Assemblée générale

Distr. générale
23 janvier 2019
Français
Original : anglais

Conseil des droits de l'homme
Quarantième session
25 février-22 mars 2019
Point 3 de l'ordre du jour
Promotion et protection de tous les droits de l'homme, civils,
politiques, économiques, sociaux et culturels,
y compris le droit au développement

Table ronde sur les droits de l'homme et l'albinisme : définir un consensus et des priorités en matière de plaidoyer et de recherche

Rapport de l'Experte indépendante sur l'exercice des droits de l'homme par les personnes atteintes d'albinisme*, **

Résumé

　　Dans son rapport, Ikponwosa Ero, l'Experte indépendante sur l'exercice des droits de l'homme par les personnes atteintes d'albinisme, présente les conclusions de la Table ronde sur les droits de l'homme et l'albinisme, qui s'est tenue à Genève les 20 et 21 septembre 2018. La Table ronde a réuni des universitaires, des décideurs et des acteurs de la société civile dans le but de définir un consensus concernant les priorités en matière de recherche, de plaidoyer et d'élaboration de politiques concernant l'albinisme, les pratiques philosophiques et culturelles et les droits de l'homme. Le rapport présente les conclusions de la Table ronde et formule des recommandations pertinentes.

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　** Il a été convenu de publier le présent rapport après la date normale de publication en raison de circonstances indépendantes de la volonté de son auteur.

Merci de recycler ♲

Annexe

Report of the Independent Expert on the enjoyment of human rights by persons with albinism on the round table on human rights and albinism: seeking consensus and priorities on advocacy and research

I. Introduction

1.   The round table on albinism and human rights, held on 20 and 21 September 2018 in Geneva, was a side event at the thirty-ninth session of the Human Rights Council. It was convened by the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, together with a research team from Canada led by Sheryl Reimer-Kirkham and Barbara Astle.[1]

2.   The round table brought together scholars, policymakers and civil society stakeholders with the aim of building consensus on priorities for research, advocacy and policy on albinism, spiritual and cultural practices and human rights. The present report summarizes the outcomes of the meeting, highlighting the need for interdisciplinary research on human rights and albinism, the value of intersectoral partnerships, and the imperative to promote inclusive discourses and systems. In the African context, accounting for spiritual and cultural beliefs and practices is especially important, given their influence on how albinism is viewed and their material consequences, whether for good, for example, social support, or bad, for example, negative representatives and harmful practices. At all levels, inclusion of persons with albinism is vital.

3.   **Human rights and albinism**. Worldwide, persons with the genetic condition of albinism, in particular oculocutaneous albinism, lack melanin or pigmentation in their skin, hair and eyes, and are vulnerable to vision impairment, often leading to disabilities, and various health issues, most notably and most commonly skin cancer, which often leads to premature death. Not only do persons with albinism face a variety of health risks, many encounter discrimination and stigma on account of colourism. In parts of Africa, spiritual and cultural practices, sometimes related to witchcraft, are expressed as fears about curses and social ostracism. [2] As detailed in the Independent Expert's previous reports (A/HRC/31/63 and A/HRC/37/57), the need to address human rights violations associated with the mutilation and murder of persons with albinism for the extraction of their body parts for use in witchcraft-related rituals and for sale on the black market is of the utmost urgency.

4.   **Spiritual and cultural practices in relation to the security of persons with albinism**. Although the condition of albinism is sometimes seen as a blessing or positive omen, negative views are more common, based on a lack of knowledge about the genetic

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[1] The round table was convened as part of a research project entitled "The welfare and security of persons with albinism: developing a research-policy network to address the interplay of spiritual, cultural practices and human rights" (2017–2019). The host research team is composed of Sheryl Reimer-Kirkham, Barbara Astle, Emma Strobell (Trinity Western University, Canada), Lori Beaman (University of Ottawa), Wisdom Tettey (University of Toronto, Canada), Bonny Ibhawoh (McMaster University, Canada) and Kristi Panchuk (University of British Columbia, Canada). The collaborators were Duncan Dixon and Rick Sawatzky (Trinity Western University). Funding was provided by the Social Sciences and Humanities Research Council of Canada and the Under the Same Sun Fund.

[2] Awoniyi Babafemi Adeyanju, Omisakin Folorunso Dipo and Alao Mose Taiye, "Health and psychosocial complaints of elderly albinos in Ondo State, Nigeria", *Indian Journal of Gerontology*, vol. 29, No. 3 (2015), pp. 364–381; Cora Butler-Jones, "The impact of help-seeking behavior among people with albinism in Tanzania", PhD dissertation, The Chicago School of Professional Psychology, 2013.

inheritance of albinism, and traditional beliefs that construe albinism as God's will or the consequence of past misdeeds.[3] Belief in natural causes coexists with belief in supernatural causation.[4] Also pervasive are beliefs about witchcraft, in which persons with albinism are "feared as the cause of misfortune and sought after for success, wealth, and other advantages in life".[5] Understood in this light, research is needed at the nexus of religion and security. Due to the interplay of traditional spiritual and cultural practices, it is necessary to have a careful and complex reading of religion and witchcraft, intersecting with colonial histories.

5.   **Research on welfare and security of persons with albinism**. Without coordinated, sustained and multisectoral efforts across academia, policy, government and civil society, persons with albinism remain at risk of human rights violations. Human rights organizations, including within the United Nations system, and civil society organizations are addressing human rights violations associated with a lack of access to health services and with discrimination and the threat of attacks. Academic research is needed to understand the scope of the problem, the underlying mechanisms and possible social responses to address the welfare and security needs of persons with albinism.

A.   Objectives of the round table

6.   The round table was held in conjunction with a three-phase Canadian-led research project. The objectives of the round table were to:

     (a)   Serve as a forum for bringing the voices of activists into the processes of research;

     (b)   Deliberate on key domains of research, advocacy and policy related to albinism and human rights;

     (c)   Prioritize areas for research, advocacy and policy;

     (d)   Strategize intersectoral approaches to knowledge mobilization;

     (e)   Support the research vision of the Independent Expert.[6]

7.   On the first day, three panels presented the work of leading experts and key stakeholders. The second day consisted of working through a consensus-building process to shortlist research topics, advocacy strategies and policy priorities.

B.   Opening statements

8.   Sheryl Reimer-Kirkham welcomed participants and provided an overview of the origin, objectives and key goals of the round table. She anticipated the following tangible outputs:

     (a)   Clarity on research, advocacy and policy priorities;

     (b)   A final report;

     (c)   Deeper understanding of the lived experience of persons with albinism;

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[3] Giorgio Brocco, "Labeling albinism: language and discourse surrounding people with albinism in Tanzania", *Disability & Society*, vol. 30, No. 8 (2015), pp. 1143–1157; "Albinism, stigma, subjectivity and global-local discourses in Tanzania", *Anthropology & Medicine*, vol. 23, No. 3 (December 2016), pp. 229–243.

[4] Michael Bourdillon, *The Shona peoples* (Zimbabwe, Mambo Press, 1987); Adeyanju, Dipo and Taiye, "Health and psychosocial complaints"; Charlotte Baker and others, "The myths surrounding people with albinism in South Africa and Zimbabwe", *Journal of African Cultural Studies*, vol. 22, No. 2 (2010), pp. 169–181.

