United Nations agencies. It is chaired by the Deputy Prime Minister’s Office, while UNESCO acts as the secretariat. It has used a multisectoral approach to develop a detailed and promising strategy to ensure the protection and well-being of persons with albinism in the United Republic of Tanzania.

Persons with disabilities

39. The National Advisory Council for Persons with Disabilities was established by the Persons with Disabilities Act (2010) to monitor and ensure the implementation of the rights of persons with disabilities. It is chaired by the Office of the Prime Minister responsible for policy, parliamentary affairs and matters involving labour, employment, youth and persons with disabilities. However, it was stressed that resources for the Council’s full functioning are still lacking.

40. To implement the Persons with Disabilities Act, the Prime Minister’s Office, through the President’s Office on Regional Administration and Local Government, has issued a circular to establish disability committees at the village, ward, district and regional levels. These committees are to be involved in data collection and reporting on issues — both opportunities and challenges — affecting persons with disabilities, including persons with albinism.

41. The Independent Expert was also informed that the National Fund for Persons with Disabilities, created by the Persons with Disabilities Act, would be set up in 2018 and that Parliament had allocated specific funds to that effect. The Fund will be used to support education and vocational training, rehabilitation programmes and research. It will also issue grants to civil society organizations.

Law enforcement

42. The Attorney General’s Office provides legal advice and drafting services to the Government. Through its Directorate of Public Prosecutions, it conducts prosecutions and coordinates the investigation of all criminal cases. In 2009, the Directorate took steps to address the attacks on and killings of persons with albinism by assigning such cases to a unit responsible for gender affairs and vulnerable groups.

43. The measures taken by the country to respond to attacks on persons with albinism included the placement of specialized personnel in the department responsible for offences against persons and trafficking-related offences at police headquarters and in its subordinate units. Standing operational task forces with specialized law enforcement personnel were deployed at the peak of the crisis to focus on crimes against persons with albinism.

44. Community policing started in 2006; each of the country’s 3,633 wards has a community police officer. Community police officers work closely with village leaders, traditional authorities, religious leaders, teachers and traditional healers. They ensure that village security committees, which set local priorities, are effective. A number of security committees have identified attacks against persons with albinism as a particular concern.

Centres and schools used as shelters

45. As a provisional, emergency response to the surge of attacks, the Government referred children with albinism to primary schools with boarding facilities, which were to be used as temporary shelters to ensure their safety. In 2015, the Government intensified its efforts to refer children with albinism to these shelters.

46. Although the emergency that triggered the creation of these shelters appears to have become less acute, the shelters are still being used, and persons with albinism were reportedly still being brought to them for protection (although the number of these arrivals is far less than at the peak of the attacks between 2008 and 2010). Civil society organizations informed the Independent Expert that there were more than 32 known schools and other facilities used as shelters in the country. If the needs of persons with albinism are to be met, it is fundamental for the Government to ensure the collection of accurate and comprehensive data on the whereabouts of displaced persons with albinism and share them with other stakeholders providing services to such persons.

National Assembly

47. The National Assembly, as constituted in 2015, has 390 members. They include 263 Members of Parliament, elected to represent constituencies across the Mainland and Zanzibar, 113 special seats for women members, 5 members elected by the Zanzibar House of Representatives from among its members, the Attorney General and 8 members appointed by the President. In 2008, using his prerogative, the President nominated Alshaymaa Kwegyir as the first Member of Parliament with albinism. She served two full terms. Regrettably, the Parliament no longer has a member with albinism appointed under this presidential prerogative.

Health

48. The Regional Dermatology Training Centre, in the municipality of Moshi, was created in partnership with the Tanzanian Ministry of Health, Community Development, Gender and Children to provide dermatological services, including through training for medical professionals and clinicians from the country and the subregion. Its skin cancer prevention and treatment services are provided regularly to persons with albinism. In addition, the Centre runs mobile clinics periodically, mainly in the north of the United Republic of Tanzania.

