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### **Promotion and protection of human rights: human rights situations and reports of special rapporteurs and representatives**

## **Enjoyment of human rights by persons with albinism**

### **Note by the Secretary-General**

The Secretary-General has the honour to transmit to the General Assembly the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, in accordance with Human Rights Council resolutions [28/6](#) and [46/12](#).

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\* [A/77/150](#).



## **Report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond**

### **People with albinism on the move**

#### *Summary*

In the present report, the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond, focuses on persons with albinism on the move, in particular refugees and asylum seekers. She assesses the drivers of mobility and notes that persons with albinism on the move are often displaced from their countries of origin owing to various reasons, including insecurity and threats to life, aggravated forms of discrimination, inadequate access to critical health services and the harsh impact of hot and tropical climates on their skin, which can lead to skin cancer without adequate protection. In addition to raising the key human rights concerns for persons with albinism on the move, she highlights positive practices as important references for stakeholders. The Independent Expert hopes that this first report on this subject will lead to further dialogue, research and initiatives to effectively address the human rights challenges of persons with albinism on the move.

## I. Introduction

1. The present document is the report of the Independent Expert on the enjoyment of human rights by persons with albinism, Muluka-Anne Miti-Drummond. It is submitted pursuant to Human Rights Council resolutions 28/6 and 46/12.

2. In preparing the report, the Expert sent a questionnaire on 21 and 25 April 2022 to various stakeholders, including Member States, United Nations offices, civil society organizations and persons with albinism. The Expert received written submissions and virtual consultations from 50 stakeholders, including Member States,<sup>1</sup> United Nations agencies and civil society organizations in Europe, South America, Asia and Africa.<sup>2</sup>

3. The report is focused on persons with albinism on the move, in particular refugees and internally displaced persons with albinism, and highlights some of the human rights challenges that they experience. In the report, the term persons with albinism on the move is used as an umbrella term that includes migrants,<sup>3</sup> refugees,<sup>4</sup> asylum seekers,<sup>5</sup> migrant workers,<sup>6</sup> internally displaced persons<sup>7</sup> and other groups which fall into well-defined legal categories.<sup>8</sup> It should be noted that many persons with albinism also identify as persons with disabilities owing to their visual impairment and susceptibility to skin cancer.

4. Relatively little research has been done to date on the situation of persons with albinism on the move; hence the present report aims to shed some light on the topic in order to provide a better understanding of the human rights challenges within this context and to prompt further research, data collection, dialogue and action on the issue.

<sup>1</sup> Member States that responded to the questionnaire were Azerbaijan, Italy, Mauritius and Mexico.

<sup>2</sup> The Expert is particularly grateful to the Global Albinism Alliance and Advantage Africa for their support with research for the present report. Stakeholders who are named throughout the report gave consent to be identified.

<sup>3</sup> There is no universal legal definition of “migrant”. The Office of the United Nations High Commissioner for Human Rights (OHCHR) defines an international migrant as “any person who is outside a State or location of which they are a citizen or national, or, in the case of a stateless person, their State or location of birth or habitual residence.” (see <https://www.ohchr.org/sites/default/files/Documents/Issues/Migration/GlobalCompactMigration/MigrantsAndRefugees.pdf>). An internal migrant is any person who moves within the boundaries of a State, including internally displaced persons.

<sup>4</sup> According to UNHCR, refugees are people who have fled war, violence, conflict or persecution and have crossed an international border to find safety in another country. Refugees are defined and protected in international law. The 1951 Refugee Convention is a key legal document and defines a refugee in article 1 (A) (2) as any person who “owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of [their] nationality and is unable or, owing to such fear, is unwilling to avail [themselves] of the protection of that country, or who, not having a nationality and being outside the country of his former habitual residence ... is unable or, owing to such fear, is unwilling to return to it.”

<sup>5</sup> According to the Office of the United Nations High Commissioner for Refugees (UNHCR) an asylum-seeker is any person who is seeking international protection. In some countries, it is used as a legal term referring to a person who has applied for refugee status or a complementary international protection status and has not yet received a final decision on their claim. It can also refer to a person who has not yet submitted an application but may intend to do so, or may until their asylum claim has been examined in a fair procedure, and is entitled to certain minimum standards of treatment pending determination of their status.

<sup>6</sup> The International Convention on Migrant Workers, article 2 (1), defines a migrant worker as “a person who is to be engaged, is engaged or has been engaged in a remunerated activity in a State of which he or she is not a national”.

<sup>7</sup> An internal migrant is any person who moves within the boundaries of a State, including internally displaced persons. UNHCR defines internally displaced people as people who have not crossed a border to find safety. Unlike refugees, they are on the run at home.

<sup>8</sup> For example, victims of human trafficking.

## II. Background

5. The Office of the United Nations High Commissioner for Refugees (UNHCR), in “Global trends: forced displacement in 2021”, posits that, at the end of 2021, as a result of persecution, conflict, violence and human rights violations, 89.3 million people worldwide were forcibly displaced.<sup>9</sup> Some 27.1 million of these people were refugees while 53.2 million were internally displaced. These numbers are projected to increase, fuelled by ongoing conflict in countries including Afghanistan, Democratic Republic of Congo, Somalia, South Sudan, the Syrian Arab Republic<sup>10</sup> and Ukraine.

6. The information received by the Expert for the present report showed a lack of available data with regard to persons with albinism who have been forcibly displaced.<sup>11</sup> There is a general lack of data on persons with albinism as the albinism condition is not usually considered when data is disaggregated and used to compile information on people on the move. Where countries and other entities do collect statistics on migrants with disabilities, persons with albinism are subsumed in this data, and information on their situation and challenges is difficult to extrapolate. As of 2021, UNHCR integrated the Washington Group Questions on Disability Statistics<sup>12</sup> into systems of registration to better identify persons with disabilities during data collection efforts. However, as these sets of questions do not include specific reference to persons with albinism, it is difficult to obtain comprehensive data specifically identifying persons with albinism among those registered with UNHCR.

7. Nonetheless, a considerable amount of information on persons with albinism who have been displaced was provided by civil society organizations and individuals with albinism who directly engaged with the Expert. Although most of the statistics provided are specific to a particular country and limited in scope, they do suggest that there is a growing number of refugees and internally displaced persons with albinism. Information shared with the Expert showed that, in East Africa,<sup>13</sup> there were at least 73 persons with albinism in one particular refugee camp, many of whom had fled from an armed conflict in a neighbouring country. In another camp within the same country there were 56 persons with albinism, some 30 of whom were children below the age of 18 years.<sup>14</sup> In another country in the region, there were 23 persons with albinism at one of the refugee camps in 2020.<sup>15</sup> Several civil society organizations reported speaking to people with albinism who wanted to relocate for various reasons, including escaping persecution. A research paper on the United Republic of Tanzania

<sup>9</sup> UNHCR, <https://www.unhcr.org/afr/figures-at-a-glance.html>.

<sup>10</sup> United Nations, “2021 Year in Review: UN support for countries in conflict”, 28 December 2021.

<sup>11</sup> Submissions from civil society organizations; Ghana Association of Persons with Albinism, Albinism Foundation of Zambia; Organization for Integration and Promotion of People with Albinism, Rwanda; Sierra Leone Albinism Foundation; Genespoir France; National Organization for Albinism and Hypopigmentation; Standing Voice Malawi; Norwegian Albinism Association; NOAH Albinismus Selbsthilfegruppe e.V. (Germany), inter alia, all indicate that there were no statistics on migrants with albinism.