[5] John Alan Cohan, "The problem of witchcraft violence in Africa", *Suffolk University Law Review*, vol. 44, No. 4 (Fall, 2011), p. 805.

[6] A/HRC/31/63, paras. 63–65.

(d)   Knowledge about how to generate and mobilize research of service to advocacy and policy;

(e)   International, intersectoral collaboration, including by persons with albinism, in the establishment of a research-advocacy-policy network;

(f)   Other outputs, such as academic papers and working groups.

9.   Don Sawatzky, Director of Operations of the Under the Same Sun Fund, a co-sponsor of the event, opened the round table, calling for unity in partnership-dependent advocacy work. He emphasized that ending stigma, discrimination and violence against persons with albinism required the partnership-dependent movement to observe the call for "nothing about us without us" and a commitment to mutual support among civil society organizations, researchers, government officials and other stakeholders. Those approaches to partnership served to preserve each other's dignity and to ensure the community remained strong and true to the albinism cause. While Under the Same Sun was not an academic or research-based organization, its co-sponsorship of the round table was grounded in a commitment to move away from silos in which civil society organizations and key decision makers worked apart from each other and apart from researchers. Mr. Sawatzky recognized the decades of work and commitment present in the room and applauded the combined efforts represented among the round-table participants, specifically the work of the Independent Expert.

10.   The Independent Expert gave the keynote address, setting the vision for the round table. Grounding her remarks in the lived experiences of people whose very right to life was endangered because they lacked pigment in their skin, she highlighted the opportunity present in so many key actors coming together for the two-day round table. She noted the positive gains, including the declining trends in reported attacks in certain countries, the growing awareness of the issue among government and other human rights stakeholders at the international, regional and national levels, while acknowledging that gaps remained, emphasizing that those gaps cost people their lives, security and well-being in many parts of the world. Calling for united action, in which persons with albinism were at the forefront ("nothing about us without us"), the Independent Expert urged each round-table participant, be they representatives of governments, civil society organizations, non-governmental organizations (NGOs), researchers, allied health professionals or key stakeholders, to recognize the process as part of the duty to respect, protect and fulfil human rights enshrined in the International Bill of Human Rights. While States bore the primary duty for realizing those rights, civil society actors were enablers in the process, particularly in relation to an issue such as human rights and albinism, which had been borne on the shoulders of advocates and academics for decades prior to government involvement and international action, including her mandate.

11.   Innocentia Mgijima, from the University of Pretoria, outlined the principles of engagement to guide the round table, which were:

(a)   **Mutuality and respect**. The voices of persons with albinism were vital to the research process; their perspectives were sought after, welcomed and respected. Advocates and researchers brought complementary perspectives and skills to the endeavour, from different vantage points but focused on a common goal;

(b)   **Intersectoral and collaborative**. Working across sectors, including academia, advocacy, education, health, law and social services would strengthen and broaden impact. Working collaboratively would accelerate mobilization of evidence-informed policy and advocacy;

(c)   **Historical and contemporary power imbalances**. Everyone, whether from the global South or the global North,[7] was influenced by contexts. Collaborations across the

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[7] The classifications of global South and global North are imperfect and come with exceptions (e.g., Australia and Namibia as high income and high-middle income respectively). However, for the purposes of the present report, they are useful in highlighting those regions where structural factors (lower resources) and higher incidences of albinism converge to create contexts of higher risk of human rights violations.

global North and the global South required attentiveness to the risk of reproducing power imbalances;

(d) **Feasibility and impact**. While many matters required research and advocacy to promote the enjoyment of human rights for persons with albinism, good starting points for action were those that were most feasible, had high potential for impact and were sustainable.

II. Context

12. The purpose of the overarching host project is to foster evidence-informed policy and human rights advocacy through the development of international, interdisciplinary, intersectoral research-policy collaboration and a prioritized research agenda on albinism, spiritual and cultural practices, and human rights.

13. Several United Nations reports underpin the project, including those that lay out the mandate of the Independent Expert and outline priority issues for albinism. These include the 2016 report on the Independent Expert's vision for the mandate (A/HRC/31/63) and her 2018 report on the right to health (A/HRC/37/57).

Methodology of research projects

14. The host team began with a scoping review[8] of 40 articles on the three overlapping concepts of albinism, health and health services, and cultural and spiritual beliefs. Although most articles do not make explicit reference to human rights, embedded in the literature was evidence of threats to the rights to an adequate standard of living, health, education, employment, family life and participation in cultural life.

15. Extending the scoping review, the research team is conducting a metanarrative review (83 articles and 68 reports) to summarize the current state of knowledge (academic literature, grey literature and expert opinions) on albinism and human rights.

16. A Delphi survey consisting of three cycles is concurrently under way to gather feedback on research priorities for albinism and human rights from researchers, policymakers and advocates.

17. The round table held in Geneva was integral to mapping current research and future directions. Gathering experts from around the world to develop consensus on research, advocacy and policy priorities informs the mandate on albinism by collaborating on the "how" and the "what" in order to move forward for the well-being and security of persons with albinism.

III. Human rights and albinism (panel 1)

A. Theoretical framing: framing the rights of people with albinism within the global human rights movement

18. Bonny Ibhawoh, professor of history, asserted the need to firmly locate the rights of persons with albinism within the broader international human rights movement. He said that approach was essential to the task of mainstreaming the rights of persons with albinism and bringing more visibility to those rights. It was essential to strategically frame discrimination and violence against persons with albinism as part of a global historical movement for rights inclusion. In his book on the history of human rights in Africa,[9] he discussed the "new causes" in human rights struggles. Disability rights and the rights of

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[8] Sheryl Reimer-Kirkham and others, "The influence of spiritual and cultural practices on health and healthcare of persons with albinism: a scoping review", in press. Forthcoming at https://doi.org/10.1080/09687599.2019.1566051.

[9] Bonny Ibhawoh, *Human Rights in Africa: New Approaches to African History* (Cambridge, Cambridge University Press, 2018).

persons with albinism fell within that category. While those causes may be relatively new, the same exclusionary sociocultural and political barriers confronted by vulnerable persons in earlier human rights struggles, including against slavery, colonialism, apartheid and dictatorships, stood in the way of actualizing those rights. To foster inclusion, Mr. Ibhawoh affirmed the need to mobilize the same political commitments and social alliances that had sustained earlier human rights struggles against slavery, colonial repression and post-colonial authoritarianism. Framing the rights of persons with albinism within the broader history of rights movements allowed the mobilization of those forces of inclusion, underscoring the commonalities of all human rights struggles. That approach reinforced the rights of persons with albinism not as fringe rights, but as rights integral to the collective well-being of all humanity.

B. Summary of research on human rights and albinism

19.   Sheryl Reimer-Kirkham, professor of nursing, reported on the scoping review of the academic literature. Forty articles had been found at the intersection of albinism, spiritual and cultural practices, and health and health services. Of those, 13 (32 per cent) included explicit reference to human rights, and only 5 (12 per cent) incorporated a substantive discussion on human rights.