49. One of the main partners of the Centre’s mobile operations is the non-governmental organization (NGO) Standing Voice. Its mobile skin-care clinics bring dermatologists to 33 sites in eight regions of the country every six months. The programme consists of an awareness-raising component, a full screening for precancerous lesions on persons with albinism, cryogenic treatment where necessary, the distribution of sun hats and sunscreen and referrals for surgery. Clinic outreach is carried out with the support of the Tanzania Albinism Society, and the Centre’s dermatologists provide treatment. Memorandums of understanding signed with local schools and hospitals ensure that mobile clinics come to the same premises every six months. This model prevents many early deaths from skin cancer — which reportedly kills most persons with albinism in the United Republic of Tanzania before they reach the age of 40[7] — and the Independent Expert encourages expanding the model to the entire country, with greater support from the Government.

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50. The sunscreen distributed through mobile clinics, KiliSun, is the first of its kind in the region. It is locally made and formulated for general use with specific attention to the needs of persons with albinism. Local production is particularly important, as it ensures constant availability of an item that is a basic necessity for persons with albinism. It avoids the cost and delays associated with imports and ensures that the sunscreen is distributed well before its expiry date, which is not always the case with imported sunscreen.

51. Treatment for skin cancer is provided in a limited number of hospitals and clinics. In all, two centres are equipped for radiotherapy and four for chemotherapy. Ocean Road Cancer Institute, where the offices of the Tanzania Albinism Society are located, provides both services.

IV. Main findings and challenges

A. Attacks

Context

52. Violence, including physical attacks against persons with albinism in the United Republic of Tanzania, began receiving national attention in 2006 and international attention the following year. The seriousness of those attacks, many of which led to death, mutilation and displacement, prompted national initiatives from the Government, civil society and international actors. According to data provided by the Attorney General’s Office, 66 cases of attacks against persons with albinism had been reported at the time of the visit of the Independent Expert. Fifty-five of those cases, it was reported, had led to court proceedings, while 11 were still under investigation. Civil society disputes those numbers, providing a much higher aggregate figure and reiterating that these are reported cases alone. All records — both government and civil society — show that the regions of Mwanza, Kagera and Geita are particularly affected by violence.

53. In 2015, joint supervision missions were conducted in eight regions of the Lake Zone (Tabora, Shinyanga, Simiyu, Geita, Mwanza, Kagera, Mara and Kigoma) with a high number of reported attacks. The Directorate of Public Prosecutions, the Police Force and the NGO Under the Same Sun took part in these missions to compare the data they had received. The objective of the missions was to harmonize data, identify cases of attacks against persons with albinism, obtain accurate records and determine the challenges to investigating and prosecuting cases. Such joint missions are a positive example of cooperation between the authorities and civil society and should continue, not only to address data discrepancies but also to step up cooperative efforts to eradicate the problem and its root causes.

54. The Independent Expert was informed by persons with albinism that a number of cases of targeted violence and attacks had not been reported to the authorities. The reasons for not reporting such cases through official channels included the victim’s preference for reporting to civil society, the growing sense of national shame around the attacks and a corresponding unwillingness to report the crimes in the media and the difficulty of reporting attacks from remote areas, despite the work of the community police. In addition, some cases are unlikely to be reported either to officials or to civil society because of a lack of awareness of these avenues and other circumstances, such as the involvement in the crime of a parent or other family members.

55. Data provided by the Attorney General’s Office suggest that the focus has been on grave offences such as murder and assault (41 cases) or grievous bodily harm (13 cases). Since 2006, only one case of a person being found in possession of body parts has been recorded, despite the nature of these crimes, which often involve the harvesting and trafficking of body parts. Other cases included one exhumation of a body, one kidnapping, two conspiracies to commit murder, two abductions, two instances of human trafficking and five attempted murders. These data contrast with information recorded by civil society and reported by persons with albinism.
56. Information received from both the Government and civil society confirm a decrease in the number of reported attacks. However, the Independent Expert also received information stressing that it had recently become more complicated to publicly report and denounce such cases, in particular through the press, social media or documentaries. The Independent Expert notes that to fully comprehend the situation of persons with albinism and the extent of the reduction in the number of attacks, it is important to facilitate the reporting of cases through all channels and to continue encouraging the law enforcement authorities to respond proactively.

57. Furthermore, the Independent Expert stresses the importance of collecting data on the security of persons with albinism and of information sharing between civil society and the Government. This should include information gathered from relatives of victims as well as witnesses to human rights violations both within and outside temporary shelters. Replicating past examples of data sharing and initiatives to harmonize information, such as joint missions of diverse stakeholders, including the Government and civil society, can help fill this gap.

