Global ALBINISM Alliance (Pilot)

Report on 2020
Worldwide Survey

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Introduction

On January 26, 2020 in Paris, France, representatives of albinism organizations and others advocating on behalf of those with albinism from 6 continents (23 countries) attending an exploratory meeting voted unanimously to form an official albinism alliance (cf. Figure I-1). The vote was a first step to promote solidarity among albinism groups around the world. Delegates also approved a three-phase Pilot Project to establish a Global Albinism Alliance within 15 months.

A primary objective of Phase 1 of the Pilot is to gather information and report on what albinism groups around the world consider as important for a permanent alliance. To accomplish this goal, the Pilot Team constructed a survey with expert consultation made possible by a generous grant from *Under The Same Sun*. The survey was designed to fulfil the main objective of Phase 1, learn about albinism organizations and their leadership, and to determine the level of interest and support for the creation of a global albinism alliance.

This report:

- gives a brief history of albinism organizations,
- describes the survey methodology,
- reports the findings of the survey with respect to the characteristics of albinism organizations and their leaders,
- addresses language considerations relative to the formation of a global albinism alliance,
- reports on organization opinions on a global albinism alliance,
- reports the presence or perception of challenges from a human rights perspective
- provides analysis and recommendations.

It should be mentioned that, although our worldwide survey was the main source of information for the analysis conducted in this report, additional information gathered on websites and social media pages was also used from time to time to reach a higher degree of analysis.

Any comment or question regarding this report and the worldwide survey present herein can be sent to albinismalliance.pilot@gmail.com.

Figure I-1 - Group photo of the Participants of the 2020 Paris Global Albinism Alliance Exploratory Meeting

Chapter I   A Brief History of Albinism Organizations and Worldwide Albinism Associations

1.   Early Albinism Organizations

The community of albinism organizations and NGOs started its development in the late 1970's and 1980's. The earliest national albinism organizations were the Tanzania Albinism Society which began operation in 1978 and was registered in 1980, the Albinism Fellowship of the UK & Ireland which was registered in 1979 and the North American organization NOAH (National Organization for Albinism and Hypopigmentation) which was founded in 1982 and registered in 1984. About 22 albinism organizations began operations in the 1990s.

Since 2000, the rate of creation of organizations in support of people with albinism increased continuously with a dramatic number of new groups being created in the 2000's and 2010's in every region of the world.

2.   Attempts to Build an International Coalition of Albinism Organizations

The first known attempt to structure and formalize collaborations at the international level between albinism organizations goes back to the creation of the *Albinism World Alliance* (AWA) in 1992. The AWA had representatives from Australia, Canada, Tanzania, the United Kingdom, the United States, Germany, Mali, Malawi, the Netherlands, Puerto Rico, Norway, and South Africa. However, the AWA failed to become a sustainable organization and eventually stopped operating at the turn of the century.

At the beginning of the 2010's, the *Albinism Fellowship of Australia*, under the initiative of its former Secretary, Dr. Shari Parker, pushed for the creation of a new international alliance for albinism, the *World Albinism Alliance* (WAA). Although this project seemed very promising and could benefit from the development of the Internet and the possibility to interact at distance in a much easier, faster and cheaper way, it unfortunately did not reach the point of becoming a sustainable operating organization.

Starting in 2013, thanks to the hard work of a few albinism advocates and NGOs, several resolutions concerning albinism were adopted by the United Nations including the creation of the International Albinism Awareness Day (to be celebrated every year on June 13th).

In June 2015, the Human Rights Council appointed Ms. Ikponwosa Ero as the first United Nations Independent Expert on the enjoyment of human rights by persons with albinism. In the frame of her mandate, Ms. Ero significantly drove several international initiatives within the albinism community, starting from but not limited to Africa. Over the course of her mandate and throughout her different actions, particularly following the completion of a report on Albinism Worldwide, Ms. Ero saw the need for an association at the global level to foster and structure collaborations between albinism groups and to be the voice of the albinism community outside of the United Nations. In 2019, in collaboration with

several key leaders of the global albinism community, she decided to launch a new attempt at the creation of a world alliance for albinism: the *Global Albinism Alliance* (GAA).

Chapter II   Survey Methodology

This chapter describes in detail all aspects of the planning and execution of the global consultation. A survey was used to collect information.

1.   Survey Goals

The main goals of the GAA worldwide survey were the following:

- Gather information on what albinism groups around the world would like to see in a permanent alliance (e.g., future missions of the alliance),
- Update and enrich a worldwide database of albinism organizations with contact information,
- Get an overview of the nature and characteristics of albinism organizations around the world and identify major commonalities among them
- Gather general information on challenges faced by persons with albinism around the world

2.   Survey Target

The Pilot Team focused on the following albinism organization types:

- associations and organizations whose primary focus is albinism
- organizations that might be among the future membership of the GAA because of a strong connection to albinism

The idea was to start with those groups most likely to be interested in a future global alliance. Non-albinism-specific organizations, such as organizations for blind and visually impaired people or human rights organizations not specifically focused on albinism were not targeted, although it is anticipated that a global albinism alliance would build collaborations with such groups. As the survey was specifically designed for albinism organizations, direct contributions from individuals were not expected.

3.   Survey Population

At the beginning of Phase 1 of the GAA Pilot, the Secretariat was granted access to a worldwide database of albinism groups by the team of the UN Mandate on Albinism. The database had been in continual development since the launch of the mandate in 2015 and significantly enriched in the first months of 2019 while the UN Expert conducted a survey on albinism worldwide. A total of 214 groups were listed in the database when first accessed by the GAA Pilot team. From that point:

- 8 groups were identified as no longer existing
- 41 new groups were added
- 52 groups had contact and other information updated

Once updated the database contained 247 groups worldwide covering 90 countries.

4.   General Planning

Given the expected number of responses (between 100 and 250), the deadline to complete the survey, the limited human resources available, the diversity of languages and time zones, and the limited availability expected from the addressees of the survey, it was decided to base the survey on the use of an online survey translated into the minimum necessary languages.

5.   Drafting and Testing

A first version of the survey was drafted in English by members of the GAA Pilot Team using *Google Forms*. The initial draft was reviewed by the GAA Technical Team as well as by the GAA Technical Advisor (i.e. the UN Independent Expert). The draft was then sent to the Paris meeting regional delegates for a pre-test (in English only). Nine complete responses were received, and three additional persons made comments without completing the draft survey.

Feedback led the team to conclude that the survey was too long, and several aspects of *Google Forms* made the survey complicated to answer. The Pilot Team concluded that a different online platform was needed.

Given the lack of experience of the Pilot Team in running worldwide surveys and the little time available, it was decided to hire a survey expert to help improve the survey based on the input of the pre-test. A two-week consultation with a survey expert was funded by *Under The Same Sun* and coordinated by the focal points of the Technical Team and Secretariat. A new version of the survey, significantly shorter than the first, and hosted by *SurveyMonkey* instead of *Google Forms* was the result of the work of the consultant and team representatives.

This new version was pre-tested (in English only) by six albinism group leaders from Chile, Norway, DRC, Rwanda, China, and the Philippines. Half of these people had been regional delegates at the Paris meeting. After filling out the survey, each pre-tester was interviewed by the survey expert with the help of a Pilot Secretariat member to identify the last adjustments that were to be made. Based on the outcome of the pre-test, the survey was once again updated and a third and final version was created.

6.   Question Selection

The first version of the survey was relatively long and included mandatory and optional questions. The final version, with only 26 questions was significantly shorter and included mostly mandatory questions. Five questions were set to be optional, either because they did not apply to all organizations, or because they addressed topics that could be considered as too confidential. The final version of the survey is presented in Appendix 1.

7.   Language and Translations

The survey was initially drafted in English, as this is the only common language within the Pilot Team. However, in order to receive a maximum number of contributions, be as

inclusive as possible, avoid preventing some organizations from participating in the survey due to the language barrier, and to permit as many organizations as possible to express themselves freely in a language that they master well, the necessity to provide several translations of the survey was apparent from the beginning of the drafting process.

Based on the albinism group database received from the UN Mandate, as well as on experience (organization of the Paris meeting) it was decided to translate the survey into French, Portuguese, and Spanish. This was done by volunteers; members of the Secretariat with the help of one Paris meeting delegate, none being professional translators. The choice to translate into a limited number of languages was also based on financial considerations. The GAA Pilot Phase started without funding. It is to be noted that, due to lack of time, the French, Portuguese, and Spanish versions of the survey were not pre-tested before the survey was launched.

8.   Dissemination of the Survey

The survey was disseminated by email using the contact addresses contained in the existing database. A first email was sent on June 23rd, 2020 for the launch of the survey. A second email was sent on July 14th, 2020 to those groups that had not yet responded. All addressees of the survey were encouraged to share the information with all the groups that they were in contact with, because some organizations may not have been listed in the database.

At the beginning of the Pilot Phase, the GAA appointed the following Regional Contact Points (RCPs) selected among the Paris meeting regional delegates:

- **Western & Central Africa**: Nicodeme Hakizimana, Mouhamadou Bamba Diop
- **Southern & Eastern Africa**: Nomasonto Grace Mazibuko, Overtsone Kondowe
- **North America**: Donté Mickens
- **Latin America**: Claudia Nuñez
- **South Asia**: Prakhar Deep Gupta
- **South-East Asia**: Maizan Mohd Salleh
- **East Asia**: Lei Xiao, Daisuke Ito
- **Europe**: Agnese Marchesini
- **HPS**: Donna Appell
- **Middle East**: Burcu Cakir Keskin
- **Oceania**: Elizabeth Beales
- **Pacific**: Sainimili Tawake

These RCPs were asked to help disseminate the survey using their contacts and their knowledge of the interconnections of albinism groups in their respective regions. It is worth noting that the different RCPs are all involved in formal or informal regional albinism groups and networks that the Pilot Team are aware of.

The launch of the worldwide survey was published on the Pilot GAA Facebook Page.

A significant number of emails sent for the dissemination of the survey were blocked

or bounced back (due to email addresses being incorrect or not being active anymore). All reasonable efforts were made to solve these situations including:

- Looking online for new email addresses
- Contacting the organizations via their Facebook pages (Messenger) and online contact forms
- Contacting the organizations via WhatsApp

It is worth noting that several groups listed in the database lacked email addresses or contact information.

9. Survey Collection

Two main ways to participate in the survey were offered to the potential contributors. The main and most preferred was by responding to an online version of the survey hosted on the well-known survey platform "*SurveyMonkey*". However, a PDF version of the survey was also attached to the survey launch email for organizations with limited or unstable Internet service.