<sup>12</sup> The Washington Group short set of questions on disability is used to gather information on people with disabilities. Recommendations on how to better capture persons with albinism in data collection are provided at <https://www.washingtongroup-disability.com/wg-blog/are-people-with-albinism-included-in-the-washington-group-questions-119/#:~:text=The%20WG%2DSS%20does%20not,communication%2C%20and%20self%2Dcare>.

<sup>13</sup> Unless consent has been given, the names of the country concerned and camps with persons with albinism will not be specified in the present report.

<sup>14</sup> Expert’s discussion with refugees and migrants with albinism.

<sup>15</sup> Submissions from Standing Voice.

suggests that more than 10,000 persons with albinism have reportedly been displaced from their homes in an attempt to escape persecution.<sup>16</sup>

8. The information received provides a profile of refugees with albinism, indicating that they are mostly young, usually below the age of 40. There is a perception that men tend to dominate these statistics and that more refugees with albinism are apparently male, although women are increasingly represented in this group.

9. The Expert received information from refugees with albinism who were mostly from Africa, Eastern Europe and the Middle East. Refugees also identified themselves as originally from countries that include Burundi, Cameroon, the Democratic Republic of Congo, Mali, Nigeria, Rwanda, South Sudan and the United Republic of Tanzania. Some of the identified countries of destinations include Australia, Canada, France, Italy, Kenya, Malawi, South Africa, Spain, Uganda and the United States of America<sup>17</sup>.

### III. Drivers of mobility

10. The drivers for mobility identified in the present report are based primarily on the information available to the Expert. The Expert noted that motivational factors for persons with albinism on the move include escaping extreme forms of persecution and human rights violations, often involving violent attacks, widespread societal stigma and discrimination. Failure to access essential health-care services was also commonly cited as a reason for being on the move. Situations of conflict and natural disasters further exacerbate these situations. There is often more than one motivational factor for mobility. Sometimes persons with albinism seek asylum on multiple grounds, not only due to the albinism condition but also on other grounds that have been the basis of persecution.

#### A. Insecurity and threats to life

11. Fears of attacks, particularly in countries where attacks are reported, is one of the primary motivations for persons with albinism and their families to seek refuge in other countries or in other regions. Since 2006, more than 700 attacks on people with albinism in 30 countries have been recorded.<sup>18</sup> These numbers are thought to be underestimated as authorities do not systematically monitor and document such crimes. Attacks have included abductions, rape, mutilations, and killings are driven by false beliefs that the body parts of persons with albinism can bestow fortune when used for ritual purposes.<sup>19</sup>

12. Many of the refugees that provided submissions to the Expert had either experienced similar violence first-hand or witnessed it, and were not confident that

<sup>16</sup> Monaliza Seepersaud, "The plight of Tanzanian persons with albinism: a case for international refugee and asylum procedure reform", *Emory International Law Review*, vol. 32, No. 1, (2017) p. 115. Available at: <https://scholarlycommons.law.emory.edu/eilr/vol32/iss1/3>.

<sup>17</sup> The choice of host countries is influenced by many different factors, such as language. Migrants with albinism from French-speaking countries are likely to choose France as a destination. Similarly, migrants from the United Republic of Tanzania go to Kenya, where Swahili is spoken. Migrants with albinism may also choose to migrate to a country where they have relatives or acquaintances, where no attacks have been recorded.

<sup>18</sup> OHCHR, *People With Albinism Worldwide: A Human Rights Perspective 2021*, at [https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism\\_Worldwide\\_Report\\_2021\\_EN.pdf](https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report_2021_EN.pdf).

<sup>19</sup> See A/71/255.

the authorities in their respective countries could provide ample protection for them. One case relayed to the Expert was that of a mother of two children with albinism from a refugee camp in East Africa who reportedly sold all her possessions and ended up in a refugee camp in 2015 after someone had broken into her home and kidnapped one of her children with albinism. In another case a young man with albinism who had been in another camp for 17 years said he had left his country after he became aware of a plot to abduct and kill him.

13. In the Africa region, many people with albinism live in rural areas. A high number of attacks and threats have been recorded in rural areas, forcing persons with albinism and their families to move to urban areas. Those who have survived attacks often do not want to continue to stay in the communities where they were attacked. One particular civil society organization assisted a young girl in 2021 who was attacked in the northern part of the country to move to the capital. Similar patterns have been seen in other countries in the region, where persons with albinism and their families are forcibly displaced by attacks from their communities. There appears to be a correlation between the number of attacks recorded in a country and movement of persons with albinism from that country.

14. The vulnerability of persons with albinism to attacks and other human rights violations also appears to increase during volatile periods such as wars, civil unrests and natural disasters. In one francophone African country, it was reported that attacks against persons with albinism increased during the civil war owing to myths that the body parts of persons with albinism had the power when used in rituals to provide divine protection for combatants on the battlefield by making them invincible.

## **B. Aggravated forms of discrimination**

15. Displacement among persons with albinism and their families is also driven by pervasive social rejection, exclusion, isolation, stigma, intolerance, persecution and discrimination. In societies where the condition is not well understood, persons with albinism can be subjected to cruel and degrading treatment by their communities because of their condition forcing them to leave in search of more inclusive communities. In a country in West Africa for instance, a culture of banishment of persons with albinism in five communities in the eastern region was reported. It was alleged that the traditional authorities in these communities issue decrees that persons with albinism are not permitted to reside there owing mainly to a belief that their presence will bring the wrath of the gods on these communities. Persons with albinism in those communities are therefore threatened or coerced into leaving and are told that their safety cannot be guaranteed.

## **C. Inadequate access to critical health goods and service**

16. In some cases, persons with albinism move because they are experiencing health issues and/or concerns for which they cannot access appropriate health care in their countries or communities. This is particularly the case for skin cancer screening and treatment, which is often unavailable in many low-income countries, resulting in the premature death of persons with albinism.<sup>20</sup> Data published by the World Health Organization (WHO) in 2020, for example, showed skin cancer deaths in Zimbabwe were 264, or 0.24 per cent, of total deaths, making it the country with the seventh highest skin cancer-related deaths in the world. Information showed that there is an overall shortfall in basic radiological equipment resources, including radiography

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<sup>20</sup> See [A/HRC/37/57](#).

equipment, in many parts of the world.<sup>21</sup> There have been reports of families of children with albinism from Eastern Europe migrating to France and other Western European countries for medical attention because of limited knowledge and expertise regarding albinism in their countries.<sup>22</sup>

17. In some parts of the world, particularly in Puerto Rico, where Hermansky-Pudlak syndrome is prevalent,<sup>23</sup> persons with albinism must leave their homes and travel to have lung transplants on the United States mainland because there is no transplant centre on the island. There is no treatment for the pulmonary fibrosis which accompanies the syndrome, and at present the only hope of survival is a lung transplant.

#### **D. Challenges relating to distribution of social services**

18. The unequal distribution of social services needed by persons with albinism also leads to the internal displacement of persons with albinism. In some Western countries, families of children with albinism have moved school districts. Although the law requires that all school districts provide reasonable accommodation and tailored support for children with disabilities, including those with albinism, this is not always consistently implemented, resulting in some school districts providing very little support and forcing parents to move to districts with better service provision.<sup>24</sup> In some European countries, many persons with albinism cannot drive owing to the low vision associated with the condition, resulting in some opting to move to places with better public transportation services. People with albinism have also been forced to move from rural to urban areas, which are more developed, in order to access better health, inclusive education, accessible transport and/or other services in countries. This type of migration or movement was commonly found in situations of persons with albinism in Africa, Asia and Europe.