Law enforcement and prosecution

58. The reported decrease in the number of attacks was achieved in part through measures put in place by the Government and other actors. The measures included the prioritization of investigation and prosecution of attacks against persons with albinism, the use of standing task forces with specialized law enforcement training at the peak of the attacks and major awareness-raising programmes. Those efforts were part of a timely response that enhanced deterrence.

59. However, persons with albinism, including survivors of attacks and families of victims, appeared to be largely unaware of the status of relevant investigations and prosecutions. They were also unaware of how or whether those found guilty of attacks were sentenced. This lack of information on judicial proceedings has a detrimental effect on the reporting of cases to authorities. Developing channels to enhance the flow of information is important to enhance deterrence. It is also important to ensure that victims and their families have access to relevant information and to prevent mob justice at the community level, which is often the result of perceived inaction or insufficient action by the State.

60. In this regard, the Tanzania Albinism Society, which has a wide network at the local level, and other civil society organizations, should be given greater support for their efforts to keep victims and their families informed of the outcomes of cases involving attacks on persons with albinism.

61. Strategies for upholding the human rights of persons with albinism must be firmly grounded in international human rights law. The Independent Expert notes that there are calls for the implementation of the death penalty for crimes against persons with albinism. On this matter, the Independent Expert stands with the Secretary-General in affirming that the death penalty has no place in the twenty-first century. This is especially the case where — as in these cases — investigations are challenging.

62. Challenges in investigation, as identified by the Attorney General’s Office, include a lack of adequate and reliable information, deep-rooted beliefs in witchcraft and the remote and isolated locations where attacks have occurred.

63. The judicious use of multiple pieces of legislation is likely to strengthen the legislative framework in cases of attacks against persons with albinism. They include the Penal Code, the Anti-Trafficking in Persons Act (2008) and the Law of the Child Act (2009). The provisions of the Penal Code on possession of body parts, for example, are fundamental to combating trafficking of body parts. The Independent Expert notes, however, that they have not yet been invoked for that purpose.

64. Similarly, in investigating and prosecuting crimes against persons with albinism, greater emphasis should be given to identifying the criminal masterminds, organizers, criminal customers, the end users of body parts and the witch doctors involved. According to reports, there are no cases where the mastermind was prosecuted. The dissemination of information on prosecuted masterminds would significantly enhance deterrence.
65. Furthermore, some of these crimes involve a cross-border element, such as trafficking in persons and in body parts, that complicates investigation. In places such as Kibondo, a district that shares a border with Burundi, regular meetings are being held between the police of both countries, at the local level, to facilitate cross-border police cooperation. Consular authorities in Kibondo are also involved in facilitating cooperation. While these are positive steps, they should be complemented by a clear police cooperation agreement between the United Republic of Tanzania and its neighbouring countries, and relevant international organizations should be involved. The development of a subregional plan on trafficking, an ongoing process being promoted by the International Organization for Migration and the United Nations Children’s Fund (UNICEF), could also facilitate international cooperation in this regard.

Persons with albinism in refugee camps

66. Persons with albinism living in refugee camps in the United Republic of Tanzania can also find themselves living in precarious situations. In situations of forced displacement, persons with albinism face particular protection risks, especially in regions where myths about albinism are rampant. The distress of displacement, coupled with the destruction of trusted social networks, is among the many factors that can aggravate the insecurity of displaced persons and refugees with albinism.

67. In Kasulu, such security concerns were brought by families of children with albinism to the police. As a result, those families were relocated to areas in close proximity to the police unit of the refugee camp.

Support for victims

68. Support for victims of attacks and their families, including legal, medical, psychosocial and socioeconomic support, is fundamental to enabling them to rebuild their lives and restore their dignity. The Government has provided a certain amount of medical and material support to some victims of attacks, and this is to be commended. In the provision of such support, however, the security needs of persons with albinism should be given all due consideration, and the measures taken in that regard should be grounded in legal and international standards regarding redress for victims.

B. Root causes

69. Although the safety of persons with albinism appears to have increased in recent years, the situation remains very precarious. Not only do the attacks continue — albeit less frequently — but the root causes thereof are also still present. Fear persists in various regions of the country, driving persons with albinism and/or their families to continue to seek protection in shelters. In addition, persons with albinism living in shelters often fear returning to their villages, given the widespread belief in witchcraft, the persistence of myths and the disproportionate levels of poverty they face.

