*Name of the respondent:*

*Organization:*

*Position held in the organization:*

*Country:*

**Instructions**

Respond to the best of your ability. Include statistics where available. You may choose to answer **only** those questions within your area of knowledge. Type or write your answers under each question and take as much space as you need (feel free to use additional paper).

**How to submit**

Please submit the completed questionnaire either in English, French, or Spanish via email albinism@ohchr.org

**Deadline**

The **deadline** for submission is **1 May 2019**.

**Permission to publish**

Kindly indicate if you have any objection to your response being made available on the UN webpage of the Independent Expert: ……………………………………………………………

**PART A: ALBINISM WORLDWIDE**

**Awareness-raising**

a) How is albinism perceived in your country?

b) Are there any public campaigns to raise awareness on the issues faced by persons with albinism?

c) If so, who are the persons/organizations organizing/leading these campaigns?

**Data**

1. Summarize the situation of persons with albinism in your country.
2. Number of people with albinism in your country?
3. What is your source of the population data provided at (b) e.g. census, survey, association records? Please identify the year when data was gathered.
4. Where do most people with albinism reside? In other words, do they tend to be concentrated in certain parts of your country ? Do you have information on their ethnic origins?

**Legislation and Policy Frameworks**

a) Please provide information on measures that relate to persons with albinism (refer to relevant legislation or policy if any).

b) Comment on how these legislative and policy frameworks impact the human rights situation of persons with albinism.

**Human Rights issues**

1. Do you have information on the human rights challenges faced by persons with albinism?
2. More specifically, do you have information on challenges relating to::
* social inclusion or exclusion in all aspects of life
* access to education
* access to health (e.g. skin cancer prevention)
* disabilities (e.g. visual impairment)
* barriers in accessing employment
* discrimination based on colour
* violence

c) Do persons with albinism experience harmful practices? Infanticide, physical attacks, mutilation, trafficking, other?

d) Are you aware of investigations or court cases related to the human rights of persons with albinism? List and/or comment on them.

e) Other information on other barriers and challenges faced by persons with albinism

**Good practices**

Do you have examples of good practices in relation to persons with albinism? If so, describe them below and indicate what entity provides them.

For example:

* *Awareness Raising:* are there any awareness raising programs (in school curricula, international albinism awareness day, others?
* *Health:* are there any measures in place that address the specific health needs of persons with albinism? e.g. skin cancer, psychological care, vision etc.?
* *Disability:* are there measures in place to assist persons with albinism regarding reasonable accommodation (at school and work) for visual impairment?
* *Discrimination:* are there measures in place to address discrimination on the basis of colour, disability or other basis related to albinism?
* *Access to Justice:* are there measures in place to ensure access to justice for persons with albinism. Access to Justice is broad and encompasses access to, and information about remedies for all types of discrimination in all spheres.

**Regional/ International activities**

Are there any regional activities that take into account the human rights of persons with albinism ? For example at the African Union, European Union, Association of South East Asian Nations, Inter-American Commission on Human Rights, Asia-Pacific fora? etc.

**Comments and recommendations**:

Include other information and suggestions you have that are not provided above on persons with albinism generally, in your country or region.

**PART B: WOMEN AND CHILDREN**

(Indicate source of data)

**Stigma and social exclusion**

a) Do women with albinism face exclusion and stigma in the communities that they live in (*include stigma and exclusion faced by mothers who have children with albinism*).

b) Do children with albinism face exclusion and stigma in the communities that they live?

c) Do girls with albinism face particular issues?

d) Do boys with albinism face particular issues?

b)Are women and children with albinism affected with expulsion from their community (by others or self-imposed) or displacement within your country?

If yes, what are the main reasons for the expulsion and displacement?

**Data for decision making**

a) Is disaggregated data available (through surveys, or organizational data) on the population of people with albinism in the country?

b) Is disaggregated data being used for initiatives to support women and children with albinism?

c) Are there any forum or structures in which women and children with albinism can meaningfully participate in decisions that affect them?

**Education**

a) Are there any adaptive devices (large print, glasses, monocular etc) in place to address concerns for children with albinism within the educational setting?

b) Are there particular challenges that children with albinism face in school (for example, any type of bullying, stigmatization, physical challenges)?

c) Are the challenges above different for school-aged girls compared to school-aged boys?

d) What is the percentage of girls with albinism who complete primary school?[[1]](#footnote-1)

f) Are there any initiatives or mechanisms in place to support girls with albinism to remain in school or access education?

e) Do you have information on whether children with albinism experience violence (physical, sexual or emotional) within the school setting (e.g. from peers, teachers etc.)? Are there any particular types of violence within the school setting that predominantly affect girls with albinism?