#### **E. Climate change**

19. Although further research is needed on this particular aspect of mobility, it seems that climate change or environmental impact are increasingly becoming motivational factors for moving from one place to another. The information received suggests that migration owing to climate change tends to be more internal within a country. In at least three countries in Africa, organizations stated that persons with albinism who rely on subsistence farming and who spend a great amount of time in the sun are often compelled to relocate to regions with lower temperatures where they can continue to farm in less harsh and sunny climates. At least one person interviewed also mentioned the migration of persons with albinism from one Asian country to another, owing to the extreme heat and the need for a cooler climate.

<sup>21</sup> Maboreke T, Banhwa J, Pitcher RD, “An audit of licensed Zimbabwean radiology equipment resources as a measure of healthcare access and equity”, *Pan African Medical Journal*, vol. 1, No. 34, p. 60.

<sup>22</sup> Global Albinism Alliance.

<sup>23</sup> Submission from the National Organization for Albinism and Hypopigmentation and Hermansky-Pudlak Syndrome Network. Hermansky-Pudlak syndrome (HPS) is a rare, hereditary disorder that consists of two characteristics: decreased pigmentation (albinism) with visual impairment, and blood platelet dysfunction with prolonged bleeding: see <https://rarediseases.org/rare-diseases/hermansky-pudlak-syndrome/>.

<sup>24</sup> Submission from civil society organizations.

## IV. Relevant international and national human rights standards

### A. Asylum and refugee status determination

20. There are a growing number of cases by courts and tribunals in different countries that provide insight on how States are making refugee assessments in relation to asylum seekers with albinism, whether persons with albinism fleeing the above discussed scenarios fit within the definition of a refugee and what challenges, if any, they come across in proving their claims.

21. Under the Convention relating to the Status of Refugees, refugees are, by definition, persons in need of international protection and should be granted asylum. In the Convention, refugees are defined as anyone who (a) has a well-founded fear of being persecuted due to, inter alia, their membership of a particular social group; (b) is outside their country of nationality, and (c) is unable, afraid or unwilling to seek protection in their country of nationality or the country of their habitual residence if they are stateless.<sup>25</sup> In a 2007 case involving a man with albinism from Indonesia seeking refugee status in the United States, the judge held that the claimant was a member of a particular social group because of his albinism. According to the judge, “albinism is an immutable characteristic that [one] is incapable of changing. It clearly identifies [one] on sight.” Similar to this, in 2020, the European Asylum Support Office, which has since become the European Union Agency for Asylum, produced guidance on membership of a particular social group in which it recognizes persons with albinism as members of a particular social group for asylum purposes.<sup>26</sup>

22. Persecution as a ground for a refugee claim includes persecution from non-State actors.<sup>27</sup> This was confirmed in relation to albinism in a 2016 case involving a 7-year-old boy with albinism in the United Kingdom of Great Britain and Northern Ireland facing deportation. In this case, the court noted, “if there is a failure to provide necessary protection against persecution, ..., then there is a proper basis for finding that [persons with albinism] are refugees.”

23. Furthermore, discrimination combined with other adverse factors, such as a general atmosphere of insecurity in the country of origin for persons with albinism can reasonably justify a claim to well-founded fear of persecution on “cumulative grounds.”<sup>28</sup> France, for example, granted refugee status to a Nigerian woman with albinism who had fled from Nigeria after being blamed for the death of men in her clan, because of her albinism. The court took into account the strong beliefs, traditions and customs relating to albinism in Nigeria, as well as the dearth of protective measures for persons with albinism, in deciding that there was a real risk of persecution if she were to return to Nigeria.<sup>29</sup> The European Asylum Support Office in its guidelines has gone further, to include a well-founded fear of severe discrimination or stigmatization as amounting to persecution in some circumstances, and particularly point to this in relation to persons with albinism.<sup>30</sup>

<sup>25</sup> Convention relating to the Status of Refugees, art. 1 (A) (2); and Protocol Relating to the Status of Refugees, art. 1.

<sup>26</sup> See <https://www.easo.europa.eu/sites/default/files/EASO-Guidance-on%20MPSG-EN.pdf>.

<sup>27</sup> UNHCR, *Handbook and Guidelines on Procedures and Criteria for Determining Refugee Status under the 1951 Convention and the 1967 Protocol Relating to the Status of Refugees* (HCR/1P/4/ENG/REV.3) (Geneva, 2011).

<sup>28</sup> UNHCR, *Handbook and Guidelines on Procedures and Criteria for Determining Refugee Status*.

<sup>29</sup> Guidelines on International Protection (HCR/GIP/06/07), “Membership of a particular social group” within the context of article 1A (2) of the 1951 Convention.

<sup>30</sup> <https://euaa.europa.eu/sites/default/files/EASO-Guidance-on%20MPSG-EN.pdf>.

24. What is essential when it comes to determination of refugee status of persons with albinism is, as noted by the Expert in the report on protection of persons with albinism, that “those making refugee status determinations are aware of the multiple layers of discrimination and other human rights violations persons with albinism are often exposed to ... which would warrant the application of relevant guidelines such as those on discrimination, persecution, child asylum, gender and potentially trafficking. Further, tribunals determining refugee status should be aware of the severity of attacks and the lack of accountability in relation to attacks in some countries.”<sup>31</sup>

25. In addition, the principle of non-refoulement prohibits the return of any person, in any manner whatsoever, to territories where they may be at risk of persecution, torture, or other forms of serious harm. The prohibition of refoulement is considered to be a principle of customary international law. In relation to this, the Committee against Torture and the Committee on the Rights of the Child have stated that attacks against persons with albinism can, in certain circumstances, amount to torture.<sup>32</sup>

## **B. Refugees, asylum-seekers and internally displaced persons with albinism**

26. While there are no international treaties which specifically mention the rights of refugees, asylum-seekers or internally displaced persons with albinism, article 11 of the Convention on the Rights of Persons with Disabilities requires State Parties to the Convention to:

take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict [and] humanitarian emergencies.

27. This provision has been interpreted to mean that disability should be mainstreamed in migration and refugee policies.<sup>33</sup> Such policies would need to take into account the other provisions of the Convention on the Rights of Persons with Disabilities, including: article 5, which requires States to ensure that reasonable accommodation is provided in these policies; article 4.3, requiring consultation and active participation of persons with disabilities in the formulation and implementation of such policies; article 25, on the right to health, including health services needed by persons with disabilities specifically because of their disabilities; and article 28, on an adequate standard of living and social protection.<sup>34</sup>

28. Further light on the rights of refugees, asylum-seekers and internally displaced persons with disabilities has been provided by the Committee on the Rights of Persons with Disabilities in its interpretation and application of article 11 of the Convention on the Rights of Persons with Disabilities. The Committee has called on States to ensure the systematic registration of internally displaced persons with disabilities;<sup>35</sup> monitor the situation of persons with disabilities in refugee camps with the purpose of ensuring an adequate standard of living;<sup>36</sup> make information available in formats

<sup>31</sup> [A/75/170](#), para. 25.

<sup>32</sup> See [CAT/C/BDI/CO/2](#); and [CRC/C/CAF/CO/2](#). See also [A/72/131](#), paras. 33–36.

<sup>33</sup> [CRPD/C/EU/CO/1](#), para. 35.

<sup>34</sup> Thematic study on the rights of persons with disabilities under article 11 of the Convention on the Rights of Persons with Disabilities, on situations of risk and humanitarian emergencies ([A/HRC/31/30](#), paras 9–12).

<sup>35</sup> [CRPD/C/UKR/CO/1](#), para. 25.