70. Commendable measures have been taken by the Government to address witchcraft, including the registration of traditional healers to differentiate their practices from those of witch doctors. However, only a small number of traditional healers have registered, and the confusion persists, particularly in rural and remote areas. Putting an end to that confusion is a long-term process that requires specific measures, such as dispelling myths about persons with albinism and increasing awareness of the differences between traditional medicine and witchcraft. The participation of registered traditional healers in awareness-raising activities would be particularly effective in dispelling confusion. In addition, the current review of the Witchcraft Act provides an opportunity to address the issue.

71. Deep-seated myths about persons with albinism, including the belief that they do not die but disappear or that their body parts have special powers when used in rituals and concoctions prepared by witchcraft practitioners, remain widespread. These myths are at the root of attacks against persons with albinism. They have also led to the abandonment of children with albinism and the rejection of parents of children with albinism by their families or communities. Furthermore, the hypervisibility and colouring of persons with
albinism, along with the lesions that skin cancer often leaves on their skin, combined with a lack of general education on albinism, contribute to and strengthen the myths dehumanizing persons with albinism.

72. As long as such myths persist, the risk of a resurgence of attacks remains present. Intensive, long-term awareness-raising in all national languages and reaching all areas, particularly rural and border areas, is necessary. It will require joint efforts by all stakeholders, including the authorities, persons with albinism, local leaders, traditional healers and faith-based organizations.

73. A good example of such awareness-raising was a pilot project carried out by UNESCO in 2015–2016 on community sensitization. The project made use of community radio stations and took a sociocultural approach by empowering key community stakeholders and family members of persons with albinism to mobilize their communities to protect and promote the well-being and rights of persons with albinism. The project’s success in changing mindsets is a strong indicator that similar preventive and protective efforts are required immediately and for the longer term.

C. Centres and schools used as shelters

74. To protect persons with albinism, particularly as the number of reported attacks peaked, schools and similar centres were used as temporary shelters. This measure probably contributed to the decrease in the number of attacks, as there have been no reported cases from these shelters. Moreover, as the measure does not address the root causes of the attacks, the schools and other such centres used as temporary shelters are bound to become permanent.

75. Many persons with albinism living in the shelters do not feel safe outside and are afraid of going back to their villages on a long-term basis, as the risk of attacks remains high. Moreover, children with albinism are still being sent by their families to some of these shelters. In addition, some adults with albinism have chosen to live in such places, and students in secondary school or college have no choice other than to return to them during school holidays either for security reasons or because they have been abandoned by or could not trace their families.

76. Considerable efforts have been made by civil society and the Government since the visit of the African Committee of Experts on the Rights and Welfare of the Child in August 2015, particularly with regard to reducing overcrowding in select shelters. Efforts in that regard began in 2016 in seven regions and involved local authorities and civil society organizations representing persons with albinism. At least 65 children have been reunited with their families; however, many children whose families were identified and contacted in this process opted to go home only for short-term visits or during school holidays, as they do not feel safe at home for longer periods. In the shelters visited by the Independent Expert, a relatively large number of children with albinism are still staying during the holidays. The process of reducing the number of persons with albinism in shelters and reuniting them with their families could be slowed or halted by the risk of attacks outside the shelters, the lack of adequate protection, health and education structures in local communities and the lack of sensitization of families or receiving communities.

77. In addition, reducing shelter populations is complicated by the absence of a registration and family-tracking strategy. In some cases, locating family members of some of the children with albinism brought to the shelter at the peak of the attacks is problematic, as they arrived with no birth certificates and, given their young age at the time, do not remember their place of origin. The intervention of the Tanzania Albinism Society and other organizations in this process has been fundamental in facilitating family reunification and visitation. However, this is a long-term process that requires more governmental and non-governmental support and resources.

78. Transferring children with albinism from shelters also took the form of finding additional boarding schools, including private schools, for some of the children. The number of de facto shelters therefore seems to be growing. A list of all existing shelters,
along with the number of students with albinism in them and relevant services available to them, should be securely shared with all stakeholders, including social workers and other front-line service providers.