**Access to health care**

a) Are there specific barriers faced by (a) women with albinism and (b) mothers of children with albinism in accessing health care services and products? (*in your answer, describe any barriers related to cost of health-care services, availability of health insurance schemes, early medical interventions, availability of health-care services in remote and rural areas, any stigma and discriminatory attitudes or practices by community members or health service providers that deter women with albinism from seeking health services*)

b) Are there any initiatives or mechanisms in place to facilitate the provision of and access to health services and products, for women and children with albinism?

c) Are there any early interventions tailored for mothers of children with albinism?

**Sexual and reproductive health**

a) Are sexual and reproductive health services easily accessible and available to women and adolescent girls with albinism? (*evaluate the quality of services identified*)

b) Are there any barriers that deter women with albinism from seeking sexual and reproductive health services? (*including stigma by health care providers*)

c) Are there any initiatives or mechanisms available to support women and adolescent girls with albinism in accessing sexual and reproductive services?

**Access to information**

a) Are there any barriers that children with albinism and/or mothers with albinism face in accessing information regarding their rights? Are there any support services available to them to address these barriers?

b) Are there any public/community education efforts being made to dispel myths and misconceptions about women and children with albinism as well as mothers with albinism? (*including those targeting service providers)*

**Access to income generating opportunities/employment**

a) Are there any challenges that (a) women with albinism and (b) mothers of children with albinism face in accessing or benefitting from economic empowerment opportunities? (*such as access to loans, jobs, productive assets, skills development, market information. financial services, property and other income generating opportunities*)

b) What is the poverty ratio of women with albinism in your country?[[2]](#footnote-2)

c) What is the poverty ratio of mothers of children with albinism in your country?[[3]](#footnote-3)

d) Outline any economic empowerment opportunities for women with albinism? (*include access to loans, jobs,* *productive assets, skills development, market information. financial services, property and other income generating opportunities)*

**Sexual violence and harmful cultural practices**

a) Are there any incidences of sexual violence that commonly target women and girls with albinism (include all forms of violence including physical, sexual and psychological harm)

b) Are there any harmful practices that predispose women and girls with albinism to any physical, social or psychological harm?

**Heightened vulnerability to attacks**

a) In the last 2 years, how many attacks have occurred against women with albinism in your country?[[4]](#footnote-4) What about children with albinism?[[5]](#footnote-5) (*mention particular cases if available. Attacks include all forms including trafficking of person*).

b) What are the factors that heighten the vulnerability of women and children to these attacks?

**Enhanced protection for women and children from attacks**

Do you have information on initiatives or mechanisms in place for the protection of women and children with albinism from attacks.

**Access to justice**

a) What are the main challenges for women and children with albinism in accessing justice? (Justice in this sense includes laws, procedures, understanding of the legal system and access to mechanisms for redress)

b) Are there any child friendly procedures and systems in place for children with albinism who have to go through the justice system (either as victims or witnesses to crime)?

c) Are there any gender sensitive procedures in place for women with albinism who access the justice system either as victims or witnesses to crime?

d) Are there any legislative or administrative measures taken to facilitate access to justice, specifically for women and children with albinism? (*including legal aid services*)

**Redress and rehabilitation**

Is there any support in place for women and children with albinism who are victims of attacks and discrimination, or their families (*include any available psychological support, medical support, shelters or other forms of housing, witness and victim protection measures, livelihood or financial support and counselling)?*

**Thank you**

1. If you do not have national wide data, provide any statistics on school completion rate that you may have in your specific community, region etc. [↑](#footnote-ref-1)
2. If you do not have national wide data, provide any statistics you have on poverty levels of women with albinism, even if the data is limited to a specific region or area of the country [↑](#footnote-ref-2)
3. If you do not have national wide data, provide any statistics you have on poverty levels of women with albinism, even if the data is limited to a specific region or area of the country [↑](#footnote-ref-3)
4. If you do not have data that extends to the last two years, please provide any data (monthly, annual) on attacks against women and children with albinism [↑](#footnote-ref-4)
5. As above [↑](#footnote-ref-5)