<sup>36</sup> [CRPD/C/KEN/CO/1](#), para. 22 (c).

accessible to persons with different types of impairments;<sup>37</sup> and to ensure disability-awareness training for all potential actors involved in humanitarian emergencies.<sup>38</sup> As persons with disabilities, these standards are also applicable to persons with albinism.

### **C. Migrants with albinism under international law**

29. Migrant workers with albinism and their families are protected by the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families. This Convention requires States to, *inter alia*: implement measures to respect and protect their right to life;<sup>39</sup> ensure that they receive any medical care that is urgently required for the preservation of their life or the avoidance of irreparable harm to their health on the basis of equality of treatment with nationals of the State concerned;<sup>40</sup> and ensure access to education for their children on the basis of equality of treatment with nationals of the State concerned.<sup>41</sup> As with refugees, asylum-seekers and internally displaced persons, these rights should be interpreted taking into account the provisions of the Convention on the Rights of Persons with Disabilities.

### **D. National laws**

30. The Expert did not receive adequate information on the protection of persons with albinism on the move under national legal and policy frameworks. She notes that, generally, the rights of persons with albinism on the move are recognized within the broader national legal and policy frameworks protecting migrants in domestic law and policies. The extent to which these frameworks are inclusive and cognizant of particular issues facing persons with albinism on the move requires more research. Without a clear articulation in law, policy and programmes, the particular issues affecting persons with albinism on the move are likely to be neglected and no sustained measures taken to protect, assist and provide for them. The widespread ratification of the Convention on the Rights of Persons with Disabilities has resulted in the adoption of disability laws and policies by many countries. Whether persons with albinism on the move also enjoy the rights set out in these frameworks remains to be established. The Expert thanks Member States who responded with information regarding national legislation and policies.<sup>42</sup>

## **V. Human rights concerns**

### **A. Challenges in seeking asylum and other migration related procedures**

31. The Committee on the Rights of Persons with Disabilities has identified concerns regarding the rights of migrants, asylum seekers and refugees with disabilities in general. For example, in relation to the European Union, it highlighted, “the precarious situation of persons with disabilities in the current migrant crisis in

<sup>37</sup> [CRPD/C/SLV/CO/1](#), para. 26; [CRPD/C/DEU/CO/1](#), para. 40; [CRPD/C/MEX/CO/1](#), para 22 (b); and [CRPD/C/GAB/CO/1](#), para. 27.

<sup>38</sup> [CRPD/C/AZE/CO/1](#), para. 25; [CRPD/C/MEX/CO/1](#), para. 22 (c); and [CRPD/C/DEU/CO/1](#), para. 31.

<sup>39</sup> International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, arts. 9 and 28.

<sup>40</sup> *Ibid.*, art. 28.

<sup>41</sup> *Ibid.*, arts. 30, 43 and 45.

<sup>42</sup> See footnote 1.

the European Union” and in particular raised concern that, “the migration decision-making procedure is not accessible for all persons with disabilities and that information and communication are not provided in accessible formats.”<sup>43</sup>

32. Similarly, many persons with albinism seeking asylum reportedly find the process complex and challenging and need, but struggle to access, legal representation to help navigate the processes involved. It is not common for reasonable accommodation and support to be provided for persons with albinism during the immigration process. From several of the experiences reported, some are turned down when they first apply for refugee status. They are granted refugee status only on appeal. Persons with albinism with low vision, and in many cases, low educational qualifications, struggle with immigration or asylum procedures because they may not be able to complete their applications correctly, particularly where these are not available in large print. In addition, linguistic and cultural barriers, as well as a lack of psychosocial support during the immigration or asylum process for trauma experienced in the home country may also make it difficult for asylum seekers with albinism to express themselves well during interviews. Many people on arrival in host countries have no financial resources and reportedly spend the first few days or weeks homeless sleeping on the street. The process of seeking asylum can also be lengthy.

33. Based on requests for support made by persons with albinism on the move to local organizations of persons with albinism in the countries to which they have already migrated, assistance is needed in obtaining information on the immigration processes, processing their applications, legal representation, obtaining employment in the country, for specific needs related to their albinism, such as health needs while waiting for status to be determined, and for more general support because they are asylum seekers, such as financial support.

34. Furthermore, knowledge of albinism and issues affecting persons with albinism by government officials (case workers, immigration officials, immigration lawyers and judges) is limited. This is often a reflection of the generally limited knowledge of albinism by society. In many instances, immigration officials are not regularly exposed to persons with albinism on the move, which impacts on how they handle such cases. The limited understanding of the risks experienced by persons with albinism, especially in contexts where the persons conducting the refugee status determination have little exposure to issues related to albinism means the connection between albinism and refugee claims might be missed. This highlights the importance of available and comprehensive country-of-origin information on albinism as a key element to ensure that the refugee claims will be properly addressed, resulting in fair individual decisions on the international protection needs of persons with albinism on the move.

## **B. Refugees and asylum seekers with albinism in refugee camps**

35. The lack of recognition of refugees with albinism as persons with disabilities or as a vulnerable group in need of additional protection often means that their needs are neglected. Their stays at refugee camps are often lengthy and the particular situation of refugees in camps means that they are more likely to be dependent on authorities for accommodations and other needs. Individuals with albinism in refugee camps directly engaged with the Expert through virtual interviews to provide insights on their experiences.

36. Refugees with albinism staying in refugee settlements complained of irregular to no access to critical health services and products needed by them, including

<sup>43</sup> CRPD/C/EU/CO/1, para. 34.

dermatological and ophthalmology services. Refugees with albinism in camps commonly struggle to access goods and services related to their skin care, i.e., sunscreen lotion, protective clothing, skin cancer screening and treatment services, skin clinics and sun protective behaviour information. This increases their vulnerability to developing skin cancer. In addition, psychosocial support is often not adequately provided for persons with albinism who have sustained trauma from experiences of discrimination, insecurity and displacement that lead them to flee their countries.

37. Skin care information, products and services are often provided by civil society organizations. Some of those interviewed by the Expert in one camp stated that, in the previous six years, they had received essential products and services such as soap, sunscreen lotion, hats and umbrellas and skin cancer screening from civil society organizations. Similarly, in another refugee camp in East Africa, the sunscreen received by persons with albinism in the last few years has also been donated by a number of civil society organizations.<sup>44</sup> These organizations, many of which rely on donor funding, are, despite their best efforts, unable to provide consistent and sustained access to skin care products and services and so there are often gaps, and sometimes overlaps, in the provision of goods and services. In addition, the quality of sunscreen provided is unregulated and the appropriateness for use unchecked, with some having insufficient levels of sun protection factor for a specific climate. Refugees have complained that some of the sunscreens are damaging to their skin or ineffective in protecting them from the sun when applied. UNHCR, through various partners, also provides sunscreen and protective wear to refugees with albinism in a number of cases.

38. The continuous exposure to the sun without protective clothing and sunscreen often results in refugees with albinism becoming sunburned and developing moles, blisters, wounds and precancer lesions. One medical practitioner, during his visit to a refugee camp where he examined 53 persons with albinism, observed that most of them had developed pre-cancer lesions. At least two of the people had cancer.

39. Refugees with albinism staying in refugee settlements also struggle to access ophthalmology services. Those in camps stated that, since arriving at the camps, they had not received any consultation for their visual needs. Consequently, most of these individuals did not have the necessary visual aids, on which they relied. In one camp, a civil society organization provided sunglasses but these were generic and not tailored to specific visual needs. Persons with albinism in this particular camp were reportedly provided solar-powered headlamps by a civil society organization, to enable them to be out in the evenings and at night, and to have a sense of safety.