79. More remains to be done to enhance the living conditions in shelters. Projects such as the one to build a new dormitory in Buhangija School or to provide new mattresses at Lake View School should be priorities. Other basic measures ought to be taken, including ensuring adequate food supplies to all residents in the shelters, children and adults alike. In addition, some shelters visited have severely overcrowded classrooms, with more than 100 students per class. This overcrowding has a negative impact on the quality of instruction, particularly for children with special needs, including those with albinism.

80. One of the key priorities, given the precarious safety situation of persons with albinism, particularly in rural areas, is to educate and sensitize communities and families of persons with albinism. This includes close cooperation with security committees at the district and ward levels, the provision of basic security items such as mobile phones and the structural reinforcement of unsecured homes by ensuring that they have doors and locks. In addition, mobilizing communities goes beyond an immediate protection strategy and should include long-term strategic awareness-raising to demystify the condition of albinism, increase social inclusion and ensure that adequate structures are in place to support persons with albinism, including to facilitate their integration in local schools and access to health services.

D. Health

81. Because persons with albinism have reduced levels of melanin or colour pigment or none at all, they are particularly vulnerable to skin cancer. Consequently, in a number of countries, skin cancer is reported to be the number-one killer of persons with albinism. Chemotherapy and radiotherapy are available in the country. The Tanzania Albinism Society has its offices at Ocean Road Cancer Institute, which specializes in treating skin cancer. This proximity illustrates the importance of access to health for persons with albinism.

82. However, the cost of diagnostic services and travel to hospitals, given the poverty in which many persons with albinism live, is one of the main barriers to access to health care. Those who are poor and likely to need treatment the most are the least likely to receive it.

83. The result is that persons with albinism, many of whom lack knowledge of preventive measures, may seek medical support only as a last resort, often when it is too late for treatment to succeed. The average age of persons with albinism diagnosed with skin cancer is about 35, a very early age, given the time skin cancer takes to develop. A number of the Independent Expert’s sources, themselves persons with albinism, reported the significant frequency of deaths of persons with albinism before the age of 40. Such early deaths are preventable through low-cost measures, including the use of long-sleeve shirt, wide-brimmed hats and sunscreen. To increase awareness, the Government should consider rolling out a national skin cancer prevention strategy similar to strategies that have been rolled out for other forms of cancer plaguing Tanzanians.

84. The Independent Expert welcomes the inclusion of sunscreen on the list of priority medicines and in the health kits delivered to all hospitals. However, to ensure a regular supply, local production of sunscreen ought to be supported. In particular, the Government should invest more substantively in initiatives such as that undertaken by KiliSun and facilitate efforts to import the relevant raw materials.

85. Although vision impairment varies in severity from one person with albinism to another — and often in proportion to the residual pigment in each person — States have a duty to provide reasonable accommodation to persons with albinism in order to ensure de facto equality with others. Free clinical assessments should be provided by ophthalmologists to persons with albinism. Glasses and adaptive devices should also be provided.
86. In this regard, the Regional Dermatology Training Centre/Standing Voice mobile clinic model is a best practice and should be replicated across the country. In addition to dermatological services and the distribution of KiliSun, the clinics bring services and assistive devices to persons with albinism and visual impairments twice a year in specific regions and districts. As these clinics provide critical health and vision services to persons who would otherwise not have access to such services and thus save lives, it is fundamental to increase the support they receive, strengthen their public-partnership structure and broaden the scope of services they provide, thereby enabling them to reach many more persons in need.

E. Education

87. The country’s Inclusive Education Strategy (2012–2017) was adopted to ensure that all children had equal access to quality education in inclusive settings. The aims included ensuring that teachers were able to respond to the diverse needs of learners and that educational support was available to all learners. In addition, the new education and training policy, adopted in 2014, seeks to increase access to educational facilities for children with disabilities, including children with albinism.

88. However, children with albinism cannot benefit from the Strategy if they are not provided with necessary reasonable accommodation, including visual aids such as glasses, monoculars and large-print material. The Government has recognized that there is a shortage of assistive devices for persons with albinism, a gap that is being partially filled by civil society organizations.