10. Deadlines

The survey was launched on June 23, 2020. The initial deadline was July 19, 2020. Although most responses were received by that deadline, a few responses were received the following week and accepted.

11. Survey Responses

11.1 Totals

145 complete responses were received covering 80 different countries.

- 69 responses were received through the English version of the survey
- 41 responses were received through the French version of the survey
- 22 responses were received through the Spanish version of the survey
- 13 responses were received through the Portuguese version of the survey

The rate of completed surveys was satisfactory. Answers to the questions about the organizations provide valuable information about the global albinism community. The Pilot Team is confident that the data collected in the survey is significant and will provide a solid basis for further discussion relative to the mission and structure of a global alliance.

The Team was flexible with regards to how the survey was completed. The goal was to make participation as open as possible. All answers were entered into *SurveyMonkey* for tabulation and analysis.

Out of the 145 complete responses:

- 134 were received through *SurveyMonkey*
- 10 were received by email with an attached file containing the answers
- 1 was received via WhatsApp

11.2 Response Rate

Out of the 145 complete responses received:

- 129 were received from organizations already listed in the database
- 16 were received from organizations not listed in the database

It is worth noting that among the 247 organizations listed in the database at the beginning of the survey:

- 55 were lacking contact email address
- 8 had an inactive email address

Therefore, in practice only 184 groups out of the 247 listed in the database could be contacted via email. However, 5 organizations of which the database did not have any operating email address did eventually respond to the survey, indicating that they received the information through a different channel than emails.

Therefore, the rate of responses among the known organizations considering the groups that could be reached is approximately 129/189 = 68%.

We hypothesize that the main reasons for the organizations listed in the database not responding to the survey might be among the following:

- Organization not operating anymore
- Very small organization lacking time / resources
- Organization not supporting the project of global alliance
- Language barrier

Further effort should be made to contact the 58 organizations that could not be contacted directly. It would be good to know if they are still in operation and if so, what needs to be done to communicate with them.

A similar approach could make sense with the 32% of the organizations listed in our database that could be contacted directly but did not take part in the survey.

11.3 Incomplete responses

The survey designed on *SurveyMonkey* included 4 pages. Answers were automatically saved at the end of each page, thus allowing the responders to stop in the middle of the survey and defer their answers to the rest of the questions to a later time. When a response did not include answers to all mandatory questions of all four pages, it was tagged as being incomplete.

The Secretariat contacted every organization whose response was identified as incomplete to encourage them to finish completing the survey.

In total 10 incomplete responses were never completed, 9 of them including only an answer to the first question (email address of the person responding).

11.4   Late Responses

Very few responses were received long after the deadline and were therefore not included in the survey. Also, as a new organization was and is identified by the GAA Pilot Team, the Secretariat gets in contact and shares the survey.

12. Regions considered in the response analysis

Two questions included in the survey lead to gathering geographical information from the respondents about the country of operation and country of headquarters. To allow a fruitful and insightful analysis of these responses, it appeared important to divide the world into regions.

This division of the world was made after analyzing the responses received. It was done by considering the following principles and criteria:

- Official list of geographic regions used by the United Nations Statistics Division in its publications and databases (https://unstats.un.org/unsd/methodology/m49/)
- Necessity to have a significant enough number of groups in each region for statistical relevance
- Similarities between neighbor countries not belonging to the same UN region leading to making exceptions to the first rule (principle already applied to the selection of regional delegates to the Paris Global Alliance Exploratory meeting)

Note that this division of the world slightly differs from the one used for the selection of the regional delegates of the Paris Global Albinism Alliance Exploratory meeting.

Table II-1 shows the composition of each region used in the next chapters of this report. Figure II-2 below shows these different regions on a world map.

Region	Composition
Asia	- Eastern Asia - South-eastern Asia - Southern Asia
Europe	- Eastern Europe - Northern Europe - Southern Europe - Western Europe
Eastern & Southern Africa	- Eastern Africa (except Burundi and Rwanda) - Southern Africa - Angola

Western & Central Africa	• Western Africa • Central Africa (except Angola) • Burundi • Rwanda
Western Asia & North Africa	• Western Asia • North Africa
Latin America & Caribbean	• Caribbean • Central America • South America
North America	• North America
Oceania	• Australia & New Zealand, Melanesia

Table II-1 -Composition of Regions Considered in Response Analysis

No response was received from Central Asia, Micronesia, and Polynesia. These subregions of the world are therefore not included in any of the above defined regions.
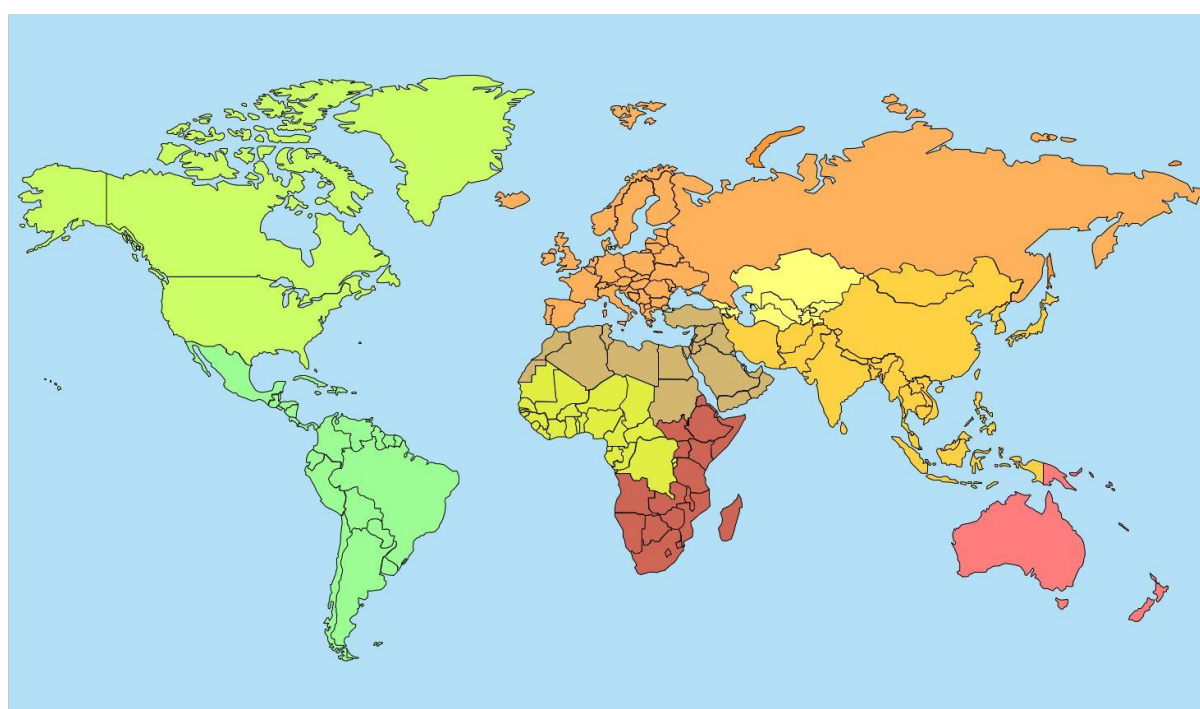
Figure II-1 – Map of the world showing the division into regions as considered in response analysis

The detailed maps of every region are presented in Appendix 2.

Chapter III   Survey Results - Organization and Leader Characteristics

This chapter reports the results of the survey with respect to organization and leader characteristics. The data provides an overview of the nature and characteristics of albinism organizations around the world and their leaders. For each characteristic polled this chapter will:

- state the question(s) related to the organization and leader characteristic,
- state the goal for collecting the data if not self-evident,
- report the results,
- list considerations for further study if applicable,
- Identify important considerations for the future alliance revealed in the data.

The total number of answers for organization characteristics questions is 146. The total number of answers to leader characteristics is 145. Appendix 1 is the complete list of survey questions.

1.   Organization Characteristics

1.1   Type of organization

Respondents were asked, *"Of the following, which best describes your organization? (Please check only one.)"* The choices offered were:

- local organization,
- national organization,
- regional federation (several countries within a continent) and
- other.

Knowing the types of organizations that are most likely to be members of a global alliance will inform decisions about the structure and membership of the future alliance. Two issues were considered when including this question in the survey.

- Will the alliance have regional groups to rely on, or need to interact directly with national and local groups?
- Will the alliance have to deal with different categories of organizations, or mostly one type?

Just over three-quarters of respondents (113) described their organizations as national. 11 organizations said that they were local. 5 described themselves as regional federations. 17 answered that they were some other type of organization. See Figure III-1 below.
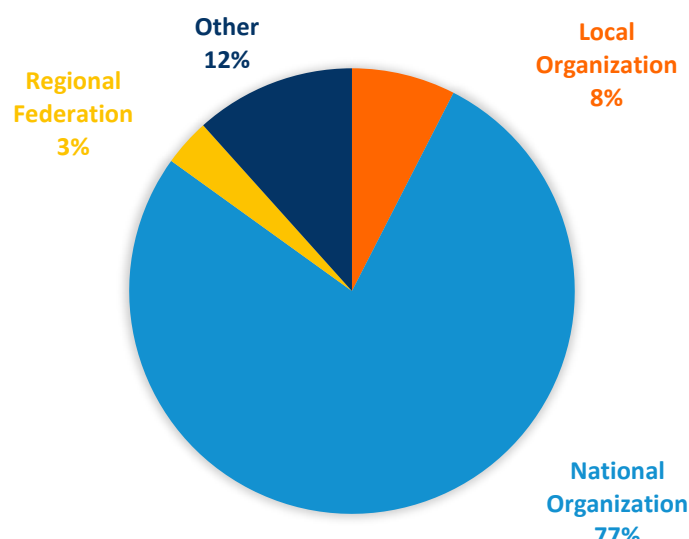
Figure III-1 - Organizations by Type

Organizations answering "other" were given the opportunity to specify their situation. Out of the 17 organizations who chose this answer:

- 8 used the word "international" in the description of their group. Based on other data collected, three of these groups appear to be relatively small. The rest of these groups vary greatly in size, budget, and mission.

- 1 appears to be in fact a regional federation

- 3 appear to be in fact national organizations

- 2 appear to be in fact local organizations (one describing itself as a state organization within a federal country)

- 1 could be considered as a national group although it is in fact a non-registered online community

- 1 is a group of artists running social activities within one country

- 1 is a charity created and run by a health-care provider operating within one single country

The survey results indicate that national organizations will likely make up a significant majority of future alliance members. However, it is highly probable that there are differences in the way that national organizations are structured, how they operate and their connection to their community through programming. Further study is needed to determine if there are subcategories of national organizations (e.g. depending on their main mission, on their membership or on their leader's connection to albinism).