40. Despite the trauma experienced by many of the refugees with albinism in these camps, continuous psychosocial support to those in need of it is often not provided. One medical practitioner in his assessments of refugees with albinism noted that some persons with albinism were psychologically distressed while others showed signs of severe depression.

41. The clinics within these refugee camps are often already stretched beyond capacity and often do not have the ability to provide the specific health-care services needed by persons with albinism. The best that they have been able to do is to refer patients with albinism to the nearest hospitals outside the camp for further assistance but this referral system does not seem to work well in most instances, leaving the health needs of refugees with albinism unattended.

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<sup>44</sup> Percy Chikwela, "Malawi: refugees with albinism find succour in camp", Office for the Coordination of Humanitarian Affairs, press release, 3 February 2015. Available at <https://reliefweb.int/report/malawi/malawi-refugees-albinism-find-succour-camp>.

### C. Stigma and discrimination

42. Discrimination against persons with albinism and their families often persists in refugee camps. Refugees with albinism reported incidents of name calling, segregation, harassment, bullying and physical violence in camps. Refugee camps often house refugees from many different countries who come from different tribes, cultures, clans and religious beliefs, some of which have harmful superstitions and beliefs about albinism. This tends to heighten the discrimination experienced by persons with albinism in these camps, particularly in the absence of awareness-raising campaigns to correct misconceptions on albinism. In a number of refugee camps, refugees with albinism were considered to be small gods, demons or spirits, and as a result some of the other refugees did not want to associate with them. Mothers of children with albinism in camps reported being despised and ridiculed for having a child with albinism.<sup>45</sup> Refugees in one camp recounted how, when they tried to fetch water, people would push them away, chase them off and at times even beat them, wounding them.<sup>46</sup>

### D. Persisting insecurity

43. Continued insecurity and threats of attacks from within and outside the camps are a significant concern for refugees with albinism in camps. The Expert was informed of a case where a refugee with albinism was found unconscious outside of the camp, two days after his family had alerted police that he was missing. In another camp, refugees with albinism reported that a man with albinism had disappeared from the camp and no further information had been received regarding his whereabouts. In other countries, refugees with albinism reportedly returned to their countries because of security concerns at the camp. In a particular province, which hosts a high number of refugees and internally displaced persons, there have been allegations that persons with albinism have also been kidnapped. Such reports have the effect of increasing the feeling of insecurity and mental anguish of refugees with albinism in the camp.

44. Persisting insecurity has resulted in instances where refugees with albinism move several times before they settle.<sup>47</sup> This normally happens in contexts where they experience similar or worse discrimination, insecurity and hostility in host countries to that which they experienced in their own home countries.

### E. Inadequate standard of living

45. The Expert, in her discussion with refugees in a particular country, was informed that the allowance that they received in camps was often not adequate to maintain an adequate standard of living. It also did not take into account disability-related additional costs (e.g., purchase of protective clothing, sunscreen and eyewear). In some cases, for instance, refugees stated that they received a monthly allowance of the equivalent of \$3 to cover all basic needs (it is not clear whether the amount was per person or per household). Most noted that this was insufficient to also cover additional expenses that they incurred, such as purchase of sunscreen lotion and that

<sup>45</sup> See [A/HRC/43/42](#).

<sup>46</sup> In some instances, negative perceptions about refugees with albinism exist outside the walls of the camps in the host communities. Refugees with albinism tend to be seen as a burden to the health system and economy and as people who will not contribute positively to the host society. Some of the negative perceptions reflect perceptions of migrants generally in that country.

<sup>47</sup> Adediran Ikuomola, “‘We thought we will be safe here’: narratives of Tanzanian albinos in Kenya and South Africa”, *African Research Review*, vol. 9, No. 4 (2015).

they also suffered discrimination when trying to access employment in contexts where they were permitted to work. Some individuals receive additional financial support from their families in their country of origin to help cover living costs. Many live in abject poverty and have to make hard choices between purchasing food and essential sunscreen. They also report difficulties in affording three meals a day, and this results in malnutrition. The situation worsened during the coronavirus disease (COVID-19) pandemic, when the frequency of food donations provided to refugees declined. Many refugees complained of extreme hunger and long queues for food when food parcels did arrive during this time. Persons with albinism report having had to stand in long queues in the sun to receive food aid; no exception was made.

## **F. Discrimination in accessing employment opportunities**

46. The Expert was informed that refugees with albinism struggle to earn a livelihood, and finding employment is often very difficult. Employers are reluctant to employ persons with albinism. Some refugees with albinism have been told outright by employers that they do not employ persons with albinism. This affects both low-skilled and highly skilled refugees with albinism. Those who work often do odd jobs such as gardening, laundry, fetching water for people, working on farms and making bricks, which require them to spend a number of hours in the sun. At the height of the COVID-19 pandemic, some refugees with albinism reported that they had lost their jobs because employers believed that they were more susceptible to contracting the virus. Many employers, out of ignorance, do not provide employees with albinism with reasonable accommodation. For instance, migrants with albinism in a north African country reported that, because of the low prevalence of albinism in the country, employers did not understand albinism. This often hampered their ability to reasonably accommodate employees with albinism because they did not for instance understand why the employee had to be exempted from responsibilities that exposed them to the sun. They expected all employees to work under the same conditions.

47. Refugees with albinism who are self-employed struggle to get customers. In the interviews, one of the women with albinism shared that, when she took her goods to the market, people did not want to buy them because of her albinism. Many lost their sources of income when economic activities slowed down during the first years of the COVID-19 pandemic, which was a huge blow to their livelihood from which they have not recovered.

48. Cases of associated discrimination were also reported. Family members of persons with albinism were denied employment because of their relationship to someone with albinism. Some organizations have attempted to assist with income-generating activities for persons with albinism in camps. However, some of these initiatives raise concerns regarding the persons with albinism. For example, at least one organization has reportedly implemented brickmaking and homebuilding projects carried out during the day and thus increasing their susceptibility to skin cancer.<sup>48</sup>

49. In addition to the challenges that refugees with albinism experience, they also stated that it was difficult to obtain redress or support when they informed the relevant authorities in the camps about their situations. They often received feedback that did not demonstrate an understanding of their vulnerable situation and there was a tendency to be accused of exaggerating their struggles in order to expedite their resettlement. They further stated that human rights complaints mechanisms were not always responsive to their complaints and that this led to a number of refugees with

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<sup>48</sup> See <https://uganda.lutheranworld.org/content/refugees-albinism-brave-scorching-sun-and-mud-living-106>.

albinism feeling that their rights were not safeguarded and their confidence in these institutions was undermined.

## **VI. Persons with albinism in vulnerable situations in refugee camps**

### **A. Children**

50. Children with albinism experience bullying, physical assaults, name-calling and segregation in the refugee camps, including in the schools that they attend, which are normally located in the camps.<sup>49</sup> One girl interviewed recounted how her family had sent her to buy food and she had been beaten up by people who told her that they did not want her “type” in the camp. Children with albinism thus find it difficult to socialize with other children in the refugee camp and spend a lot of their time isolated or with their families.

51. The right to education for children is also compromised in the camps. Many do not attend school or have dropped out for a number of reasons. Some children with albinism do not attend school because their families cannot afford to pay the fees and buy the stationery required. The discrimination experienced at the hands of both teachers and fellow students caused some students with albinism to drop out of school completely or be absent from school. In one camp, the mother of a child with albinism reported that her child often came home early owing to the abuse that she experienced at the hands of other children. Reasonable accommodation is rarely provided in these schools for students with albinism. Requests for accommodations by students such as for the teacher to write in a larger script on the board or for a student to sit in front of the class, are not always received positively and sometimes even elicit hostile responses. In the absence of support from the teachers, students have to be resourceful and rely on their classmates for assistance, for instance by copying notes from them. Most of these students do not receive eye screening or assistive devices such as glasses, monoculars or magnifying glasses that would amplify their vision. This hinders their ability to read well, see the board and charts and at times make their way around the school confidently. Many students with albinism, as a result of the lack of support in school and the discrimination experienced, perform poorly in their classes, or drop out.