20.   Building on the scoping review, the Canadian research team had conducted a metanarrative review (literature search) on albinism research and human rights, which had yielded 83 articles and 68 reports. A summary of that literature indicated that:

(a)   There had been an increase in human rights-related publications in the previous 10 years;

(b)   Lead authors were most often from the disciplines of sociology and anthropology, followed by religion, philosophy and social work;

(c)   Some 82 per cent of the articles on human rights and albinism focused on Africa;

(d)   Some 40 per cent of the articles on human rights and albinism had a substantive focus on witchcraft. Some 25 per cent of the articles had a disability framing, 18 per cent focused on representation and albinism, 15 per cent on stigma, 10 per cent on religion or ontology, and 5 per cent on economies and markets;

(e)   Some of the human rights and albinism literature foregrounded moral imperatives, while other literature focused on legal frameworks.

21.   Threats to the right to health for persons with albinism that had a solid evidence base were posed by: (a) inadequate access to the social determinants of health, such as income, housing and education; (b) limited health-care access; (c) decreased quality of life and well-being due to stigma and social exclusion; and (d) hazards to safety and security, due to attacks and violence.

C. Stakeholder perspectives: bringing together knowledge from political arenas with discourses of human rights and disabilities

22.   Using the Kenyan model as an exemplar, Isaac Mwaura, a senator in the National Assembly of Kenya, addressed the intersection of politics, albinism, human rights and disability. Arguing that human rights and disability were not divisible, he challenged definitions of disability, asserting that disability itself was a social construct. Locating albinism within the social construct of disability, albinism existed in the "in between" spaces of disability narratives, where, for instance, persons with albinism had visual impairments but were often assumed to be blind or were taught Braille instead of being given visual aids in order to read. The benefits of locating albinism within disability included access to civil and political rights, socioeconomic benefits, and broader group rights. Considering the way forward, he argued for engagement in advocacy, including sharing stories and role modelling, publications, including research and academic papers to

support policy, and involvement in politics. Critical engagement in the political arena, amplifying the voices of persons with albinism, coalition-building and increasing visibility and representation to change current narratives were of critical importance. Ritual killings did not speak to the entire experience of persons with albinism, and therefore economic empowerment, safeguarding access to education, employment and health services, and addressing social concerns must be ensured. Highlighting his Government's commitment, he reported that the Government of Kenya allocated a substantial annual budget to persons with albinism.

D. Stakeholder perspectives: advocacy for the human rights of persons with albinism

23.   Overstone Kondowe, President of the Association of Persons with Albinism in Malawi, gave a presentation on the situation concerning the protection and promotion of the human rights of persons with albinism in Malawi. Since its inception in 1994, the Association of Persons with Albinism in Malawi had continued to affect change and hold political leaders accountable. Since 2014, there had been 151 reported attacks against persons with albinism in Malawi. Children and women constituted 72 per cent of the victims, and over 90 per cent of the attacks had occurred in border districts. Utilizing the Association's four priority areas – security and access to justice, socioeconomic inclusion, education and health – Mr. Kondowe reviewed strategies, gaps and recommendations. Strategies included government investment in housing for persons with albinism, and skin care. Gaps included limited property rights for persons with albinism. In addition, there was a lack of a detailed strategic plan such as memorandums of understanding to give effect to cross-border treaties where they existed, or prosecution of perpetrators of attacks against persons with albinism. Advocacy, skin cancer screening and education on skin care were recommended for Malawi.

IV. Spiritual and cultural practices affecting persons with albinism (panel 2)

A. Theoretical framing: human rights and religion

24.   Lori Beaman, professor of sociology, gave a presentation on the intersection of human rights and religion, arguing that there might be alliances between human rights and African traditional religion that could be mobilized to protect people with albinism. That required taking a "lived religion" approach – understanding that religion was lived and that examining the practices of everyday life revealed a great deal. That approach asked not only about harmful practices, but also about practices that were healing, reassuring or comforting. Religion played a role in the persecution of people with albinism and in the elimination of it. She asked what happened when the discourse was shifted from "witchcraft" into African traditional religion and thought about in terms of "faith" and "community". She also asked what might happen if one more fully engaged with witchcraft as religion and not as "other", or as superstition or magic and not "real" religion. An intersectoral and intersectional response must be developed that addressed the root causes of the inequality of persons with albinism and included religion.

25.   Ms. Beaman said that instances of "deep equality"[10] must be looked into. Inspired by frameworks like human rights declarations, they could assist in mapping those places in which people exhibited caring, neighbourliness, respect and even love. It was there that alliances between witchcraft, African traditional religion and others who did not identify with that tradition could be determined. If people paid close attention to those moments, practices and exchanges, they could replicate them, thus mobilizing religion to support and instantiate human rights practices.

26.   Ms. Beaman outlined the following elements as vital to achieving equality for persons with albinism: (a) attention to biases about what counted as religion; (b) religion could be both a driver of positive change and a perpetuator of discrimination, harm and inequality; (c) religion as institutional and abstract and religion as lived; and (d) seeking to map similarity in ways that countered other-producing discourses of difference.

B.   Summary of research on spiritual and cultural beliefs and albinism

27.   Sheryl Reimer-Kirkham presented a synthesis of the existing research on spiritual and cultural beliefs and practices in relationship to albinism, drawing on the two systematic reviews undertaken by the host research team. The literature on albinism and spirituality and culture was focused predominantly on the geographic region of Africa, which shaped how spiritual and cultural meanings were viewed, to the extent that they were central to understanding albinism and human rights.

28.   She noted that associations between spirituality and albinism were predominantly framed as negative in the literature. The most common term in the literature within the spectrum of spiritual and cultural meanings was "witchcraft", far exceeding other terms such as religion, religious, spiritual, spirituality, faith, church, pastor, worldview or ontology. Although Christianity and Islam were about equally represented in Africa, Christianity was referenced more often in the literature on albinism and spiritual and cultural beliefs and practices. African traditional religious practices were resorted to simultaneously (or sequentially) to cope with adversities. Faith communities could offer social support and inclusion but might also play a role in isolation and discrimination.

29.   There was disagreement in the academic literature (and at the round table) on how and how much research should address the domain of religion, spirituality, cosmology and witchcraft. Those with closer personal proximity to threats to human rights for persons with albinism tended to put much stronger emphasis on the need to conduct research in that domain. Moreover, there was growing consensus that because of material consequences of spiritual beliefs and practices, intersectoral attention, including research, was needed.

C.   Stakeholder perspectives: African ontology, albinism and human rights

30.   Elvis Imafidon, lecturer in philosophy, provided a philosophical perspective grounded in African ontologies, explicating how powerful and deeply entrenched representations of a group could be. In reference to the three key principles that the framers of the Universal Declaration of Human Rights had envisaged, namely, "a set of general principles; the codification of these principles into law; and practical means of implementation",[11] he asserted that the first two principles presented few challenges, while the third was very difficult to achieve. As was the case for persons with albinism in various parts of the world, if people were not considered fully human, implementing such laws was very difficult since the enjoyment of such rights was tied to being human. Thus, there was a need to disrupt the false ontological representations of albinism entrenched in African

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[10] Lori G. Beaman, *Deep Equality in an Era of Religious Diversity* (Oxford, Oxford University Press, 2018).

[11] Gordon Brown, ed., *The Universal Declaration of Human Rights in the 21st Century: A Living Document in a Changing World* (Cambridge, Open Book, 2016), p. 81.

societies.[12] That disruption must be explored at both the individual level, with persons with albinism rising above that false ontological representation and earning worth and respect in their society, and at the social level, with society becoming enlightened.