The data collected from the 113 respondents describing themselves as national organizations shows that:

- 29 countries have more than one group saying that they are a national organization,

- 52 countries are covered by only one organization each.

Potential explanations for the existence of multiple organizations in one country may be:

- organizations with different missions
- organizations not covering the entire country (categorized between local and national)
- difficulties in collaboration between people/groups with similar missions

Further study is needed to understand the reason that multiple national organizations operate in a single country and to understand the implications of this for the future alliance.

More generally, the survey provided a good description of the variety of organizations that will make up the future membership of the alliance. However, it seems that further study would be needed to get a more comprehensive and exhaustive picture of the variety of types of organizations. This information will be very helpful when making decisions on the different types of members.

1.2   Geographical area of operation

Respondents were asked to *"Please indicate the country where your organization is based or headquartered"* and *"Please indicate the country or countries in which your organization operates."*

There were three reasons for asking albinism organizations to say where they operate:

- To identify areas covered and not covered
- To get an idea of the number of organizations per country and region
- To get a more accurate picture of the situation given that the distribution of albinism organizations around the world is a factor taken into consideration when dividing the world into regions (with Regional Contact Persons) for the operations of a future alliance.

Albinism organizations who participated in the survey operate in 80 countries on 6 continents. 10 countries listed in the database (before the launch of the survey) are not covered by the survey as the corresponding organizations did not respond to it. These are the Czech Republic, Haiti, Iran, Jordan, Romania, Samoa, Somalia, Sweden, Taiwan, and Uruguay.

It is worth noting that an organization based in Russia stated that it operates also in "post-soviet countries". This means that this organization could technically be operating in up to 15 different countries. The clarifications received after submission of their response indicate that a large majority of their members are living in Russia. For this reason, it was decided in this report to take only Russia into account as country of operation of this organization. Further exchanges will be needed to get a better picture of the geographical area of operation of this organization.

The map below shows the countries in which albinism groups operate.

Figure III-2 - Map of Countries where Albinism Organizations are Operating

The data shows, as mentioned in section 1.1 above, that there are several countries in which two or more albinism organizations are operating. It is important to note, here, that no definition of "operating" was provided in the survey, and there are good reasons to think that the different answers received were based on several interpretations of this term. It is reasonable to think that the organizations who listed several countries of operation might fall into one of the following situations:

- International organizations running programs / activities in different countries
- National organizations serving not only the albinism community of its own country but also persons with albinism based in regions of neighboring countries sharing the same language and / or culture
- Albinism organizations whose headquarters are not located in the country where the organization is mostly operating. In that case, the country of headquarters might be listed as another country of operation because the organization might be running awareness-raising, fundraising and PR activities in that country.
- National organizations collaborating with albinism organizations in other countries, and therefore considering their geographic area of operation as going beyond the borders of its own country. This situation is obviously the one of several survey respondents, given that the corresponding organizations' name clearly suggest that they are national groups serving the albinism community of their very country (e.g. "national albinism organization of [name of the country]")

The map below shows the number of organizations operating in each of the countries covered by the survey.
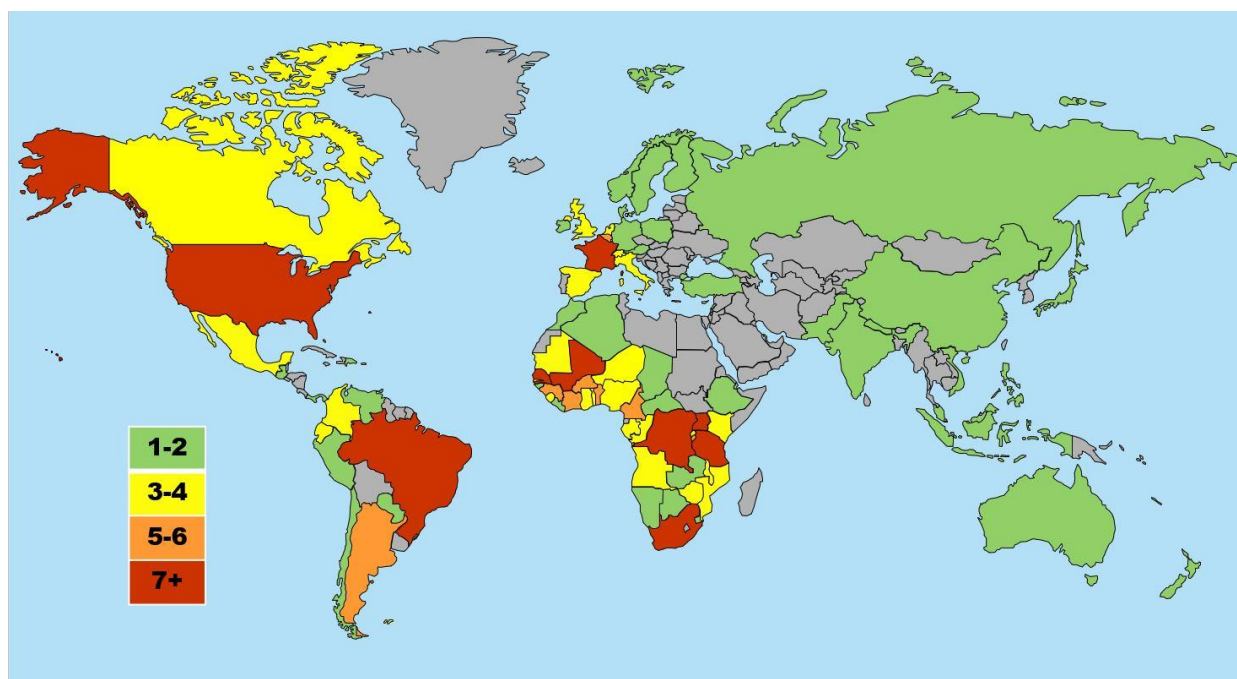
Figure III-3 - Map indicating the number of organizations operating in each of the countries covered by the survey

Further study will be needed to draw a more accurate map of the geographical area of operation of the different albinism organizations around the world.

The survey also asked respondents to **"indicate the country where your organization is based or headquartered."**

The answers show that a wide majority of organizations (94%) are registered and based in the country (or one of the countries) where they operate. They correspond to local and national groups. However, 9 exceptions were found: 5 based in North America and 4 in Europe. All 9 of these operate in either S & E Africa and/or W & C Africa.

Among those 9 organizations:

- 4 classified themselves as national organizations, 3 of these declared not having paid staff, and 2 have a very limited budget.
- 4 classified themselves as international organizations, 3 of these declared having paid staff.
- 1 chose "Regional federation" and declared having paid staff

By going through the answers provided by these 9 organizations to the different questions of the survey and based on additional information gathered on websites and social media pages, it appears that some of the answers are probably erroneous. It would be wise to contact these different organizations to understand exactly to what type of organization they belong to.

It is interesting to notice that these organizations operate in countries where one or several albinism organizations are already based and operate. It could be useful to find out what type of collaboration might exist in these countries between the two categories of organizations (with or without headquarters in the country of operation).

Based on the division of the world into regions presented in Chapter II, and to allow a more comprehensive analysis in the frame of this report, each of the 146 organizations who responded to the survey was associated to a given region, depending on the country(s) where it operates. Table III-1 below shows the outcome of the distribution by region of the organizations that took part in the survey.

Region of operation	New organizations	Organizations already listed in database	Total of organizations who responded to the survey	Number of countries represented
Asia	2	8	10	10
Europe	1	12	13	13
Eastern & Southern Africa*	4	33	37	13
Western & Central Africa**	3	45	48	22
Western Asia & North Africa	0	4	4	4
Latin America & Caribbean	6	22	28	13
North America	0	3	3	2
Oceania	0	3	3	3
Totals	16	130	146	80

Table III-1 - Information About Albinism Organizations by Region

* 3 organizations counted here are operating both in Western & Central Africa and Eastern & Southern Africa

** 2 organizations counted here are operating both in Western & Central Africa and Europe

It appears that the total number of organizations from Oceania, North America, and Western Asia & North Africa is relatively small. For reasons of statistical relevance, analysis of the responses received from these regions further in this chapter will be limited.

Areas currently not covered or little covered by albinism organizations are:

- Southern & Eastern Europe

- Pacific (Melanesia, Micronesia and Polynesia)
- Central America
- Central Asia
- North Africa & Western Asia
- Southern, Eastern & South-eastern Asia

It is worth noting that some large countries (either geographically and/or in terms of population) have only one or two national groups. The future alliance would be well served to determine whether these organizations are facing difficulties in covering their country's entire population, and, if not, how they manage a large population and/or geography. Countries to investigate could be: China, Indonesia, India, Pakistan, USA, Brazil, Nigeria, Russia, Mexico, Canada, Australia.

1.3   Length of operation

Survey respondents were asked, ***"In what year did your organization begin operating? (Check one.)"*** The possible answers were:

- Pre-1990,
- 1991-2000,
- 2001-2010,
- 2011-2016,
- 2017-2020.

Figure III-4 shows the number of albinism organizations by length of time in operation based on the year they began operating.
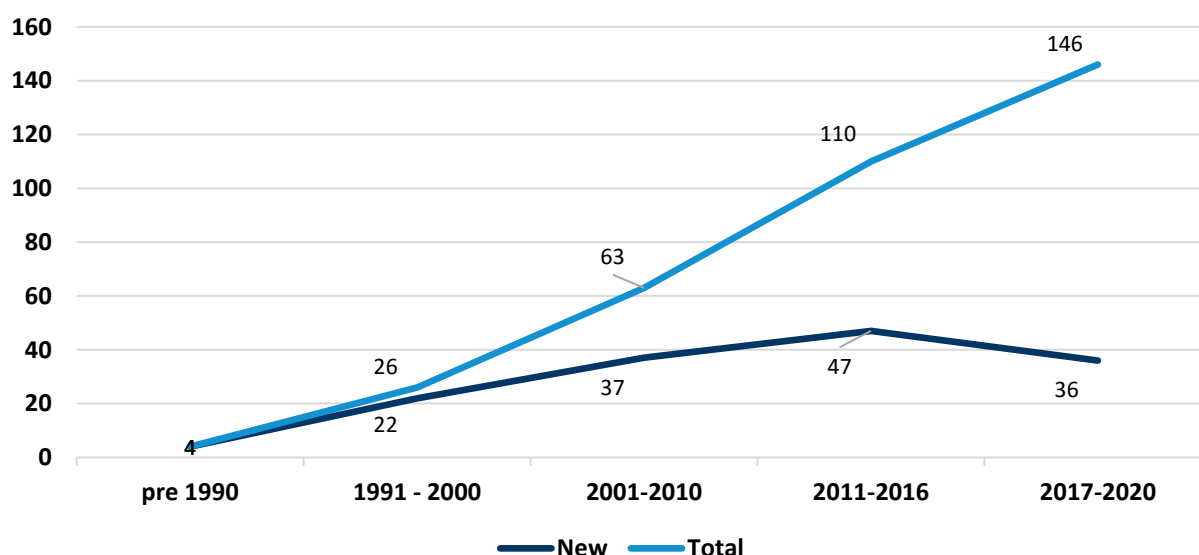
Figure III-4 – Number of albinism organizations by length of time in operation / evolution of the number of organizations created throughout the past decades

Figure III-4 demonstrates the steady growth of albinism organizations over the past four decades. Rapid growth occurred in the 2000's and 2010's including 36 organizations beginning operations since 2017. It is interesting to note that the number of albinism

organizations has more than doubled since 2010. Much of this growth occurred after the former World Albinism Alliance was established (cf. Chapter I-§2).