52. There is also a continuing danger of children with albinism falling victim to attacks while making their way to school. A teenage boy with albinism residing in one of the camps was reportedly attacked by two men with pangas on his way back from school. He narrowly survived the incident because a passer-by came to his rescue.<sup>50</sup> UNHCR has discussed the risk faced by children with albinism in a research paper published in 2011, noting that children accused of witchcraft do not fit one single profile, but some, such as children with disabilities or albinism, are targeted owing to their physical appearances.<sup>51</sup>

### **B. Women and girls**

53. The intersection of albinism and gender makes females with albinism in camps vulnerable to sexual harassment, assault and violence, which are common issues affecting women and girls in many refugee camps. A young girl with albinism from

<sup>49</sup> Engagement by the Independent Expert with refugees with albinism in a camp.

<sup>50</sup> Ibid.

<sup>51</sup> UNHCR, “Breaking the spell: responding to witchcraft accusations against children”, research paper No. 197, January 2011.

one camp reported that she was sexually assaulted in 2017 when she was 15, by someone known to her father. She reported the incident to the police and has been following up but to date nothing has been done to apprehend the perpetrator. Females with albinism also receive indecent and unwanted proposals from men who are curious about what sexual intercourse would be like with a person with albinism. As one respondent put it, “men want to test whether women with albinism are like “real” girls”. Young girls with albinism who drop out of school are in danger of being coerced into early marriages. Mothers of children with albinism are also vulnerable. In one case, a mother of a child with albinism related being propositioned by a man who wanted to have a child with albinism with her apparently because he believed having the child would increase his chances of being relocated overseas.

## VII. Migrants, asylum seekers and refugees living outside of camps

54. Although most of the information received by the Expert was in relation to refugees with albinism in refugee camps, some helpful information on the situation of migrants and refugees with albinism living in host countries outside camps was also received. Like most other refugees, persons with albinism often struggle to integrate into the society and culture of the host country even after being granted permission to legally stay there.<sup>52</sup> Related to this is also the struggle to obtain employment and make a living.

55. Many struggle to access social and other services and benefits available to nationals with albinism in a country. The degree of access to services and benefits differs from country to country. Much of the access to services and benefits depends on immigration status and the entitlements that flow from that status, so this creates many variables depending on the country’s system. Access to services and benefits also depends on whether or not nationals are provided these services and benefits. For instance, in countries which have few benefits and services for nationals with albinism, it follows that these will be even fewer for refugees.

56. Most persons with albinism on the move are also not aware of the services and benefits available or how to access them. For example, in relation to psychosocial support, some countries have policies in place from which refugees with albinism can benefit. The Reception Conditions Directive (2013/33/EU), for instance, provides that “An individual assessment must be made in order to assess the needs of vulnerable people (children, disabled people or victims of abuse)”. It also stipulates that “vulnerable asylum seekers must have access to psychological care”. However, a lack of understanding of albinism and knowledge of the experiences of persons with albinism in their home countries means that persons with albinism may not always be identified as persons with disabilities or vulnerable people. Furthermore, depending on their own experiences, persons with albinism may not themselves be aware that they qualify as vulnerable people.

57. In general, access to these services is normally complex and challenging, even for nationals with albinism to navigate. For instance, social protection systems in some Western countries are considered to be complex, at times cumbersome to navigate, by beneficiaries with albinism.<sup>53</sup> There is a sense that some migrants do not request or insist on services or benefits, even if they are legally entitled to them, for fear of being perceived as a burden by their host countries.

<sup>52</sup> Being relocated brings with it issues of displacement, such as cutting ties with families, inter alia, which are often not considered from the perspective of persons with albinism.

<sup>53</sup> Consultation between the Expert and civil society organizations from Western countries.

58. From the consultations held with different groups and individuals, it seems that migrants and refugees with albinism often struggle to be included in the local albinism organizations of the countries to which they have migrated. Some of the reasons put forward for this are differences in language, cultural and socioeconomic status. Few end up forming their own organizations.

59. In addition, in many host nations, refugees and migrants tend to gravitate to neighbourhoods where there are other refugees or migrants from their home country or continent. In these neighbourhoods or groupings, the misbeliefs and dangerous misconceptions related to albinism from home countries may persist, resulting in stigma and discrimination against refugees with albinism.

## VIII. Internally displaced persons

60. From submissions received it would seem that barely any support is offered to internally displaced persons with albinism. Internally displaced persons with albinism often relocate on their own. Support provided by Governments to internally displaced persons in general is not always disability inclusive. In one country, according to personal accounts by internally displaced persons with albinism, although the Government provided some services and shelter for those fleeing the conflict that was taking place in parts of the country, these services did not specifically take into account the additional needs of persons with disabilities and albinism more broadly. In particular, concerns related to the safety of persons with albinism in temporary shelters provided and to exposure to the sun did not appear to have been taken into account. The trend suggests that, where Governments assist internally displaced persons with albinism, they tend to prioritize assisting people displaced because of attacks over those displaced because of other reasons, including climate change and discrimination within society. They also prioritize the safety of children and offer greater assistance in cases where a child is involved but often do not assist the whole family to relocate, resulting in children being separated from their families and placed in institutional care.

61. Some of the other challenges that families face in internally migrating include: making the transport and other logistical arrangements to move; safety while in transit to a new location and on arrival; financial resources to pay for their upkeep once they have moved, especially where they have moved to cities where life is more expensive compared with where they are coming from; and accessing social and other services in transit and where they relocate, including psychosocial support, rehabilitation services and temporary safe houses. This is particularly the case in countries where proof of residence in the area where medical attention is being sought, or proof that someone who is a resident of that area is being visited, is required in order to obtain full access to the local health services.<sup>54</sup> Most of the support received by internally displaced persons with albinism is again mainly from civil society and humanitarian organizations. Some of the help provided is towards migration from rural areas either to urban areas or safer neighbourhoods within the same district or province. However, owing to lack of resources, these organizations can help people only for a short period of time and are forced either to encourage people to return home or withdraw support even though the internally displaced person is not yet able to sustain themselves.

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<sup>54</sup> For example, Parirenyatwa Hospital.

## IX. Positive practices

62. As previously mentioned, much of the information regarding persons with albinism on the move is subsumed in the research information on persons with disabilities. However, the Expert was able to identify some promising practices by States. Most of these relate to asylum determination for persons with albinism. There are also promising policies and practices from States and civil society organizations related to the provision of rights and services for refugees and migrants with albinism.

### A. European Union guidance documents and tools

63. In 2022, the European Asylum Support Agency was transitioned into the European Union Asylum Agency in an effort to establish a formal and harmonized European Union-wide identification process for migrants, including migrants with special needs and disabilities. The European Union asylum framework leaves it to the discretion of each Member State to decide the methodology for identifying and assessing the needs of applicants for international protection, but develops tools based on good practices to support Member States in these tasks, as well as guidance documents which specifically mention albinism.

64. The guidance on membership of a particular social group under this framework recognizes persons with albinism as members of a particular social group for asylum purposes. It also includes a well-founded fear of severe discrimination or stigmatization as amounting to persecution in some circumstances, and specifically mentions this in relation to persons with albinism.