D. Stakeholder perspectives: killings of people with albinism in Tanzania – deconstructing dominant causal narratives

31.   Florence Chaki, a representative of the Commission for Human Rights and Good Governance of Tanzania, used her study on deconstructing dominant causal narratives regarding the killings of persons with albinism in Tanzania [13] as a basis for her presentation on that violence. She referred to the concept of the occult economy,[14] which reconciled traditional, cultural and economic narratives. Interrogating the widespread killings of persons with albinism from a supply and demand perspective challenged simplistic causal narratives and provided a broader base on which to develop effective policies. Poverty and the desire for money, success and wealth could push people to seek such alternative solutions. Policy must address the various aspects of the problem simultaneously, interrogating belief systems while undermining the economic market in the buying and selling of body parts of persons with albinism. Beliefs in mystical powers, including charms or amulets made from the body parts of persons with albinism, existed at the intersection of religious beliefs based in, for example, Christianity or Islam, and African traditional beliefs. It was therefore necessary to engage witchdoctors, traditional healers and religious leaders, including priests, imams and pastors, in demystifying ideas about the bodies of persons with albinism. The potential for traditional healers and spiritual leaders to become allies in the campaign against killings and attacks on persons with albinism must be explored. She urged governments and other actors working towards ending violence against persons with albinism to no longer sidestep the question of widespread cultural-religious demand for supernatural solutions.

V.   Advocacy and social change (panel 3)

A.   Theoretical framing: media, globalization and human rights

32.   Wisdom Tettey, professor of political science, drew on a critical ontology framework to argue that the challenges faced by persons with albinism stemmed from the construction of persons with albinism as "the demonic other" in cultures characterized by the normativity of skin pigmentation and in which albinism connoted a disequilibrium within the metaphysical realm. The disequilibrium, attributed to some action by, or character flaw within, the child or other relation, was perceived to have grave repercussions for the social order. That construction of the "other" was led by moral entrepreneurs who presented the condition as constituting existential insecurity for the community, which required systems of regulation to restore the balance between the spiritual and social orders.[15]

33.   He noted that the problematization of persons with albinism and the resultant moral panic were sustained through structures of representation, which pathologized and stigmatized the condition. Related systems of regulation justified their dehumanization and

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[12]   Elvis Imafidon, "Dealing with the other between the ethical and the moral: albinism on the African continent", *Theoretical Medicine and Bioethics*, vol. 38, No. 2 (April 2017), pp. 163–177; *African Philosophy and the Otherness of Albinism* (London, Routledge, 2019).

[13]   Florence Honest Chaki, "Killings of persons with albinism (PWAs) in Tanzania: deconstructing dominant cause narratives (2007–2015)", Master's thesis, International Institute of Social Studies, The Hague, Netherlands, 2013.

[14]   Jean Comaroff and John Comaroff, "Occult economies and the violence of abstraction: notes from the South African postcolony", *American Ethnologist*, vol. 26, No. 2 (1999), pp. 279–303.

[15]   Wisdom John Tettey, "Homosexuality, moral panic, and politicized homophobia in Ghana: interrogating discourses of moral entrepreneurship in Ghanaian media", *Communication, Culture and Critique*, vol. 9, No. 1 (February 2016), pp. 86–106.

the denial of their full rights of substantive citizenship, including access to State resources and protection from physical harm. The media and popular culture amplified and perpetuated those representations through rhetorical devices that embedded the negative framing within the social imagination and psyche.

34.   He said that, notwithstanding their denigration and devalorization within the social structure, persons with albinism paradoxically assumed intrinsic value in the context of the neoliberal political economy. There, the spiritual and material came together to satisfy economies of desire, as some Africans negotiated their survival within the global capitalist system and national politics. In that world, body parts of persons with albinism offered instrumental value for those seeking political or economic power.[16]

35.   In order to address the negative representations and structural inequities and dangers that persons with albinism faced, Mr. Tettey suggested the following actions:

        (a)   Promoting discourses of inclusive difference and systems of inclusive education and citizenship;

        (b)   Developing counter-discourses that undermined melano-normativity and cultivating the media as partners and agenda setters for alternative positive narratives;

        (c)   Engaging moral and political leaders as instruments for progressive change;

        (d)   Making visible and empowering persons with albinism to speak for themselves;

        (e)   Forging local, regional and global networks of collaboration for integrated, intersectional, non-zero-sum approaches to advocacy;

        (f)   Promoting an active role for the scientific and academic communities in debunking myths and in translating knowledge.

B.   Summary of research on advocacy and social change

36.   Emma Strobell, a graduate research assistant in nursing, presented a synthesis of research literature relating to advocacy and social change, which revealed that the perspectives of persons with albinism were represented in the research literature in about equal proportion to the perspectives of academics, civil society stakeholders and government and policy views. Many examples of advocacy existed in the literature and were representative of local, regional and international strategies. Common threads discussed by most stakeholders included self-advocacy and representation;[17] education and employment;[18] health and social services;[19] policy, legislative and legal strategies;[20] and

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[16] Bright Nkrumah, "'Hunted like animals': the conundrums of countering crimes against albinistic persons in the era of the UDHR", *International Journal of Law, Crime and Justice*, vol. 55 (2018), pp. 52–59.

[17] Giorgio Brocco, "Labeling albinism"; Charlotte Baker and Patricia Lund, "The role of African fiction in educating about albinism and human rights: Jenny Robson's *Because Pula Means Rain* and Ben Hanson's *Takadini*", *Journal of Literary and Cultural Disability Studies*, vol. 11, No. 3 (January 2017), pp. 271–284; Edmos Mtetwa and Watch Ruparanganda, "Disability and the quest for bureaucratic representation in Zimbabwe", *Indian Journal of Social Work*, vol. 77, No. 1 (January 2016), pp. 39–52.

[18] Charlotte Baker, "The myths surrounding people with albinism"; Peter Kisanga and Milline Jethro Mbonile, "Impact of interventions of the murder of people with albinism in Lake Victoria: a case of Shinyanga Region", *Journal of the Geographical Association of Tanzania*, vol. 37, No. 1 (2017), pp. 56–72.

[19] Elvis Imafidon, "Dealing with the other"; Jennifer Kromberg, "Interventions: preventive management, empowerment, advocacy, and support services", in *Albinism in Africa: Historical, Geographic, Medical, Genetic, and Psychosocial Aspects*, Jennifer Kromberg and Patricia Manga, eds. (London, Elsevier Academic Press, 2018), pp. 272–291.

[20] Melissa Bruynell, "The dangers of modern day belief in the supernatural: international persecution of witches and albinos", *Suffolk Transnational Law Review*, vol. 35, No. 2 (2012), pp. 393–420; Kisanga and Mbonile, "Impact of interventions"; Benson A. Mulemi and Urbanus M. Ndolo, "Albinism, witchcraft, and superstition in East Africa: exploration of bio-cultural exclusion and livelihood

media and communications strategies.[21] Effective strategies for advocacy were inclusive, empowering and representative of the achievements of persons with albinism, disarming harmful myths and the "evil albino" trope. They included the creation of and participation in albinism advocacy groups; shifting terminology and language (e.g., "persons with albinism" as opposed to derogatory labels); [22] representation within international organizations (e.g., the Independent Expert); and calling for representation within government and throughout policy development.[23]

37.   Within the research literature, much crossover existed between the perspectives of persons with albinism and those of civil society, highlighting points for collaboration. Civil society continued to be pivotal in lobbying government and international human rights organizations by elevating the concerns and welfare of persons with albinism from the local to the international level. Civil society liaised with and engaged community leaders necessary to create social change locally.[24] While the support of transnational advocacy groups and institutions was cardinal to mobilizing international pressure, the primary locus of change concerning the rights of persons with albinism remained at the local level.