Figure III-4 also demonstrates a wide range in the number of years in operations among potential members of the future alliance. There will be a significant number of member organizations with little experience and a significant number with many years of experience.

The length of time that an organization has been operating is potentially an indication of organizational maturity and sustainability. However, organizations grow and mature at different rates depending upon many factors including available human and financial resources.

The leadership of the future alliance should keep in mind the diversity among the potential members with respect to:

- their experience,
- their stage of development,
- their organizational needs,
- their capacity to dedicate time to participate in the activities of the future alliance.

An analysis of the length of operation by region reveals that:

- the first years of operations of albinism organizations in Latin American and Asia are later than overall
- the first year of operations in Europe is earlier than overall

1.4   Registration status

Survey respondents were asked, *"is your organization registered? Registered means that a governmental or civic organization has given a formal written approval that makes your group a legal entity with full legal capacity".* The possible answers were:

- yes
- no
- in process

By asking about registration status, the team wanted to get an overview of how the registration status might be a factor to be taken into consideration when defining the membership categories of the future alliance. The team also wanted to see if registration status would add to understanding of the degree of maturity of each organization.

Figure III-5 below summarizes the registration status of 146 survey respondents. About 3 of 4 (111) groups report that they are registered. 21 groups are not registered and 14 are in the process of registration.
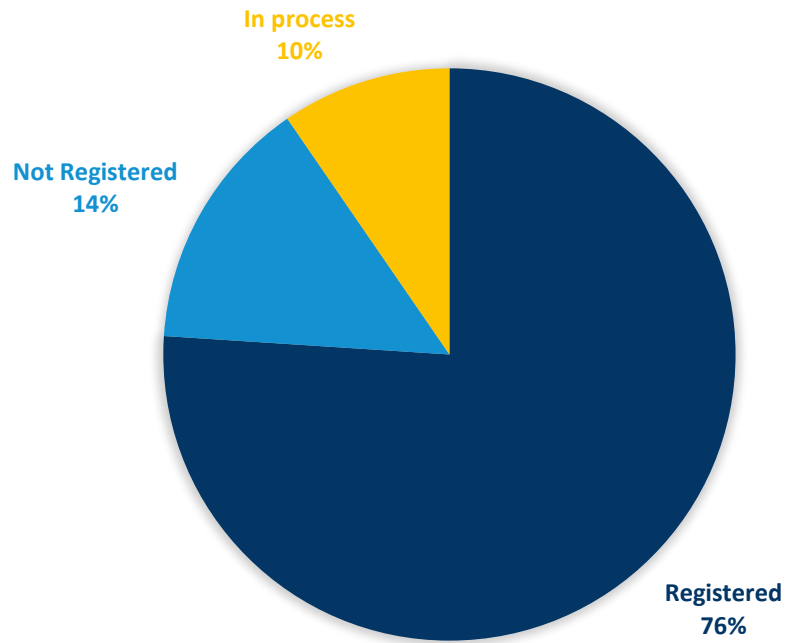
Figure III-5 - Registration Status of Albinism Organizations

The proportion of organizations not registered and where registration is in process is generally correlated to the age of the group as illustrated in Figure III-6.
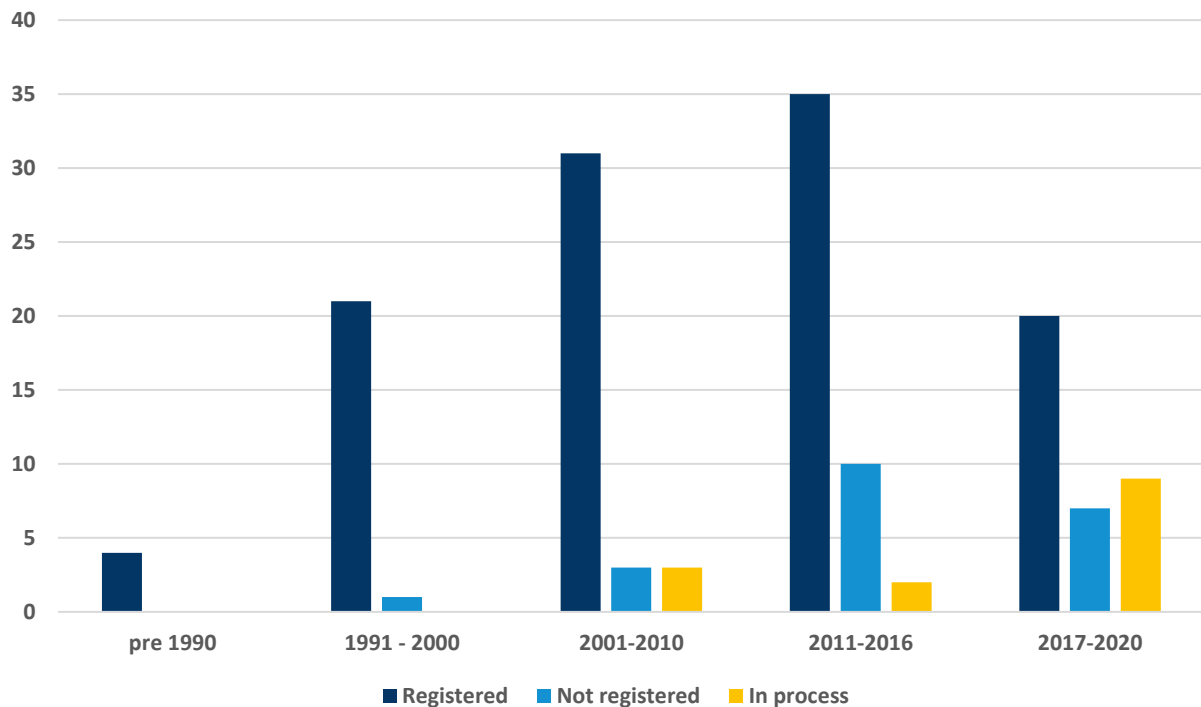
Figure III-6 - Registration Status of Albinism Organizations by number of years in operation

Figure III-7 - Registration Status of Albinism Organizations by Region

A high percentage of respondents reporting that their organizations are registered indicates a serious level of commitment to the albinism community around the world and suggests that most groups have created formal organizational structures. As illustrated in Figure III-7 above, the data shows that the percentage of registered organizations is consistently high across all regions except for Latin America & Caribbean where 14 organizations (50%) are not registered as compared to only 14% of all organizations worldwide.

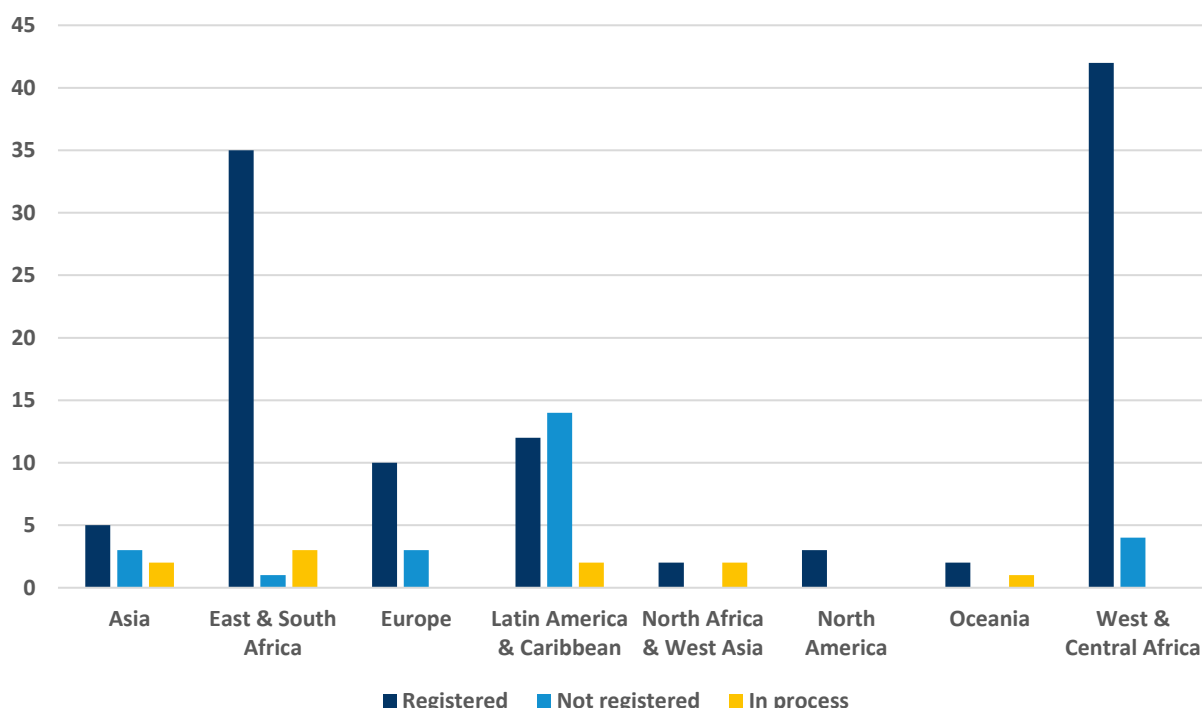Determining if there is a reason for the percentage of unregistered organizations in Latin America & Caribbean to be higher is an issue of interest. About 71% of Latin American and Caribbean organizations began operations from 2011 compared to 56% of all albinism organizations worldwide. 66% of all albinism organizations starting operations from 2011 to the present are registered, 20% are not registered and 13% are in process compared to 43% registered, 50% not registered and 7% in process in Latin America & Caribbean. It seems reasonable to think that the registration process can greatly differ from one country to another with variable constraints to meet including fees charged by the authorities. These different factors most probably contribute to explaining at least partially the observed situation.