65. It also issues country of origin information that gathers relevant information and draws up reports providing up-to-date information on third countries to support European Union asylum and migration authorities in reaching decisions in asylum procedures, or support policymaking.<sup>55</sup> It is notable that the country guidance for Nigeria was updated in 2019 to include individuals accused of witchcraft, individuals with albinism and individuals fearing ritual killings as particular profiles with regard to qualification for refugee status.<sup>56</sup> There are several other countries with a high number of attacks against persons with albinism stemming from accusations of witchcraft and ritual practices that induce threatened individuals to migrate and potentially seek refugee status. These too could benefit from accurate country of origin information guidance specifically mentioning these categories.

66. In addition, the European Union has developed an online tool for the identification of persons with special needs (IPSN tool).<sup>57</sup> The online tool, designed to support Member States migration authorities, does not mention albinism as a specific vulnerability but provides a detailed list of physical, psychosocial and environmental indicators, several of which would qualify persons with albinism as migrants with special needs. These include physical signs (such as bruises, scars, burns, fractures and deformations), injuries apparently as a result of assault, visible signs of illness (such as skin sores which might be cancerous), diagnosed health conditions, symptoms of health conditions, disability limiting the physical function of limbs, vision impairment and condition classified as a disability under national legislation.

<sup>55</sup> For country of origin information, see <https://euaa.europa.eu/country-origin-information>.

<sup>56</sup> See <https://euaa.europa.eu/country-guidance-nigeria-2021/2-refugee-status>.

<sup>57</sup> <https://ipsn.easo.europa.eu/ipsn-tool>.

## **B. Office of the United Nations High Commissioner for Refugees – framework to protect persons with albinism**

67. UNHCR has a direct interest in the human rights concerns of persons with albinism on the move as its mandate is directly focused on forcibly displaced persons and their protection. The updated UNHCR Policy on Age, Gender and Diversity (2018) requires UNHCR and partners to understand and analyse the exposure to protection risks which women, men, girls and boys of concern with albinism face during displacement and how such exposure to risks could impact them. UNHCR has been developing guidance to support programmatic response, for example the need-to-know guidance on working with persons with disabilities in forced displacement, which includes a paragraph underlining the stigma and discrimination faced by persons with albinism and emphasizes the rights-based approach. From a procedural perspective, UNHCR has integrated guidance on provision of reasonable accommodation and supporting persons of concern accessing and meaningfully engaging in processes from consultations to resettlement processes.<sup>58</sup>

68. Additionally, UNHCR has developed training materials and an e-learning module on disability inclusion and rights-based approach, and proactively reaches out to offer these materials to colleagues in order to enhance their capacities to protect and include persons with albinism. Collaboration with the International Disability Alliance supports the goal of capacity-building and mindset shift towards a rights-based understanding and meaningful participation.

69. In 2021, UNHCR identified persons with albinism in Malawi as one of those with protection needs and has been conducting meetings that include persons with albinism. While there are no special arrangement for asylum seekers with albinism in Southern Africa, UNHCR has assisted in the past in resettling refugee families, including in Zambia. UNHCR has also cooperated with the former Expert on albinism on individual cases involving persons with albinism.

## **C. Office for Refugees and Stateless Persons: information notes on the situation of persons with albinism – France**

70. Similar to the country of origin information guidance produced by the European Union are the information notes on the situation of persons with albinism developed and published by the French Office for Refugees and Stateless Persons (OFPRA). At least five of these notes have been published in relation to persons with albinism specifically from Niger, Senegal, Mali, Mauritania and the Democratic Republic of the Congo respectively.<sup>59</sup> According to the Office, they have been prepared in order to

<sup>58</sup> See for example, UNHCR accountability to affected people toolkit, tool on supporting participation of persons with disabilities (available at [www.unhcr.org/handbooks/aap/documents/UNHCR\\_AAPTool\\_PI\\_Supporting\\_Participation\\_of\\_Persons.pdf](http://www.unhcr.org/handbooks/aap/documents/UNHCR_AAPTool_PI_Supporting_Participation_of_Persons.pdf)); UNHCR Integration Handbook (available at [www.unhcr.org/handbooks/ih](http://www.unhcr.org/handbooks/ih)); UNHCR RSD Procedural Standards Unit 3.4 on applicants with specific needs, 26 August 2020 (available at: [www.refworld.org/docid/5f3115564.html](http://www.refworld.org/docid/5f3115564.html) and [www.unhcr.org/registration-guidance/chapter3/setting-up-registration-locations/](http://www.unhcr.org/registration-guidance/chapter3/setting-up-registration-locations/)), noting that “The registration site is accessible if most individuals, including those with restricted mobility or specific needs, can reach the site without undue hardship or exposure to security issues, xenophobic incidents or other protection risks.”

<sup>59</sup> Nigeria: [https://www.ofpra.gouv.fr/sites/default/files/atoms/files/1812\\_nga\\_albinos.pdf](https://www.ofpra.gouv.fr/sites/default/files/atoms/files/1812_nga_albinos.pdf); Senegal: [https://www.ofpra.gouv.fr/sites/default/files/atoms/files/3.\\_dodr\\_senegal\\_situation\\_des\\_albinos\\_ofpra\\_06042016.pdf](https://www.ofpra.gouv.fr/sites/default/files/atoms/files/3._dodr_senegal_situation_des_albinos_ofpra_06042016.pdf); Mali: [https://www.ofpra.gouv.fr/sites/default/files/atoms/files/2104\\_mli\\_albinisme\\_151792\\_web.pdf](https://www.ofpra.gouv.fr/sites/default/files/atoms/files/2104_mli_albinisme_151792_web.pdf); Mauritania: [https://www.ofpra.gouv.fr/sites/default/files/atoms/files/2106\\_mrt\\_situation\\_des\\_pva\\_153176\\_web.pdf](https://www.ofpra.gouv.fr/sites/default/files/atoms/files/2106_mrt_situation_des_pva_153176_web.pdf); Democratic Republic of the Congo: [https://www.ofpra.gouv.fr/sites/default/files/atoms/files/1805\\_cod\\_les\\_personnes\\_vivant\\_avec\\_lalbinisme.pdf](https://www.ofpra.gouv.fr/sites/default/files/atoms/files/1805_cod_les_personnes_vivant_avec_lalbinisme.pdf).

provide useful information for the examination of applications for international protection.

#### **D. National Action Plan for Persons with Albinism: Uganda**

71. In the wake of the adoption of the Regional Action Plan on Albinism (2017-2021), which was succeeded in 2019 by the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031), a number of African countries have adopted or are in the process of adopting national action plans on Albinism. This includes Kenya, Malawi, Mozambique, South Africa, Uganda and the United Republic of Tanzania. Of particular relevance to the issues discussed in the present report is the National Action Plan for Persons with Albinism of Uganda, adopted in June 2022, which incorporates specific provisions for refugees with albinism. It calls on the State to mainstream the rights and basic needs of refugees with albinism into refugee programmes; create awareness about albinism among refugees and refugee agencies; integrate the specific needs of refugees with albinism into national intervention programmes on albinism; and implement programmes for skilling and building the self-esteem of refugees with albinism.<sup>60</sup> It is hoped that other States' national action plans can also take note of this good practice where it may be of relevance to their specific context.

#### **E. Initiatives by civil society organizations and other stakeholders**

72. The National Organization for Albinism and Hypopigmentation, based in the United States, periodically supports, on request, migrants with albinism or their legal representatives by acting as an expert witness in their applications.<sup>61</sup> The organization provides factual information on the condition and the abuses that persons with albinism experience in other countries. The organization has, on at least one occasion, been asked by immigration officials in the United States to assist in verifying the needs of a person with albinism in their custody. Similarly, Genespoir, which is based in France, also provides authoritative information on albinism to immigration lawyers representing persons with albinism who reach out to it.