89. As with sunscreen, domestic production of such devices would ensure their accessibility, affordability and availability. The Prime Minister’s Office, it should be noted, has instructed the Ministry of Industry and Trade to produce assistive devices for persons with disabilities. Not all such assistive devices can be produced domestically, however. The Independent Expert therefore welcomes the instructions given to the Ministry of Industry and Trade by the Prime Minister’s Office to reduce the cost of importing assistive devices for persons with disabilities, including persons with albinism. The Independent Expert notes, however, that many items needed by persons with albinism, such as monoculars or glasses, are being imported primarily by civil society organizations and that it is important for the Government to encourage those initiatives by expediting import processes and facilitating the refund of import taxes and duties on such goods.

90. In addition, the overcrowding of classrooms in certain schools used as shelters for persons with albinism significantly complicates the full implementation of the inclusive education policy. Similarly, discrimination against and bullying of children with albinism are still problems in the country’s schools. Children with albinism thus drop out of school, with significant consequences for their life expectancy, as a lack of education often means working outdoors in the sun and/or living in poverty, which is often synonymous with living in an insecure home.

91. Furthermore, given the importance of indoor work for the health and safety of persons with albinism, efforts should be made to include persons with albinism in vocational training opportunities, regardless of their academic performance.

F. Socioeconomic situation of persons with albinism

92. A baseline survey conducted by the Tanganyika Christian Refugee Service in the regions of Mwanza, Simiyu, Geita, Shinyanga, Tabora and Dar es Salaam shows that the socioeconomic situation of persons with albinism in the United Republic of Tanzania remains highly challenging and requires substantial intervention. The Tanzania Albinism Society shares these concerns.

93. Officials have indicated that the socioeconomic situation of persons with albinism has a direct impact on their access to medical services, such as skin cancer treatment, and to prevention measures such as sunscreen, hats and protective clothing. It also has a negative
impact on their access to education, as families of children with albinism may not be able to afford the indirect costs of the protection their children would often need for the long walk to the closest school. In addition, discrimination reportedly has a direct impact on the employment of persons with albinism, as it is difficult for them to sell goods in the marketplace and provide services, given the widespread stigmatization they face. Similarly, it was stressed that only a few persons with albinism are involved in the formal economy.

94. Moreover, poverty is both a result of discrimination against persons with albinism and a root cause of attacks against them. A case in point are those persons with albinism, particularly in rural areas, who are unable to afford basic security features on their homes, such as doors and locks, and can only afford property located a significant distance from the rest of the community.

95. The combination of myths and attacks has also led to cases of discrimination in housing, as some persons with albinism have trouble finding houses to rent, both because property owners fear attacks and because there is considerable stigma attached to albinism. Fear continues to threaten the lives and livelihoods of many persons with albinism, particularly in rural areas. Unable, for security reasons, to leave their houses before sunrise or after sunset to work in their fields, their socioeconomic situation, often already made precarious by discrimination, further deteriorates. Persons with albinism should therefore be covered by programmes established by the Government to combat poverty, including through special measures and affirmative action. Similarly, it is important to fully implement the quota established by the Persons with Disabilities Act (2010), under which persons with disabilities are expected to account for 3 per cent of the payroll of companies employing more than 20 people. Raising awareness of the Act among persons with albinism and employers should be a priority of the Government.

V. Conclusion and recommendations

96. In recent years, the combination of measures taken by the Government and civil society has led to a significant decrease in the number of reported attacks against persons with albinism in the United Republic of Tanzania. However, that progress is highly tenuous, as the root causes of the attacks have not been fully addressed. In addition, the consequences of the surge in the number of attacks are still felt, as demonstrated by the continued use of shelters by persons with albinism. In general, fear continues to plague the lives of persons with albinism, particularly in rural communities.

97. Renewed political will and corresponding efforts are necessary to address the underlying causes of attacks, including discrimination, myths, witchcraft and poverty. Long-term commitment is necessary to ensure that current gains are not lost and that the fragile peace attained does not fall apart, taking with it more lives, limbs and dignity.

98. The primary responsibility for ensuring that persons with albinism are able to enjoy their human rights rests with the Government, and its strong and continued commitment is essential if the gains that have been made, particularly with regard to safety, health, education and awareness, are to be secured.

99. The need for a government champion on the issue resurfaced in discussions with nearly all interlocutors. The reassignment of the former Deputy Prime Minister with albinism to other duties was noted by all. An intragovernmental champion plays a crucial role in coordinating efforts and amassing resources. Finally, the presence of a person with albinism within the Government championing this issue is a best-practice in the region and promises to give long-term effect to government initiatives on the matter.