More generally, the high percentage of registered organizations is a positive indication that many groups may have the potential to be professionally managed and sustainable. The future alliance will need to consider that, regardless of the registration status, organizations will vary in their level of development and professionalism.

1.5 Budget

Survey respondents were asked the two following questions about budgets.

- ***"Do you have an annual operating budget?"*** Yes, No.
- ***"If so, what is the total amount of your latest annual budget? (in local currency)".***

Questions about organization budgets were included in the survey:

- to get an idea of the size and sustainability of each organization,
- to get an idea of the degree of development/maturity of the organizations, assuming that a well-structured and well-operating organization should have an operating budget, and
- to find out where financial resources are available and where they are needed.

No definition of an annual operating budget was given in the survey, and none of the respondents asked for clarification before submitting their responses. However, as the responses began arriving, the team managing the survey noticed signs illustrating some confusion with respect to the definition of an annual operating budget.

Some organizations stated that they didn't have any operating budget although:

- they have been operating for many years,
- and/or they are known to be regularly active organizations, running multiple activities every year.

In addition, in several responses coming from organizations claiming to have an operating budget, the shared amount of the latest budget seemed illogical, either too low or too high, or ambiguous based on the currency.

For these reasons, the survey team decided to contact respondents directly to clarify the information submitted, with the goal of reaching a higher degree of reliability of the data gathered and of the conclusions drawn based on this data.

A total of 47 responses were identified as either problematic or potentially problematic. For 31 responses, a clarification was received from the respondent. In most of the cases (about ⅔) the initial answer remained unchanged.

It is worth mentioning that, when discussing with some of the survey respondents and attempting to clarify their answers regarding the fact of having an operating budget, but also regarding the amount of their latest budget, several organizations explained that it was impossible for them to share an amount as "it changes every year according to the activities that are being run".

Survey results brought the following facts to light.

- 84 organizations (58%) reported having an annual operating budget.
- 62 organizations (42%) said that they did not have an annual operating budget.

The fact that about 40% of respondents don't have operating budgets shows that a significant number of potential future members of the alliance could probably benefit from peer support to help move them towards sustainability by establishing operating budgets.

It is interesting to note that in the development process of an organization, building an operating budget seems to be a step that comes after getting registered. No organization who said they were not registered has a budget.

An analysis of the responses shows a direct correlation between organizations having an annual budget and the length of operations. All organizations who started operations before 1991 have budgets. Only 38% of organizations whose operations began from 2017 to 2020 have budgets.

Table III-2 below summarizes the data collected from the organizations

	Has operational budget	Doesn't have operational budget
Pre-1990	100%	0%
1991-2000	77%	23%
2001-2010	73%	27%
2011-2016	47%	53%
2017-2020	39%	61%

Table III-2 -Budget by Beginning Year of Operation

Figure III-8 below shows the breakdown of organization with budgets by region.
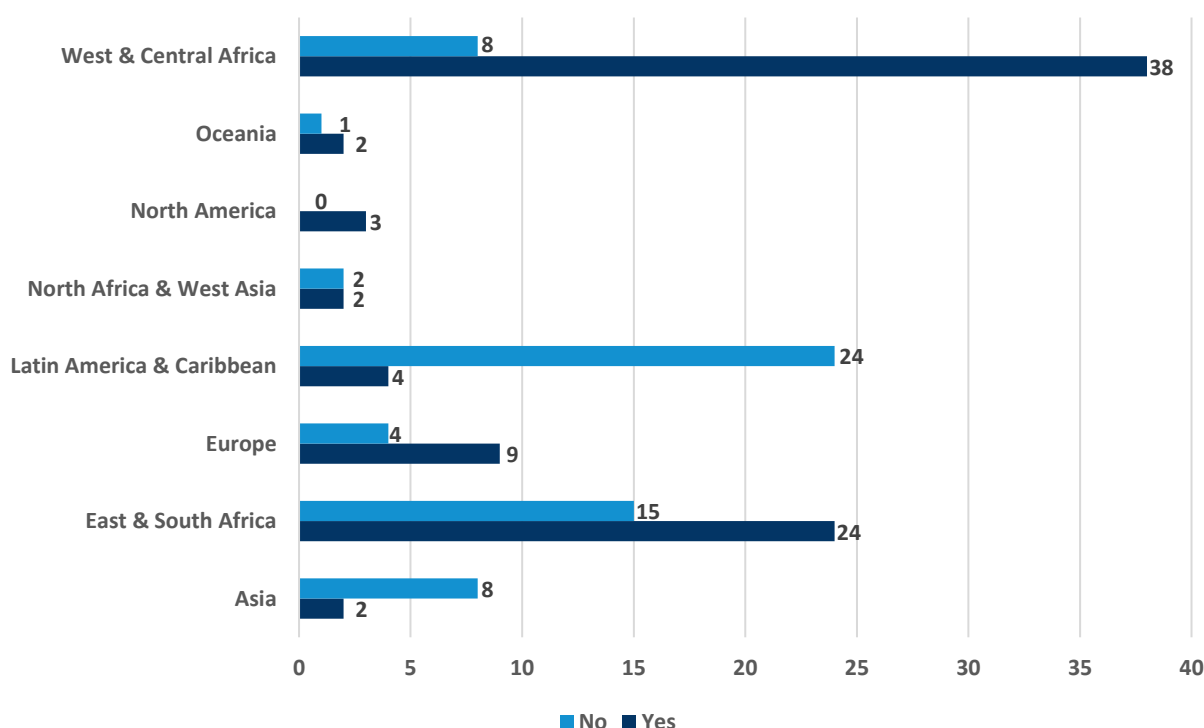
Figure III-8 - Breakdown of Albinism Organizations with Budgets by Region

The data shows that there is no clear correlation between the fact that an organization has an operating budget and the country of operation. The balance between the two categories (with or without an operating budget) is not the same from region to region. The

overall proportion of roughly 60% organizations with budgets and 40% without budgets applies to many regions. However, it is interesting to note that over 80% of organizations from Western & Central Africa have operating budgets (38/46) while the neighboring region of Eastern & Southern Africa displays a rate of about 60%. The situation in Latin America & Caribbean also stands out with an exceptionally low rate of organizations having an annual operating budget (4/28).

When considering the budgets of albinism organizations, it is important to keep in mind that volunteer labor could be included in these budgets but is most probably not, even though it is a key resource for the activities of these organizations. This view is supported by the fact that roughly half of organizations with budgets have paid staff. It is clear that all organizations rely on donated labor, particularly those without budgets.

When clarifying answers to the budget question and during the survey pre-tests it came to light that some of the organizations that don't have operating budgets have project-specific budgets, some of which are funded by specific appeals for donations.

It is difficult to do any meaningful analysis of albinism organization budgets due to the many different currencies used. Even when the data is standardized to a common currency, it is difficult to measure the relative value of the amounts due to the vast differences in the economies of the countries represented. However, it is fair to say that regardless of the difficulties required to do a detailed comparison of the different budgets, some general comparisons can be made, and conclusions drawn.

84 organizations shared their latest annual operating budget or an average of their latest annual budgets. These figures were converted into $USD using the exchange rate of January 17, 2021. This allowed a certain degree of analysis and comparison with the limitations mentioned above.

In summary, it appears that:

- 22 organizations have a budget over $95 000
- 17 organizations have a budget between $40 000 and $95 000
- 18 organizations have a budget between $15 000 and $40 000
- 16 organizations have a budget between $5 000 and $15 000
- 11 organizations have a budget below $5,000

Table III-3 below gives a complete overview of the answers received.

	Over $95 000	between $40 000 and $95 000	between $15 000 and $40 000	between $5 000 and $15 000	less than $5 000	Total of orgs with budget	Total of survey respondents
Asia			1		1	2	10
Europe	1	2	2	3	1	9	13
E & S Africa	13	2	5	1	1	22	37
W & C Africa	6	13	9	9	4	41	48
W Asia & N. Africa					2	2	4
Latin America & Caribbean				1	2	4*	28
North America	2		1			3	3
Oceania				2		2	3
Total	**22**	**17**	**18**	**16**	**11**	**85**	**146**

Table III-3 - Albinism Organization Operating Budgets by Region

* One organization declared having an annual operating budget, but mentioned that it was "variable," and therefore did not share any amount.

A few general observations can be made based on the answers received.

- Most of the organizations with an annual budget of over $40 000 are operating in Western, Central, Eastern or Southern Africa (34 out of 39)
- There seems to be a certain correlation between the number of years of operation and the amount of the annual operating budget. An illustration of the situation is the Latin America & Caribbean region where only 4 out of the 28 organizations declare having an annual budget, and the highest budget is between $5,000 and $15,000.
- In the countries where there are several albinism groups responding as national organizations, it seems common to have one organization with a much higher annual budget than the others.

In a further study, it could be interesting to find out the different sources of funding that albinism organizations manage to access by countries/regions and projects, and, given

the obvious budget differences, to collect and share fundraising best practices among organizations.

As mentioned above, it would probably be unreasonable to compare any further the different budgets and draw any more conclusions as these would probably lack reliability.

1.6 Paid staff

Survey respondents were asked, *"Do you have paid staff?"* Possible answers were "Yes", and "No".

Data regarding paid staff was collected:

- to get a further idea of the resources available to the future members of the alliance,
- to find out what, if any differences there are among albinism organizations with respect to paid staff, and
- to gather additional information that might indicate the maturity and sustainability of each organization.

The responses received show that:

- 46 organizations (32%) have paid staff.
- 100 organizations (68%) do not have paid staff.