C.   Stakeholder perspectives: representation of persons with albinism and awareness of human rights

38.   Charlotte Baker, senior lecturer in French and francophone studies, traced changing representations of albinism and pointed to the real-world influence they exerted. Historically, negative representations of albinism had been perpetuated in literature, film, photography and the media, but a new wave of more positive and nuanced representations was emerging. She emphasized the responsibility that came with representation and pointed to the opportunities the arts opened up for advocacy and as educational tools. There was a tendency to speak on behalf of persons with albinism, whether on the part of writers, journalists, advocates or academics. If understandings of albinism were to be enhanced, a more balanced narrative was needed that included the voices of persons with albinism.

D.   Stakeholder perspectives: advocacy through media and government engagement

39.   Nomasonto Mazibuko, the founder of the Albinism Society of South Africa and the leader of the Pan African Albinism Alliance, called for a cohesive movement committed to engaging a global audience through various forms of technology, including social media. She was enthusiastic in her support of a group movement increasing visibility using current technology strategies such as a common hashtag: #actiononalbinism. She said that by utilizing media outlets available to the movement, providing education, representation and increased visibility, a strong community of allies and government engagement would

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vulnerability", research report, The Catholic University of Eastern Africa, Nairobi, 2014; Abdallah Possi and Ally Possi, "The identity question versus appropriateness of legal anti-discrimination measures: endorsing the disability rights approach to albinism", *African Disability Rights Yearbook*, vol. 5 (2017), pp. 118–140.

[21]   Baker and Lund, "The role of African fiction"; Jean Burke, Theresa J. Kaijage and Johannes John-Langba, "Media analysis of albino killings in Tanzania: a social work and human rights perspective", *Ethics and Social Welfare*, vol. 8, No. 2 (2014), pp. 117–134; Francis Benyah, "Equally able, differently looking: discrimination and physical violence against persons with albinism in Ghana", *Journal for the Study of Religion*, vol. 30, No. 1 (2017), pp. 161–188; Mark P. Mostert and Martha M. Weich, "Albinism in Africa: a proposed conceptual framework to understand and effectively address a continental crisis", *African Disability Rights Yearbook*, vol. 5 (2017), pp. 101–117.

[22]   Giorgio Brocco, "Labeling albinism".

[23]   Mtetwa and Ruparanganda, "Disability"; Mulemi and Ndolo, "Albinism, witchcraft and superstition".

[24]   Adebayo Fayoyin and Noel Ihebuzor, "Advocacy for minorities in Africa: issues and lessons in advancing the rights of albinos in Tanzania and Osus in Nigeria", *Asia Pacific Journal of Research*, vol. 1, No. XVII (September 2014), pp. 113–125.

follow. She urged advocates to engage with each other, to move away from working in silos, instead partnering to create a cohesive force towards change.

VI. Research-advocacy partnerships and knowledge mobilization (panel 4)

A. Theoretical framing: partnering with persons with albinism – civil society, policymakers and academics

40.   Barbara Astle, associate professor of nursing, framed her presentation around inclusion and equity as central elements when establishing global research partnerships. She said that Sustainable Development Goal 17 emphasized that achieving a sustainable development agenda required partnerships between the private sector and civil society.[25] Partnerships should be inclusive and built upon principles and values, a shared vision, and goals that placed people at the centre. Fundamental to that goal and the Sustainable Development Goals was the premise of "leaving no one behind". Based upon Goal 17, partnerships were essential to deliver research and innovation for global health and development. She asked how civil society, policymakers and academic stakeholders should establish a network and prioritize a research agenda, advocacy strategies and policy priorities. She said that in the shift to research partnerships, it was imperative to partner with persons with albinism and other sectors.

41.   Two examples featured intersectoral partnerships within an international ethical framework. The Canadian Coalition for Global Health Research had developed principles focused on global health research for equity. The principles were: authentic partnering; inclusion; shared benefits; commitment to the future; responsiveness to causes of inequity; and humility. Equity was at the centre. [26] The focus was on how global health research was conducted, along with the importance of contextualizing the research. The second framework was that of the Council on Health Research for Development, the goal of which was to maximize research and innovation to deliver sustainable solutions to the health and development of persons living in low and middle-income countries.[27]

B. Summary of research on research-advocacy partnerships for persons with albinism

42.   Barbara Astle presented a summary of the host team's metanarrative review of the albinism and human rights literature specific to partnering, partners and partnerships. Although various partnerships existed between civil society, policymakers, academics and persons with albinism, and partnering with stakeholders informally or formally was a common goal, such partnerships were not clearly articulated in the research literature.

43.   By way of illustration, she noted that the term "partnering" occurred in one article out of 83 (1 per cent), which focused on engaging partners as part of a research process.[28] Their participatory research approach engaged those who were most affected, who in turn raised awareness in providing evidence to inform policy and advocacy efforts.

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[25] United Nations, "Partnerships: why they matter". Available at www.un.org/sustainabledevelopment/wp-content/uploads/2018/09/Goal-17.pdf.

[26] Canadian Coalition for Global Health Research, "*CCGHR principles for global health research*". Available at www.ccghr.ca/resources/principles-global-health-research/.

[27] See Council on Health Research for Development. Available at www.cohred.org/.

[28] Margo Greenwood and others, "Hear my voice: a community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania", *Knowledge Management for Development Journal*, vol. 11, No. 2 (2016), pp. 63–78.

44. The term "partnership" occurred in 11 (13 per cent) of the sources, which discussed established partnerships predominately between NGOs and other NGOs or advocacy groups, and some academic institutions.

45. The term "partner" occurred in 20 (24 per cent) of the sources, associated with relationship, for example, family. Other examples of "partner" included NGOs with academics, the medical community, and between partner country and donor country.

46. While partnering activities had been carried out locally within countries, and globally with various stakeholders, intersectoral partnership or collaboration between, for example, civil society and the health sector had not been clearly articulated in the research literature. Although the language of partners, partnering and partnerships was not widespread in the albinism research literature, there was increasing acknowledgement of the importance of listening to voices at the local level and for intersectoral partnerships linking researchers with advocacy groups, civil society and policymakers.

C. Stakeholder perspectives: benefits of and responsibilities in intersectoral partnerships and albinism research

47. Patricia Lund, principal lecturer in biosciences, explained her diverse work within various countries in sub-Saharan Africa, including genetics, inclusive education, public health, and social, security and welfare issues. Highlighting creative intersectoral partnerships in her research, such as with the Wellcome Trust, Sightsavers, Standing Voice, the International Foundation of Applied Disability Research, Advantage Africa, the Source of the Nile Union of Persons with Albinism and various other partners, she urged all parties to tend to concerns of equity and ethics throughout the collaborative process. The benefits of working directly with persons with albinism included building capacity in terms of project management, interview skills, research methodology through mentorship and inclusion throughout or at various points of the research and knowledge-mobilization process. Such collaboration had resulted in co-authorship, persons with albinism providing important research feedback, and persons with albinism as vital participants in the advocacy process. She concluded with suggestions related to developing an ethical framework for research on albinism.