Data collection

100. The Independent Expert recommends that the United Republic of Tanzania:
(a) Continue to cooperate with Tanzania Albinism Society in efforts to collect data on persons with albinism, including through existing databases and projects;

(b) Ensure that all data collected relating to the situation of persons with albinism are disaggregated at least by sex and age;

(c) Provide adequate safeguards for all data collected on persons with albinism to prevent misuse for attacks, discrimination or other illicit acts.

Comprehensive approach to the enjoyment of human rights by persons with albinism

101. The Independent Expert recommends that the United Republic of Tanzania:

(a) Ensure that a coordinated, multisectoral and comprehensive approach is taken to the enjoyment of the human rights of persons with albinism by strongly supporting the strategic plan developed by the task force working to combat the killings and abduction of persons with albinism. The strategic plan effectively mirrors the Regional Action Plan on Albinism in Africa (2017–2021), a plan promoted by the Independent Expert and recently endorsed by the African Commission on Human and Peoples’ Rights;

(b) Promote persons with albinism as role models, or champions, to facilitate the visibility and coordination of different actions taken, including through the nomination of a person with albinism to a high-level position in Government. Such visibility is important to ensure their full integration and combat myths that dehumanize them.

Legislative framework

102. The Independent Expert recommends that the United Republic of Tanzania:

(a) Continue registering practitioners of traditional medicine and monitor their work comprehensively and regularly, while sanctioning practices that do not fall within the existing legal framework;

(b) Use the ongoing review of the Witchcraft Act and the Traditional and Alternative Medicines Act as an opportunity to reflect on witchcraft in the country, take steps to mitigate its root causes and prevent the harmful practices it leads to;

(c) Submit its initial report to the Committee on the Rights of Persons with Disabilities;

(d) Review the legislative framework to ensure that existing provisions on possession of body parts sufficiently address trafficking of body parts of persons with albinism;

(e) Ratify the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.

Law enforcement

103. The Independent Expert recommends that the United Republic of Tanzania:

(a) Strengthen community policing by ensuring that adequate resources are provided and by facilitating the reporting of incidents to the police and the gathering of evidence;

(b) Strengthen the role of security committees in each village and ensure that they are trained to report attacks against persons with albinism without delay;

(c) Facilitate international law enforcement cooperation with neighbouring countries, for example through memorandums of understanding, shared databases and extradition treaties.
Reporting of cases

104. The Independent Expert recommends that the United Republic of Tanzania:

   (a) Continue promoting cooperation between the authorities and civil society with a view to addressing attacks, including through joint missions to collect, compare and assess information on cases;

   (b) Continue developing strategies and ways to facilitate the reporting of cases, and ensure prompt follow-up to reports of attacks;

   (c) Inform victims and/or their families of the outcome of cases that are being or have been investigated and prosecuted;

   (d) Ensure that the right to freedom of expression, including through the media, applies fully to efforts to report or otherwise publicize cases of attacks against persons with albinism.

Investigation and prosecution

105. The Independent Expert recommends that the United Republic of Tanzania:

   (a) Ensure the judicious use of legislation to fully address all types of attacks against persons with albinism, including those involving possession of body parts;

   (b) Ensure that all cases of offences against persons with albinism are promptly and thoroughly investigated and documented, with a view to identifying and prosecuting the masterminds of attacks and the chain of perpetrators.

Shelters

106. The Independent Expert recommends that the United Republic of Tanzania:

   (a) Gather, in cooperation with civil society organizations, comprehensive information on all shelters used for the protection of persons with albinism to facilitate a comprehensive and coordinated effort to reduce shelter overcrowding, reunite families and ensure that persons with albinism in these shelters have access to basic services;

   (b) Continue improving living conditions in shelters, including by ensuring an adequate food supply, conducting thorough assessments of specific needs at each shelter and meeting those needs promptly.