Figure III-9 below shows the breakdown of organizations with paid staff by region.
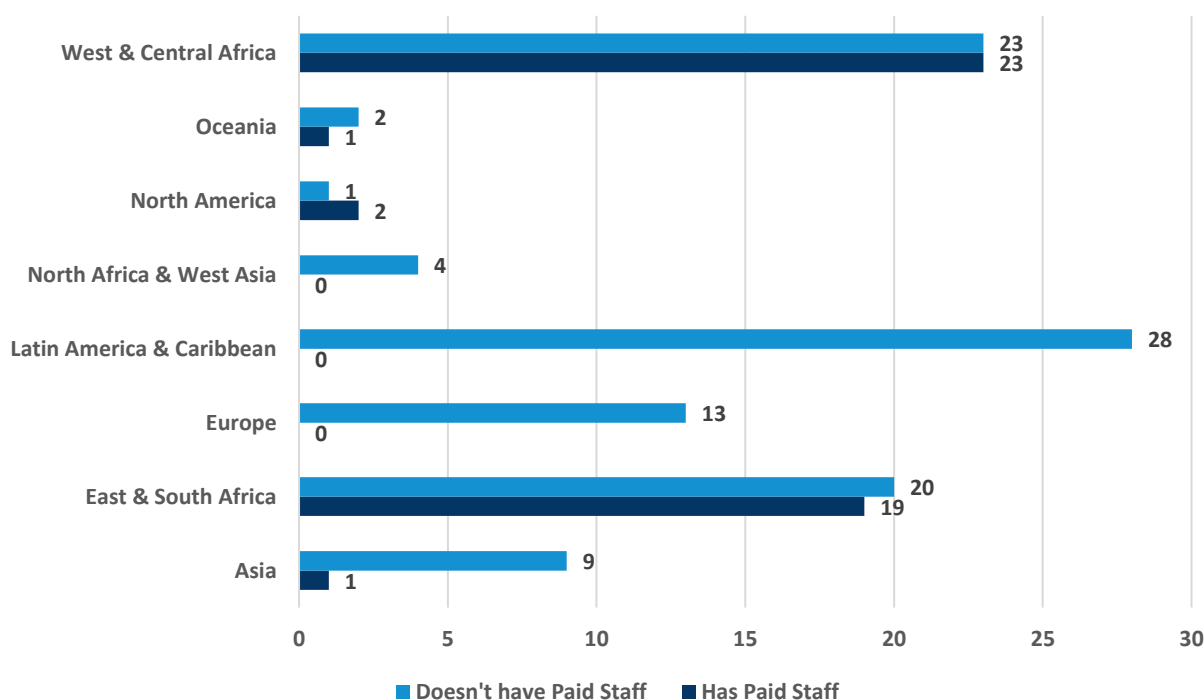
Figure III-9 - Albinism Organizations with Paid Staff by Region

The data shows that

- The 46 organizations with paid staff are part of the 84 organizations with an annual operating budget. They represent 53% of this last category.
- 42 of the 46 organizations with paid staff are operating in Africa (Western, Central, Eastern and Southern) with the exception of North Africa. Of these 42 organizations, 6 have their headquarters either in Europe or in North America.
- The remaining 3 organizations with paid staff are operating in the following countries: USA & Canada, China, and Fiji.
- Apart from these 3 exceptions, outside of Africa, all the albinism organizations are operating relying exclusively on volunteers.

2.   Regional Federations

One of the possible answers to the question on "category of organization" given in the questionnaire was "regional federation." Although no definition was given as to what a regional federation exactly is (apart from "several countries within a continent"), the intention of the Pilot GAA Team was to identify organizations whose membership is made up of national (and local) groups, thus representing the albinism community of a given region of the world (continent, sub-continent) and to a certain extent facilitating coordination among the members.

Five organizations answered the questionnaire saying that they are regional federations. However, when reviewing answers provided by these organizations, it appears that only a limited number might correspond to our definition of a regional federation. The tables below summarize the five answers received. The line "comments" suggests whether the organization does really fall into the category of regional federation.

Response 1	
Countries of operation	Ethiopia, Ghana, Namibia, Sierra Leone, Uganda,
Region(s) of operation	Western & Eastern Africa
Country of headquarters	USA
Registration Status	Registered
Has annual operating budget	yes
Has paid staff	yes
Began operation in	2001-2010
Comments	Name of the organization and characteristics don't seem to confirm that this is a regional federation but more likely an international NGO operating in several countries of the African continent.

Table III-4 – Regional federation - Details from Response 1

Response 2	
Countries of operation	Argentina, Chile, Ecuador, España, Estados Unidos, Panamá, Paraguay, Perủ, Uruguay, Venezuela, Colombia
Region(s) of operation	Latin America
Country of headquarters	Mexico
Registration Status	not registered
Has annual operating budget	no
Has paid staff	no
Began operation in	2017-2020
Comments	Name of the organization and characteristics indicate that this organization is more likely a social media group than a regional federation.

Table III-5 - Regional federation - Details from Response 2

Response 3	
Countries of operation	Europe in general, Belgium, Denmark, Finland, France, Germany, Ireland, Italy, Norway, Poland, Spain, Sweden, Switzerland, The Netherlands, Turkey, United Kingdom
Region(s) of operation	Europe
Country of headquarters	Europe
Registration Status	not registered
Has annual operating budget	no
Has paid staff	no
Began operation in	2011-2016
Comments	Name and characteristics of the organization seem to confirm that it is indeed a regional federation

Table III-6 - Regional federation - Details from Response 3

Response 4	
Countries of operation	Benin, Burkina Faso, Ivory Coast, Gambia, Guinea-Bissau, Mali, Niger, Nigeria, Senegal, Sierra Leone, Togo
Region(s) of operation	Western Africa
Country of headquarters	Senegal
Registration Status	Registered
Has annual operating budget	no
Has paid staff	no
Began operation in	2017-2020
Comments	Name and characteristics of the organization seem to confirm that it is indeed a regional federation

Table III-7 - Regional federation - Details from Response 4

Response 5	
Countries of operation	Argentina, Colombia, Ecuador, Guatemala, México
Region(s) of operation	Latin America
Country of headquarters	Mexico
Registration Status	Registration in process
Has annual operating budget	no
Has paid staff	no
Began operation in	2001-2010
Comments	The name and the characteristics of the organization suggest that it does most probably fall into the category of regional federation

Table III-8 - Regional federation - Details from Response 5

Among the organizations who answered the question on "category of organization" choosing the "other" option, one presented itself as a "sub-regional organization". Its characteristics seem to indicate that it does in fact fall into the category of regional federation. Its answers are summarized in Table III-9 below.

Response 6	
Countries of operation	Burundi, Cameroun, Congo Brazzaville, Gabon, RDCongo, Central African Republic, Rwanda
Region(s) of operation	Central Africa
Country of headquarters	Cameroun
Registration Status	Registration in process
Has annual operating budget	no
Has paid staff	no
Began operation in	2017-2020

Table III-9 - Regional federation - Details from Response 6

It is worth noting that the North America region (Bermuda, Canada, Greenland, Saint Pierre and Miquelon, United States of America) includes an extremely limited number of countries with two countries covering most of the population of the region: USA and Canada. One of the national organizations who answered the questionnaire happens to cover these two countries and might therefore have to be also considered as a type of regional federation. Table III-10 below summarizes its answers.

Response 7	
Countries of operation	USA and Canada
Region(s) of operation	North America
Country of headquarters	USA
Registration Status	Registered
Has annual operating budget	yes
Has paid staff	yes
Began operation in	Pre-1990

Table III-10 - Regional federation - Details from Response 7

In conclusion, among the 146 responses, it appears that 5 most likely do correspond to regional federations. They cover the following regions: Europe, Latin America, North America, Western Africa, and Central Africa. However, the information provided is not enough to evaluate their degree of maturity and the extent of their actions.

In addition, after going through the albinism organization database (cf. Chapter II-§3), it appears that another organization corresponding to a regional federation of the African continent created recently did not take part in the survey for an unknown reason.

A certain degree of coordination at the regional levels seems, therefore, to exist within the global albinism community. However, the information gathered through the survey is too limited to have a comprehensive portrait of the way the community is structured into regional federations. As this subject most probably plays a major role in the decisions on the structure of the future alliance, a specific study dedicated to regional federations is needed.

3.   Leader Characteristics

Survey respondents were asked to identify the organization leader and to provide some leader characteristics. No specific definition of leader was given. Therefore, in situations where there is for example a board chair and an executive director, the organization was free to designate whichever person they preferred for purposes of the survey.

3.1   Gender

Survey respondents were asked to provide the organization leader's title. The options were "Mrs., Mr., Ms., and other". The data collected is summarized in Figure III-10 below.
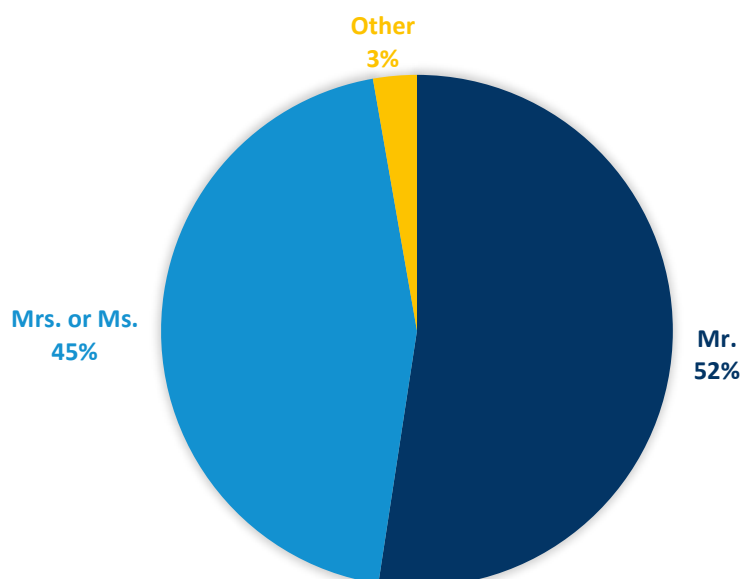
Figure III-10 - Gender/Title of Albinism Organization Leaders

The survey did not include a space to specify what the title was for those choosing "other". However, the information provided throughout the survey by the four respondents who chose that option made clear whether the leader was a male or a female. Using this information and the title as an indication of gender, the data shows that **the leadership of potential organization leaders is roughly even with 54% male, 46% female**.