D. Stakeholder perspectives: shifting public opinion and mobilizing government for a national policy on albinism

48. Jake Epelle, the founder and chief executive officer of the Albino Foundation, discussed the importance of supporting persons with albinism to pursue education and positions within government and policy development. He recounted how the Albino Foundation had supported persons with albinism to obtain education, empowering them to pursue professional careers in law and politics. With increased representation and visibility, persons with albinism would have influence on shifting public opinion and mobilizing government for a national policy on albinism. He reflected on six key areas that required particular attention: health; legislation and policy; advocacy; education; economics; and the overall rights of persons with albinism, emphasizing that any successful government intervention must address each of those key areas.

E. Stakeholder perspectives: local-global advocacy and education for people with albinism

49. Perpetua Senkoro, an advocacy and human rights officer with the Under the Same Sun Fund, made a presentation on local-global advocacy and education for persons with albinism. She questioned the fit of albinism within disability discourse, noting that albinism as a disability remained a controversial topic. Asserting that albinism was not taken seriously within government plans and policies relating to disability, she reflected on the tension created by requiring that persons with albinism "justify themselves" in order to be included, forced to respond to the question why they deserved preferential treatment.

Persons with albinism were targeted solely because of their condition. There was a need for local advocacy, recognizing that not all organizations were fully equipped and no single organization could have a presence in each community concerned. Therefore, commitment to building local capacity was vital. In order to promote capacity-building, it was necessary to ensure accountability, understanding global systems and to build a group agenda. It was also essential to liaise with the government and other stakeholders to promote and ensure access to education for persons with albinism.

F. Stakeholder perspectives: international and non-governmental advocacy to end human rights violations

50.   Jon Beale, director of development at Standing Voice, an international NGO based in the United Kingdom of Great Britain and Northern Ireland and in Tanzania, gave a presentation on the research and advocacy approaches utilized by Standing Voice, particularly the concept of social inclusion. Social inclusion, as defined by Standing Voice, was an exchange of positive influence between an individual and those around them in society. Research conducted by Standing Voice showed that people with albinism often deemed their relationship to other people in society as positive when they themselves had the ability to exert influence on those individuals. Discussion on research and advocacy approaches must move beyond simply ensuring people with albinism were passive receivers of support.[29] Drawing on Standing Voice's skin cancer prevention programme, which included comprehensive skin cancer prevention and treatment services and electronic data collection in 49 locations across Tanzania and Malawi, he suggested that the programme provided opportunities for research and advocacy to enhance patient agency through knowledge-acquisition. Since the launch of the programme in 2013, there had been a marked decrease in clinical presentation of various pre-cancer related skin conditions and in the need for surgical referrals, partly due to patient agency. He highlighted plans to communicate patient data findings to patients and to facilitate informed dialogue between patients and doctors to improve health services; produce new patient-generated findings; and open a space for patient self-advocacy. The programme aimed to develop a patient-centred approach to prevention and treatment of skin cancer among persons with albinism in Africa.

VII. Dialogue on priorities for advocacy, policy and research

51.   Structured and facilitated dialogue among the round-table participants allowed for the refinement of priorities for advocacy, policy and research.

A. Overview of the Delphi survey and participants

52.   Kristi Panchuk, a doctoral fellow in nursing, presented an overview of the research team's 3-round Delphi survey, describing the sampling and recruitment, progress to date and next steps for the project. Some 120 experts in the field of albinism research had been identified by their academic publications, established work with advocacy groups and history of developing policy to improve the lives of persons with albinism. Forty-five respondents had completed either one or both of rounds 1 and 2; about 30 per cent were persons with albinism and 50 per cent were from Africa. Many self-identified as both researchers and advocates. Round 1 had been an open-ended survey to identify priorities in research, advocacy and policy in the realm of albinism and human rights. Round 2 had used those responses and data from the literature syntheses to generate 155 items that respondents ranked on a 5-point Likert scale of importance from "not at all important" to "essential". In round 3, planned for January 2019, participants would be asked to rank the priorities in each area in order to refine the consensus on priorities.

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[29] Standing Voice, "Science, art, community – building interactive understanding of albinism in Tanzania: evaluation report". Available at https://mesh.tghn.org/site_media/media/articles/ Standing_Voice_Evaluation_Report.pdf.

53. Drawing on the preliminary findings from the Delphi survey, several discussion questions were posed. Advocates, policymakers and researchers met in separate groups to consider:

(a) How can research become a better avenue of influence for the well-being of persons with albinism?

(b) How much agreement do we need on research priorities?

(c) What are best practices for research on albinism?

B. Advocacy strategies: summary of the dialogue

54. Kristi Panchuk presented the preliminary results on advocacy strategies from round 2 of the Delphi survey. The priorities were clustered around: (a) access to health care, including vision and skin care; (b) education and employment opportunities; and (c) international cooperation to prevent cross-border crimes.

55. During the subsequent dialogue, advocates emphasized the importance of accounting for proximity to human rights violations, because that proximity shaped what changes were perceived as possible.

56. Advocates discussed the fact that university-based scholars were not the only researchers in that field. Advocates conducted research regularly as part of their work to generate the evidence to support the positions for which they lobbied and the services they supported and promoted. The "in-house" approach to research could be especially efficient because the questions and the analysis were generated, interpreted and applied by the same team. Partnerships between advocates and researchers should hold the same guarantees for relevance to persons with albinism and commitment to effective knowledge mobilization.

57. One advocacy role of researchers coming from abroad was to work in partnership with scholars at local universities to spark interest and engagement in research on albinism among local academics. Such partnerships resulted in a positive evolution of the ideas integrated into the university education of health and social-care professionals. Furthermore, graduate students of the scholars at local universities would then have the opportunity to develop capacity in research on albinism, as well as having persons with albinism make connections with the university, which could lead to their professional development as researchers.

C. Policy priorities: summary of the dialogue

58. Barbara Astle presented the preliminary findings on policy priorities from the Delphi survey and a summary of the group discussions of the round-table participants. The policy priorities from the Delphi survey were clustered around health care, education, protection and future planning.

59. Subsequent dialogue among the policy participants focused on the importance of ensuring that health-care services, specifically eye and skin care, were included in policy priorities. Discussants advocated that governments use a framework to ensure that the health-care, education and protection needs of persons with albinism were addressed. In Kenya, there was a current model, mainstreamed under disabilities policy, which provided universal health-care services to persons with albinism. The policy participants viewed that particular exemplar as a framework that might be feasible to use in other countries to ensure that the mainstreaming of health-care needs specific to persons with albinism (e.g., sunscreen, vision care, skin care) was embedded within overall health-care systems. The Independent Expert said that major policy priorities must include: (a) ensuring learners with albinism had the necessary visual aids to enable successful education for all; (b) providing child protective services; and (c) employing the parallel-track approach, including mainstreaming albinism into all relevant policy areas (health, disability and education), in addition to having albinism-specific programmes. There was agreement that governments would have to ensure that financial resources were available for those policy priorities.