Awareness-raising

107. The Independent Expert recommends that the United Republic of Tanzania:

   (a) Raise awareness of albinism to combat rampant myths about the condition through far-reaching campaigns sustained continuously for at least two years. The campaigns should be in all national languages, involve persons with albinism and target communities in rural areas in particular. They should also involve key stakeholders, including traditional authorities and faith-based organizations;

   (b) Educate and sensitize communities and families of persons with albinism who have been placed in shelters, with a view to facilitating their safe return and reintegration;

   (c) Enhance cooperation with security committees at the district and ward levels, providing basic security items such as mobile phones, contributing to the structural reinforcement of unsecured homes by ensuring that they have doors and locks and facilitating the safe return of children with albinism from shelters;

   (d) Mobilize communities to tackle myths about albinism and ensure that adequate structures are in place to support persons with albinism, including to facilitate their integration into local schools and ensure they have access to sunscreen and health care, all to ensure the safe return of children with albinism from shelters.
Health

108. The Independent Expert recommends that the United Republic of Tanzania:

(a) Ensure that sunscreen is available, including by providing strong support for domestic production within the framework of the ongoing multi-stakeholder partnership involving the Regional Dermatology Training Centre, KilliSun and Standing Voice, and facilitate the importation of relevant raw materials;

(b) Support and significantly extend the reach of early intervention and detection programmes, including through mobile clinics;

(c) Provide training and information on albinism and related health issues to mothers of children with albinism and their families immediately after the births of their children to ensure that their skin and vision are adequately protected;

(d) Continue to facilitate access to skin cancer treatment, including chemotherapy and radiotherapy, by reducing indirect costs or, where necessary, by providing financial support to ensure prompt access to treatment;

(e) Provide free clinical assessments, both dermatological and ophthalmological, to persons with albinism, along with glasses, adaptive devices and other visual aids, within the framework of efforts to provide reasonable accommodation and fulfil international obligations regarding their right to the highest attainable standard of health;

(f) Consider rolling out a national skin cancer prevention strategy similar to those that have been rolled out for the 10 other kinds of cancer most commonly affecting Tanzanians.

Education

109. The Independent Expert recommends that the United Republic of Tanzania:

(a) Ensure full implementation of the inclusive education policy, not least by allocating the necessary resources;

(b) Ensure the provision of reasonable accommodation to students with disabilities by making low vision aids, adaptive devices and large-print materials available in all schools;

(c) Ensure the systematic training of teachers on the special needs of children with albinism, who should know that children with albinism should be seated in the front row, that such children should be given teachers’ notes, that large-print writing should be used on the blackboard and that other teachers and students should learn about albinism;

(d) Ensure that schools that have children with albinism are equipped with the necessary basic protections, such as fences, and that teachers and staff are aware of the situation of students with albinism and trained to respond adequately;

(e) Facilitate access to vocational training opportunities, so that persons with albinism, regardless of their performance in academic subjects, can prepare for careers that would allow them to work indoors and lift themselves out of poverty.

Socioeconomic situation

110. The Independent Expert recommends that the United Republic of Tanzania:

(a) Ensure that persons with albinism are covered by the Government’s anti-poverty programmes, including through special measures;

(b) Enforce the quota established by the Persons with Disabilities Act (2010), under which persons with disabilities are expected to account for 3 per cent of the payroll of companies employing more than 20 people, and raise awareness of the Act among persons with albinism and employers.
Victim support

111. The Independent Expert recommends that the United Republic of Tanzania continue to provide psychosocial, medical and legal assistance to persons with albinism who are victims of attacks, survivors and their families, while taking into account their specific needs and international human rights standards.

Participation

112. The Independent Expert recommends that the United Republic of Tanzania continue involving persons with albinism in all decisions and measures taken for the full implementation and enjoyment of their rights.

International cooperation and assistance

113. The Independent Expert makes the following recommendations:

   (a) International development partners should support national efforts by integrating the issue into development programmes for persons with disabilities, older persons and groups in vulnerable situations, including those discriminated against on the basis of colour, women and children;

   (b) The United Nations system should consider providing technical assistance and support to the United Republic of Tanzania in particular for the implementation of the strategic plan developed by the task force responsible for issues related to persons with albinism;

   (c) Regional partners should enhance international cooperation to address the human rights challenges faced by persons with albinism, including through the Regional Action Plan on Albinism in Africa and the inclusion of the issue on the agenda of regional and subregional meetings. As many of the issues faced by the United Republic of Tanzania in addressing matters regarding persons with albinism are regional, transnational cooperation, joint action and exchanges of best practices are fundamental.