3.2   Age

Survey respondents were asked to give the organization leader's age by selecting one of five following age ranges:

- under 18 years
- from 18 to 24 years
- from 25 to 39 years
- from 40 to 59 years
- 60 years and older
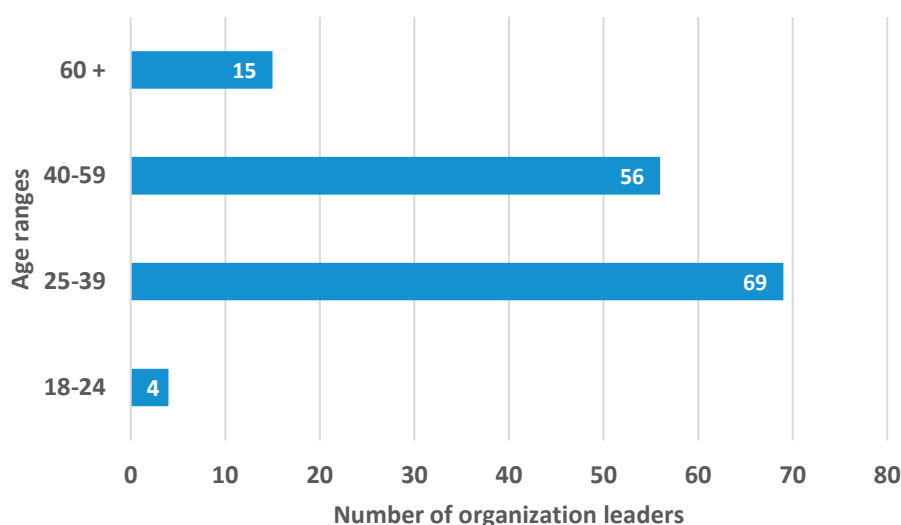
Figure III-11 - Age of Albinism Organization Leaders

Figure III-11 above shows age diversity among all albinism organization leaders worldwide.

Analysis by region indicates that:

- Asian leaders are generally younger when compared to leaders from other regions of the world
- European and Latin American & Caribbean leaders are generally older when compared to all leaders

However, no conclusion coming out of these observations appears obvious at this stage.

3.3   Number of years in position

Survey respondents were asked "***How long has [the organization leader] served as head of the organization?***" by selecting from one of four possible ranges in years.

As presented below in Figure III-12, they were given the possibility to choose among four different options.
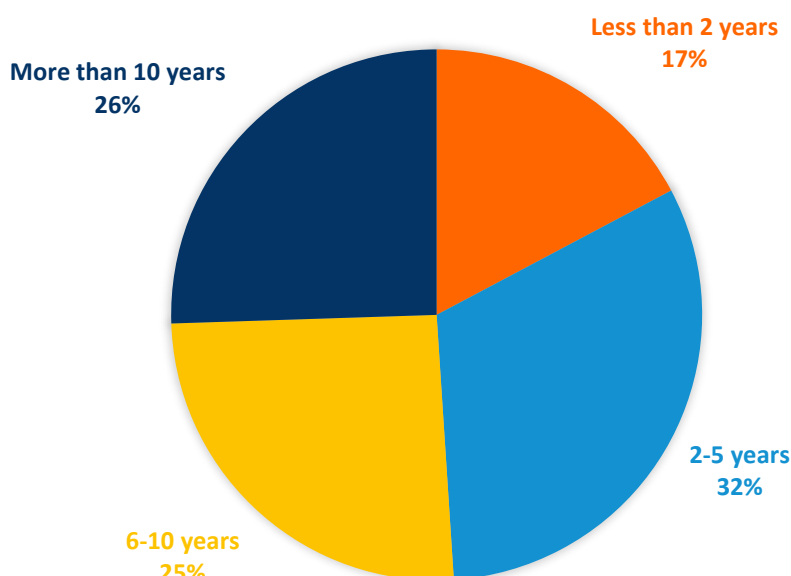
Figure III-12 - Albinism Organization Leaders: Number of Years in Position

The data shows a range of length of service. About half of the leaders have been in their positions for more than 6 years, suggesting significant commitment to service and demonstrates that these leaders have significant experience.

There are only slight differences seen when analyzing length of leader service by region except for Latin America & Caribbean. Leaders in Latin America & Caribbean have generally served shorter tenures when compared to all organizations. This may be due to the fact that Latin American & Caribbean organizations have not been in operation as long in comparison to all albinism organizations.

Further study to examine leader retention, turnover rates and succession planning may provide more information to inform the future alliance.

3.4   Connection with Albinism

Survey respondents were asked, "***What is her or his primary relationship to albinism?***" Respondents were asked to select one from a list of ten possible relationships.

Relationship to Albinism	number of responses
Person with albinism	106
Parent of a person with albinism	19
Grandparent of a person with albinism	0
Spouse of a person with albinism	1
Sibling of a person with albinism	1
Child of a person with albinism	1
Friend of a person with albinism	3

Human rights expert	4
Health care provider	8
Researcher	2

Table III-11 - Leader's Connection to Albinism

The data shows that organization leaders have an extraordinarily strong relationship to albinism. Over 70% (106 of 145) of organization leaders are people with albinism. About 15% (22 of 145) of organization leaders are relatives of people with albinism. The remaining 15% of organization leaders are friends of people with albinism or professionals.

It is interesting to note that about 5% (8 of 145) of albinism organizations are led by health-care providers, with all of these organizations (except one) operating in Africa. It would be wise for the Pilot GAA to investigate the structure, missions and mode of operations of these organizations, as well as what factors led to their creation and how much their experience and best practices could be useful in other countries / parts of the world.

Chapter IV   Language Considerations

The Global Albinism Alliance aims to become an international organization interacting with stakeholders from all regions of the world. Furthermore, being the voice of the albinism community at the global level is expected to be among the future missions of the alliance. Therefore, the Global Albinism Alliance will have to operate in such a way that all voices are heard and acknowledged, and all activities and actions of the alliance are accessible regardless of language and culture.

The expected diversity of languages within the alliance's membership should not reduce the degree of engagement of any of the members. It should be possible for any ideas and opinions to be freely expressed and for any persons and organizations to interact with the alliance.

In addition, it is worth noting that both during the selection process of the Paris exploratory meeting delegates and during the meeting itself (cf. Introduction), several issues related to the language barrier were faced. Therefore, it is important for the future alliance to act to avoid difficulties due to language barriers.

Ideally, the GAA should enable communication in the preferred language of every one of its members. However, with hundreds of different languages being spoken around the world, implementing such communication would not be realistic. It would require significant financial and human resources, would be time consuming and would generate complex logistics. It is therefore a matter of finding the right balance between simplicity (one single operating language) and inclusivity (communication in all languages). With this goal in mind, the worldwide survey sought to determine a realistic number of languages that could effectively be used by the Global Albinism Alliance.

1.   Distribution of responses among the different language versions of the survey

As mentioned in Chapter II, the survey was made accessible in four different languages: English, French, Spanish and Portuguese. Each respondent was free to select their preferred language. Ultimately, all responses received in French, Spanish and Portuguese were translated into English in order to simplify the analysis process.

A total of 145 complete responses were received. The following Table IV-1 shows the distribution of responses among the different versions of the survey.

Language of the questionnaire	Number / Rate of responses		Number / Rate of countries represented	
English	69	48%	43	54%
French	41	28%	22	28%
Portuguese	13	9%	3	4%

Spanish	22	15%	12	15%
Total	**145**	**100%**	**80**	**100%**

Table IV-1 - Distribution of Responses according to the language of the questionnaire

To allow better interpretation of this data, each response was checked as to whether or not the selected language was an official language of the country where the respondent was based. Table IV-2 summarizes our findings.

Language of the questionnaire	Number of responses received in a language that is not among the official languages of the organization's country
English	16
French	2
Portuguese	0
Spanish	0
Total	**18**

Table IV-2 - Number of Responses received in a language different to the official language(s) of the respondent's home country

2.   Preferred languages of communication with the alliance

One question included in the survey specifically addressed the language issue. It was the following: ***"Of the following widely spoken languages, which would you be comfortable using when communicating with the Global Albinism Alliance?".*** Respondents could select up to two of the following answers:

- English,
- French,
- Spanish,
- Portuguese,
- none.

These languages (as well as those in which the survey was made available) were selected after reviewing the commonalities and differences recognized among Regional Contact Points and delegates at the Paris meeting. Prominent languages at that session were English, French, and Spanish. Adding Portuguese was considered appropriate given the relatively high number of Lusophone albinism organizations listed in the database.

It is worth noting that English, French and Spanish are three of the six UN official languages along with Arabic, Chinese, and Russian.

Table IV-3 below summarizes the answers received.

Version of the questionnaire	Number of responses received	English		French		Portuguese		Spanish		none
English	69	69 (66)*		1		0		2		1
French	41	17		41 (24)*		0		0		0
Portuguese	13	5		0		13 (7)*		1		0
Spanish	22	7		0		0		22 (15)*		0
Total	**145**	**98**	**68%**	**42**	**29%**	**13**	**9%**	**25**	**17%**	**1**

Table IV-3 - Languages Respondents Would Be Comfortable Communicating in by Version of Questionnaire

* The numbers in parentheses correspond to responses where only one language was selected (the language of the survey).

3.   Conclusions and observations

The data collected and summarized in the three tables above lead us to the following conclusions:

- The survey seems to confirm that the four most frequently spoken languages among the albinism organizations from around the world are English, French, Spanish and Portuguese. No fifth language was identified as being potentially widely represented.

- If English were the only official language of the alliance, about 1/3 of the potential members (47/145) of the future alliance would be left out. This would exclude in particular at least 7 countries from Central and West Africa and 7 countries from Latin America.

- If the alliance can operate in several languages: apart from English, the following languages should be chosen in order of priority:
  o   French
  o   Spanish
  o   Portuguese

- If the alliance decided to operate in two languages (namely English and French), about 15% of the potential members would be left out. This would especially leave out a significant part of the Latin American region (7 countries out of 11 represented).

- If the alliance decided to operate in three languages (namely English, French, and Spanish), approximately 5% of the organizations would be potentially left out.

However, no country out of those represented in the survey would be completely left out if English, French, and Spanish were used. Indeed, if operating in English, French and

Spanish, the alliance would reach at least one organization in each of the 80 countries represented in the survey (in other words, at least one organization in each of the three Lusophone countries represented does speak English, Spanish or French).

Additional observations:

- Three open-ended questions were included in the questionnaire where respondents could express themselves freely on different topics including human rights challenges and best practices. A review of the answers to these different questions, especially those received in French and English shows that in some cases the level of proficiency of the respondent in that language is limited. In some extreme cases, it was challenging to understand what the respondent exactly meant.

- One group from Vietnam mentioned that most of the information available on albinism is in English, which is problematic as the members of their group generally don't speak English.

- No other comments regarding language issues or misunderstandings when responding to the survey were brought to our attention.

Based on the data collected through the survey and the overall process, we do not identify any additional questions regarding languages to be asked in a future survey.

Chapter V   Future Alliance: Support, Functions and Challenges

This chapter:

- reports on the degree of support for a global albinism alliance expressed by respondents,

- reports on the opinions of respondents relative to the most important functions of a global alliance,

- provides a summary and an analysis of the challenges faced by people with albinism as reported in the survey regarding quality of life and human rights,

- provides observations on and analysis of the links between the most important functions of a global alliance and the challenges faced by persons with albinism in terms of quality of life and human rights, as expressed by the survey respondents.