Policy participants stated that more census and survey data (evidence) on persons with albinism were needed by all States so that services could be better supported.

D. Research topics: summary of the dialogue

60.   Sheryl Reimer-Kirkham presented the preliminary findings from the Delphi survey about research. Prioritized topics were clustered around research on: (a) advocacy and how to increase its effectiveness for social change; (b) decreasing discrimination and increased social inclusion; and (c) how to respond to violence and the impact of trauma on well-being. Across those clusters, witchcraft was named as an important area for study, for example, researching attacks and how to engage witchdoctors.

61.   Subsequent dialogue among researchers extended those topic priorities to include epidemiological research for better data on carrier frequency of albinism, and research on resilience and quality of life, especially as a trajectory over the years. Research that was interdisciplinary and participatory would contribute to the Independent Expert's mandate. Both the Delphi survey results and the researcher dialogue provided insight into the importance of knowledge mobilization so that researchers influenced the well-being of persons with albinism, and research became an advocacy tool. Evidence from research was necessary to make persuasive cases to governments for resource allocation and policy decisions. Evidence from research must be shared in contextualized, accessible formats for local communities.

VIII.   Conclusions and recommendations

62.   **Overall, the field of albinism and human rights has seen remarkable progress in the past five years. Dialogue among the round-table experts contributed to conclusions about how to move forward towards the shared goal of the security and well-being of persons with albinism, and what priorities to pursue.**

63.   **Research on albinism and human rights is lacking, compared to the overall progress brought about by advocacy and policy. Research evidence is persuasive to governments, as illustrated by a participant who commented that "governments listen to data", and it can highlight the work of advocates. The theory generated by research guides policy. Research can provide more information about what advocacy strategies are effective; that research focus was strongly recommended by Delphi survey experts.**

A.   Conclusions and recommendations across advocacy, policy and research

64.   **Consensus was strong across all three sectors – advocacy, policy and research – that persons with albinism must be involved, in keeping with the maxim "nothing about us without us". This commitment requires that:**

        (a)   **Efforts be made to make more visible and empower persons with albinism to speak for themselves, while ensuring resources and support for their security and well-being;**

        (b)   **Whenever possible, researchers should encourage opportunities for capacity-building in research among persons with albinism;**

        (c)   **While albinism is currently set apart as a special population issue aimed at promoting the security and well-being of persons with albinism, the long-term aim is to mainstream albinism concerns into existing policies and services. The round-table participants therefore recommend:**

                (i)   **Effective mainstreaming of the health-care needs of persons with albinism into national (i.e., universal) health services to improve access and outcomes;**

(ii)   Increasing the visibility of the concerns of persons with albinism by mainstreaming their rights within the broader international human rights movement on disability, racial discrimination, health, gender, the environment, particularly climate change and building resilience against skin cancer, to name a few;

(iii)   Taking a parallel approach that includes both mainstreaming and specific programming targeting the issues faced by persons with albinism so that their concerns are not lost in the larger movement.

65.   Evidence-based advocacy and policy, facilitated by the involvement of local and global researchers, are necessary. Consensus and research-based evidence exist for immediate advocacy and policy to support the security and well-being of persons with albinism in the following areas:

(a)   Continue to give priority to health, especially skin and vision care, education, and occupation for persons with albinism;

(b)   Governments and international human rights organizations should use the equality and non-discrimination frameworks that exist in all States to promote policies and accountability to such frameworks to secure the human rights of persons with albinism.

66.   Intersectoral partnerships across advocacy, policy and research as local, regional and global networks make for a shared and stronger voice and for social change. Building intersectoral partnerships requires:

(a)   Strengthening and broadening relationships with all sectors, including persons with albinism, civil society, advocacy groups, research teams and government actors;

(b)   Mobilizing the same political commitments and social alliances that sustained earlier human rights struggles against slavery, colonial repression and post-colonial authoritarianism;

(c)   Engaging moral and political leaders as instruments for progressive change;

(d)   Integrating advocates into research teams, employing participatory research approaches. Advocates link researchers to community resources, assist with recruitment and facilitate knowledge mobilization;

(e)   Employing regular and clear communication on intersectoral teams.

67.   Efforts should be made to promote positive discourses through advocacy, policy and research, emphasizing similarity rather than difference, and using counter-discourses to undermine melano-normativity and colourism. These efforts should:

(a)   Focus on inclusive education and citizenship;

(b)   Cultivate the media as partners;

(c)   Employ multiple strategies in awareness-raising regarding albinism and human rights. No single approach is sufficient;

(d)   Include the academic community to play an active role in debunking myths and in translating knowledge.

68.   Spiritual beliefs and practices are highly meaningful for many African communities, and intensely influence how albinism is viewed. The three most common religious affiliations in Africa are Christianity, Islam and African traditional religion, often practised in conjunction with each other. Witchcraft, as a source of fortune or misfortune, is common in some regions of Africa. This context highlights the need to:

(a)   Draw on relevant philosophies and African ontology to advocate for the rights of persons with albinism;

(b)   Pay attention to how all religions can be used as a force for good or bad;

(c)   **Engage traditional healers, religious leaders and witchdoctors to use their influence to protect the security and welfare of persons with albinism.**

69.   **Attacks on persons with albinism have gained global attention. Motivations for these attacks are complex, but often involve misinformation and economic gain. Multiple mechanisms to prevent these attacks and prosecute perpetrators include:**

(a)   **The uptake of existing equality and non-discrimination frameworks;**

(b)   **Research on attacks, including root causes of attacks, and patterns of trafficking in persons and body parts in particular;**

(c)   **Child protection services in areas where attacks are known to occur;**

(d)   **Addressing the social determinants of health (education, poverty and employment) to manage and eliminate the risk of resorting to harmful practices and illicit acts in a sustainable way;**

(e)   **Countering myths about the subhuman or superhuman nature of persons with albinism through public education, engagement with faith communities, and positive representations of persons with albinism.**

70.   **An agenda to address human rights violations against persons with albinism comes with some risk. For example, as data are collected on patterns of violence, perpetrators of violence may become aware of the whereabouts of persons with albinism. Researchers and advocates must ensure that, in order to effect change collectively, they do not overlook the dangerous impact that may result on the ground. The following strategies are recommended to mitigate such risks:**

(a)   **Researchers must take ethical steps to mitigate risk when researching a community that is targeted or marginalized, such as persons with albinism;**

(b)   **Governments must foster principles of data privacy, respect of the principle of self-identification, and protection when collecting and storing data;**

(c)   **Researchers and governments should ensure the participation of and consultation with persons with albinism in the development of research, data collection and other strategic initiatives that impact them;**

(d)   **Governments should ensure further protection structures are implemented.**

B.   Recommendations specific to research on albinism

71.   **Along with the global research principles developed by the Canadian Coalition for Global Health Research (authentic partnering, inclusion, shared benefits, commitment to the future, responsiveness to causes of inequity, and humility, with equity at the centre), several specific recommendations on how to conduct albinism research are suggested:**

(a)   **Partnerships should be founded on the shared vision that the security and well-being of persons with albinism will allow synergies to emerge;**

(b)   **Researchers should partner with local universities and local advocacy organizations to build local interest and investment in research findings;**