73. The Government has also reached out on occasion to the organization when it had a foreign national with albinism in immigration custody to understand more about albinism and relevant reasonable accommodation needs. Other organizations in the global north indicated that they had received very few or no requests to intervene in asylum processes.<sup>62</sup>

#### **F. Humanitarian assistance to refugees in camps**

74. In Uganda, the Source of the Nile Union of Persons with Albinism, in collaboration with Advantage Africa, provides persons with albinism in two refugee settlement camps with sunscreen lotion, wide-brim hats, and dermatological examinations. It also undertakes research to gain a better understanding of the challenges facing persons with albinism in the camps. The Pierre Fabre Foundation also runs skin clinics and provides sunscreen at one refugee camp while Plan International and Standing Voice are providing sunscreen in a refugee camp in

<sup>60</sup> See <https://albinismumbrella.org/wp-content/uploads/2022/06/NAPPWA-Executive-Summary.pdf>.

<sup>61</sup> Submissions from National Organization for Albinism and Hypopigmentation and Genespoir.

<sup>62</sup> Albinism Fellowship of UK and Northern Ireland; Dansk forening for Albinisme (Denmark); NOAH Albinismus Selbsthilfegruppe e.V (Germany); Oogvereniging Albinisme (Netherlands); Alba Spain, Albinitt (Italy) and Albinizm Derneği (Turkey).

Malawi. The Jesuits Refugee Service also distributed sunscreen, protective clothing and visual aids. Other initiatives include the provision of solar-powered headlamps to persons with albinism to enable them to be out at night with more security.<sup>63</sup>

## **G. Assistance for internally displaced persons**

75. In Zambia, the Albinism Foundation of Zambia provides transport for internally displaced people with albinism who are looking to move. They further provide assistance in relation to accommodation, empowering them to start businesses or obtain employment, food and other necessities, as well as fees and psychosocial support.

76. To try to keep up with requests for accommodation from persons with albinism who have fled their homes, the Albinism Foundation of Zambia has bought a farm and is planning to build a safe home that can accommodate 20 people, allow it to accommodate not just the victims but their families as well. Under the Same Sun has a similar programme in the United Republic of Tanzania. While these initiatives provide much needed support for persons with albinism, it is essential that States work with civil society organizations to ensure long-term sustainability, the necessary security protection and appropriate strategies for the rehabilitation and resettlement of individuals and their families.

## **X. Conclusions and recommendations**

77. **The report provides a preliminary examination of the drivers of mobility and gaps in protection of the rights of persons with albinism on the move, in particular migrants, refugees and internally displaced persons with albinism. There is evidently a need for additional research and dialogue on the issue. The report provides some embryonic insights into the human rights violations experienced by persons with albinism on the move. Key among these is the violation of their right to the highest attainable standard of physical and mental health, the right to an adequate standard of living and social security, freedom from discrimination, the right of access to information and to inclusive education, the right of access to justice, freedom from exploitation and freedom from violence and abuse. In the absence of State action, the existing efforts to address challenges experienced by persons with albinism on the move are being led by a handful of organizations of persons with albinism, other civil society organizations and humanitarian organizations.**

78. **The Independent Expert makes the following recommendations to States:**

(a) **Support the capacity of those making asylum and refugee status determinations to appropriately determine cases of persons with albinism, including through raising awareness of the multiple layers of discrimination and other human rights violations to which persons with albinism are often exposed and the impact of these on the lives of persons with albinism. Associations of persons with albinism should also be approached for the training of personnel and the provision of relevant information;**

(b) **Ensure the collection of disaggregated data on persons with albinism on the move, including through the systematic registration of internally displaced persons and refugees with albinism;**

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<sup>63</sup> Consultation with civil society organizations.

(c) Take measures to increase the understanding of immigration and other relevant officials in relation to albinism, violations against persons with albinism in various countries, as well as the medical and psychosocial needs of persons with albinism;

(d) First reception and identification procedures should be set up in such a way as to allow medical, social and psychosocial staff to work in tandem with the authorities interviewing new arrivals with albinism and detect the special needs linked to their condition, including their visual impairment; the vulnerability of their skin to the sun's radiation and possible skin cancers in need of urgent treatment; the need for assistive and adaptive devices or other accommodations for their visual impairment or whether they have had limbs amputated owing to attacks in their country of origin; as well as potential mental health issues and post-traumatic stress disorder relating to trauma experienced in the country of origin and/or during the migration journey;

(e) Ensure the inclusion of persons with albinism in all migration and refugee policies, including through the consultation and active participation of groups of persons with albinism in the design, development and implementation of such policies;

(f) Formulate human rights-based, gender-responsive and child-sensitive policies to govern migration that promote gender equality and non-discrimination;

(g) Ensure the provision of services for refugees with albinism in camps that take into account their specific reasonable accommodation needs, including in relation to education and employment, as well as health, including health services needed by persons with albinism specifically because of their visual impairment and susceptibility to skin cancer, such as protective clothing, sunscreen and assistive and adaptive devices;

(h) In line with international human rights standards, ensure that persons with albinism on the move receive any medical care that is urgently required for the preservation of their life or the avoidance of irreparable harm to their health on the basis of equality of treatment with nationals of the State concerned; as well as ensure access to education for their children on the basis of equality of treatment with nationals of the State concerned;

(i) Implement specific measures on prevention, protection, accountability and non-discrimination set out in the African Union Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (2021–2031), in Member States, particularly where extreme violence and other human rights violations against persons with albinism have been reported, resulting in the forcible displacement of this group;

(j) Take all measures necessary to prevent, investigate, prosecute and sanction human rights violations and abuse against migrants with albinism, whether perpetrated by public officials or private individuals;

(k) Ensure that migrants with albinism have equal access to legal remedies and complaint mechanisms;

(l) Establish and implement services and programmes to provide comprehensive support and protection to children on the move with albinism in line with the principles and provisions of the Convention on the Rights of the Child;

(m) Cooperate with other States, including through cross-border collaboration, research, capacity-building, information exchange, the sharing of

best practices and technical and financial assistance, for the purposes of increasing the knowledge base and capacity to carry out and improve protection measures for persons with albinism and provide for the needs of those on the move.

**79. Recommendations to other stakeholders:**

(a) The Expert recommends that national human rights institutions effectively incorporate and address the human rights concerns of persons with albinism, including those with albinism on the move in their work;

(b) The Expert urges migrants with albinism to acquaint themselves with their rights and to organize and advocate to protect those rights;

(c) The Expert encourages UNHCR to pay particular attention to persons with albinism in its work and take relevant action to address the concerns of refugees and asylum seekers with albinism;

(d) The Expert also calls on United Nations agencies, international organizations and civil society organizations providing humanitarian support to persons on the move to:

(i) Mainstream albinism into their programmes of work, particularly those related to disability, and to ensure that the specific needs and vulnerabilities of persons with albinism are taken into account and addressed in their work;

(ii) Work with groups of persons with albinism in the development, design, implementation and evaluation of all programmes for the assistance of persons with albinism on the move with a view to ensuring that these services are appropriate and accessible;

(iii) Work with the authorities and other organizations to coordinate their activities for the provision of services and products for persons with albinism on the move, including the provision of sunscreen, protective clothing and visual aids, to prevent overlap and duplication of services and ensure the widest coverage of services possible;

(e) The Expert further calls on associations of persons with albinism to include asylum-seekers, refugees, internally displaced persons and migrants in their areas of work and to provide information and access to services to these groups.