(c)   **Researchers should share findings with those who provided the data and the community liaisons who facilitated the project, so that they are accountable to the people from whom they collected data and to make a difference at whatever level appropriate to the goals of the project.**

72.   **Research methods are the strategies, processes or techniques used to collect and analyse data. Given the particularity and nascent status of albinism research, recommendations for research methods include:**

(a) **Interdisciplinary research, acknowledging the value of philosophic and social sciences in conjunction with health and biomedical research;**

(b) **Community-oriented research methods that are participatory through various stages of the research process;**

(c) **Applying principles of trauma-informed practice to research design and procedures;**

(d) **Research and advocacy partnerships that promote reliable data-collection strategies and dissemination, ensuring relevancy of research. Collaboration between researchers and advocates should seek to support and encourage education and opportunities among persons with albinism.**

73. **Knowledge mobilization is a vital aspect of the research enterprise. Recommended strategies for knowledge mobilization to bridge research, policy and advocacy are:**

(a) **Communicating research evidence with actionable, targeted messages (i.e., the right knowledge at the right time) and consult with the audience for local content, appropriate language for effective messaging, and legible materials (colour and font) for those with low vision;**

(b) **Working with influencers, including the Independent Expert, and seeking local engagement;**

(c) **Developing communication strategies that are innovative and informative, and using both social and traditional media (e.g., newspapers and radio);**

(d) **Working through existing regional, national and international platforms, including:**

(i) **Sharing research on ResearchGate;**

(ii) **Sharing research on existing albinism-related websites, such as Action on Albinism;**

(iii) **Using audiovisual clips to transmit and graphically transcribe research and advocacy reports, such as those generated by the Independent Expert;**

(e) **Adopting the principle of proximity, to share knowledge more intensely with those in close proximity. Better dissemination of research within Africa is needed.**

C. Topics for research

74. **Recommended and prioritized areas for micro-level research include:**

(a) **The experience of low vision and skin cancer and how to reach those in rural regions for vision care and skin cancer prevention;**

(b) **The mental health, response to trauma, and overall resiliency of persons with albinism, including potential treatment modalities;**

(c) **Assessing the use of trauma-informed research and practice within the context of albinism;**

(d) **The experience of women and albinism (whether as persons with albinism themselves, or as mothers of children with albinism);**

(e) **The rights of the child with albinism, including round tables dedicated to this topic;**

(f) **Quality of life of persons with albinism, assessing their quality of life trajectory over the years (e.g., longitudinal design), and at different stages in life (e.g., cross-sectional design).**

75. **Recommended and prioritized areas for meso-level research include:**

(a)   **Formal and informal service providers and their role in supporting persons with albinism;**

(b)   **Exploring how to engage faith leaders, traditional healers and witchdoctors in ending violence and human rights violations against persons with albinism, with a focus on rural communities, in particular, acknowledging that rurality increases the vulnerability of persons with albinism;**

(c)   **Improved genetic services, such as access to genetic counselling;**

(d)   **Mainstreaming access to health care for all, including those in rural and remote regions.**

76.   **Recommended and prioritized areas for macro-level research include:**

(a)   **Ethical issues of genetics and albinism;**

(b)   **Epidemiological research on carrier frequency;**

(c)   **Situating albinism research in particular sectors on disability, education, health, colourism and harmful practices, among others;**

(d)   **Representation of persons with albinism;**

(e)   **Partnering with State actors to ensure prevention and protection measures are in place to counter harmful practices emanating from and related to certain manifestations of belief in witchcraft, including through judicial measures encompassing access to justice and wide-scale human rights education and awareness-raising on conditions such as albinism;**

(f)   **The impact of social determinants of health on the experiences of persons with albinism in various regions.**

77.   **Recommended and prioritized areas for meta-level research include:**

(a)   **The African philosophy of difference, for example, as an epistemology of albinism, and its impact on the human rights of persons with albinism;**

(b)   **The impact of historical trajectories, including colonial histories, on contemporary human rights of persons with albinism;**

(c)   **Applying a human rights perspective broadly to albinism research, advocacy and policy;**

(d)   **All forms of discrimination;**

(e)   **Multinational interaction at a high level.**

78.   **The round-table participants' vision for a research-advocacy-policy network to maintain the spirit of the round table included:**

(a)   **A network with shared leadership, not tied to an individual, and with a board to guide activities;**

(b)   **Global participation;**

(c)   **A centre for research;**

(d)   **A funded network;**

(e)   **Suggested possible network activities include biennial conferences, grants, knowledge mobilization, capacity-building and support services, online networking, data set sharing, such as media data and interviews.**

Appendice

List of participants

Organizers

Barbara Astle, Trinity Western University, Canada; Lori Beaman, University of Ottawa, Canada; Ikponwosa Ero, United Nations Independent Expert on the enjoyment of human rights by persons with albinism; Bonny Ibhawoh, McMaster University, Canada; Kristi Panchuk, University of British Columbia, Canada; Sheryl Reimer-Kirkham, Trinity Western University, Canada; Emma Strobell, Trinity Western University, Canada; Wisdom Tettey, University of Toronto, Canada.

Panellists

Barbara Astle, Trinity Western University, Canada; Charlotte Baker, Lancaster University, United Kingdom of Great Britain and Northern Ireland; Jon Beale, Standing Voice, United Kingdom of Great Britain and Northern Ireland; Lori Beaman, University of Ottawa, Canada; Florence Chaki, Commission for Human Rights and Good Governance, Tanzania; Jake Epelle, The Albino Foundation, Nigeria; Bonny Ibhawoh, McMaster University, Canada; Elvis Imafidon, Ambrose Alii University, Nigeria; Overstone Kondowe, President of Association of Persons with Albinism in Malawi, Malawi; Patricia Lund, Coventry University, United Kingdom of Great Britain and Northern Ireland; Nomasonto (Grace) Mazibuko, Albinism Society of South Africa, South Africa; Senator Isaac Mwaura, Kenya; Kristi Panchuk, University of British Columbia, Canada; Sheryl Reimer-Kirkham, Trinity Western University, Canada; Perpetua Senkoro, Under the Same Sun, Tanzania; Emma Strobell, Trinity Western University, Canada; Wisdom Tettey, University of Toronto, Canada.

Participants

Murray Brilliant, Marshfield Clinic Research Institute, United States of America; Jean Burke, Australian Catholic University, Australia; Katharina Ebner, Intern working with the Independent Expert on the enjoyment of human rights by persons with albinism, Switzerland; Noel Estrada-Hernandez, University of Iowa, United States of America; Rebecca Kammer, Western University of Health Sciences, United States of America; Matthias Krings, Johannes Gutenberg University, Germany; Jennifer Kromberg, University of Witwatersrand, South Africa; Simeon Mesaki, University of Dar es Salaam, Tanzania; Innocentia Mgijima, University of Pretoria, South Africa; Muluka Miti-Drummond, International Bar Association, United Kingdom of Great Britain and Northern Ireland; Judy Oder, International Bar Association, United Kingdom of Great Britain and Northern Ireland; Abdallah Possi, Ambassador of the United Republic of Tanzania, Germany; George Rhoades, Ola Hou Clinic, United States of America; Ester Rwela, Under the Same Sun, Tanzania; Don Sawatzky, Under the Same Sun, Canada.

Acknowledgements