Appendix 1 is the complete list of survey questions. This chapter covers questions 22 to 26.

1.   Degree of support

Delegates to the January 2020 Paris Exploratory Meeting voted unanimously to work towards forming a global albinism alliance. Survey respondents were asked the following question: ***"How supportive are you of the development of a formal international alliance on albinism?".***

The choices were:

- Strongly supportive,

- Supportive,

- Neither supportive nor not supportive,

- Unsupportive,

- Strongly unsupportive.
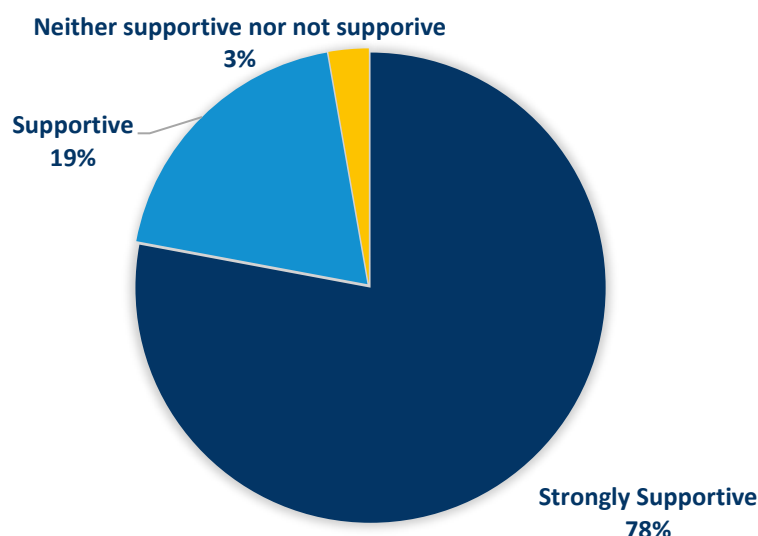
Figure V-1 - Reported Support of Respondents of the Development of a Formal International Alliance on Albinism

As shown above in Figure V-1, an overwhelming majority of respondents expressed their support for a global albinism alliance while none of the respondents were opposed to the alliance. 78% of survey respondents strongly support the alliance and 19% said they support the alliance. Only 4 of 145 respondents (less than 3%) took a neutral position on forming an alliance.

It is worth noting that no description of the potential future missions of the alliance was given while asking this question, and it is reasonable to assume that the concept of a global alliance varies somewhat across regions. However, the extraordinarily strong overall support received from the survey respondents gives the GAA Pilot Team the required legitimacy to further work on defining the missions of this alliance.

The remarkably high rate of support and the high rate of participation among the known albinism organizations provides much support for the future alliance. However, it would be unreasonable to assume that this level of support is true for all albinism organizations. It seems realistic to think that organizations supporting the creation of a global alliance would be more inclined to participate in the survey than non-supportive organizations. Even if a high percentage of the organizations not represented in the survey were opposed to forming the alliance, their numbers are relatively low as a portion of all albinism organizations and would not alter the fact that there is strong support for the future alliance.

2.   Potential Functions of the Alliance

Survey respondents were then asked the following question: ***"In your opinion, what are the most important functions of a Global Albinism Alliance? (Check the three most important.)".***

Eleven possible functions of the future alliance were listed. It is worth noting that survey respondents were not asked to select their top three priorities, but their top three most important functions. Table V-1 shows the totals for each option.

Possible functions	Number of responses	% of survey respondents
Develop a global strategy and action plan on albinism.	83	57%
Promote and spread accurate information on albinism worldwide.	62	43%
Develop and implement programs of public awareness and education on albinism.	53	37%
Facilitate collaboration among albinism groups and other stakeholders working on albinism.	49	34%
Facilitate knowledge and skill development of albinism groups worldwide.	40	28%
Promote research on albinism and human rights.	35	24%
Promote the work of albinism groups around the world.	34	23%
Promote research on albinism and life science (medical research).	31	21%
Support the founding and development of new national albinism groups.	22	15%
Support the founding of new regional albinism groups as well as the implementation of regional plans and initiatives on albinism.	17	12%
Promote research on albinism and social science.	9	6%

Table V-1 - Survey Responses: Three Most Important Functions of a Global Albinism Alliance

All 11 functions received some level of support from the survey respondents, and none were determined to be irrelevant (the function which received the least support was among the top three most important functions of about 6% of the survey respondents). These observations suggest that the future alliance should consider covering at least all of these 11 functions.

"Developing a global strategy and action plan on albinism" was chosen by 57% of the survey respondents. However, no definition of a strategy and global action plan was given. The lack of a detailed definition of this potential function of the future alliance could lead to many different interpretations. It is reasonable to assume that having a strategy for the future alliance is a given. It is not clear whether survey respondents choosing this function did so for the action plan and/or for the global strategy. For these reasons, leaders should not give too much weight to the support expressed by respondents to this function when deciding on the missions and structure of the future alliance. Further definition concerning the strategy for the future alliance and a global action plan is needed.

"Promoting and spreading accurate information on albinism worldwide" was chosen by about 43% of respondents. 37% of respondents selected "developing and implementing programs of public awareness and education on albinism" as future function of the alliance.

Upon review, it became clear that these functions cover remarkably similar concepts. Spreading accurate information contributes to spreading awareness and education.

In total, 62% of all survey respondents (90 organizations) chose one or both functions which makes them the most supported, if considered as the same function.

The remaining 8 functions each received much lower levels of support, between 6% and 34%.

Analysis of the responses reveals possible flaws in the structure of the question and the value of the answers.

Many survey respondents shared the difficulty they faced having their choices limited to three functions. Several organizations responding using the PDF version of the survey checked more if not all the boxes, which illustrates this situation. They were asked to update their answer and ultimately selected only three.

Organizations were not given an opportunity to specify additional functions, particularly those that would be of higher importance, nor make comments. Other functions of the future alliance were mentioned in answer to question 26 of the survey (*"Please add any additional comments you might have about your organization or about the questions discussed in this survey."*).

It is possible that, had the question asked respondents to rank all items from 1 to 11 or to rate the importance of each function on a numeric scale instead of choosing only the top 3, then the responses may have produced more valuable insights.

3.   Challenges faced by people with albinism around the world

The survey included the following open-ended question (Q24) regarding the challenges people with albinism face: *"In your country, what challenges negatively affect the quality of life for persons with albinism, or prevent them from exercising their human rights?"*

The answers provided to this question reveal difficulties across a wide range of sectors and human rights impacts.

3.1   Methodology of analysis

A content analysis of the answers received from the survey respondents was performed. The items (separable meaningful units mentioned) were identified in every answer, were coded and grouped as thematic clusters of challenges. These include sectoral challenges covering different aspects of life, such as health, education, and employment, as well as overarching or multisectoral challenges, such as the lack of information and awareness on albinism, discrimination in different areas, inclusion and opportunities or sociopolitical variables. Gender-specific challenges, intersectionality of challenges and cause-effect patterns were also identified in some cases and clustered accordingly. A summary of this

analysis is shown in Table V-2 below. References to human rights conventions relating to the categories are noted where applicable.

Category / Sector	References to human rights conventions[1]	Cluster	Number of Times Mentioned
Severe human rights violations, myths, and superstitions	CRPD, Art. 10, 14, 15, 16, 17; ICCPR, Art. 16, 17;	Ritual killings	3
	CAT, Art. 4	Physical violence, persecution, and crimes	8
	CRPD, Art. 6; CEDAW	Gender based violence or persecution	7
	CRPD, Art. 8, 15; ICCPR, Art. 7	Myths	10
Education	CRPD, Art. 24; ICESCR, Art. 13	General Educational challenges	36
		Illiteracy among PWA	2
		School drop-out	3
		Lack of training	2
Socioeconomic challenges	CRPD, Art. 27, 28; ICESCR, Art. 6, 7, 9	Employment	20
		Other work-related disadvantages	2
		Poverty	16
		Lack of funding	5
Health	CRPD, Art. 25; ICESCR, Art. 12	Sunlight and risk of skin cancer	20
		Adequate health treatments	35
		HPS (Hermansky-Pudlak Syndrome)	2
		Diagnosis	5
		Money/affordability of health care and support	5
		Regional and other context factors impacting accessibility of treatment	3
Information and Awareness	CRPD, Art. 8, 21, 31	Understanding/Data/Information/Awareness	40
Social interaction and inclusion	CRPD, Art. 5	Discrimination (in general)	76
		Specific contexts of discrimination	11
	CRPD, Art. 19, 23	Isolation/Banishment	9
	CRPD, Art. 17; ICESCR, Art. 12	Psychosocial effects	7
	CRPD, Art. 23	Relationships	5

[1] These are exemplary references that do not necessarily present an exhaustive list of all articles of Human Rights referred to.

Low vision, disability, and accommodation	CRPD, Art. 4, 9, 20; 26	Disability	4
		Low vision	7
		Adaptation needs: Transportation	4
		Adaptation needs: School and work settings	8
Sociopolitical, cultural, and environmental conditions	CRPD, Art. 4, 9, 13, 19; 29, 30, 33; ICESCR, Art. 9, 15	Regional/cultural differences	2
		Political and legal conditions	41
		Specific social policy and services	4
		Invisibility	2
		Organizations/support groups	7
		Opportunities and inclusion	14
Others	ICCPR, CRPD, Art. 4, 5, 12	General human rights violations and injustice	4
	CEDAW, Art. 2, 3, 5, 12, 14, 16; CRPD, Art. 6; ICESCR, Art. 3	Gender-specific challenges	20
	CRPD, Art. 6	Intersectional links / multidimensional impacts	3
	-	None/not human rights related	6
	-	Other causal chains /patterns of cause and effect	7

Table V-2 - Challenges Negatively Affecting Quality of Life Reported by Respondents in Q26 - Overview of categories, clusters and numbers of items

Key:
ICERD   International Convention on the Elimination of All Forms of Racial Discrimination
ICCPR   International Covenant on Civil and Political Rights
ICESCR   International Covenant on Economic, Social and Cultural Rights
CEDAW   Convention on the Elimination of All Forms of Discrimination against Women
CAT   Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CRC   Convention on the Rights of the Child
CRPD   Convention on the Rights of Persons with Disabilities

3.2   Challenges Categorization and Analysis

The following analysis provides an overview of the main categories of challenges negatively affecting the quality of life of persons with albinism or preventing them from exercising their human rights.

3.2.1   Severe human rights violations and attacks to physical integrity

Regarding severe human rights violations and risks to physical integrity, such as persecution, gender-based violence (GBV) and other physical violence, persecution, and murder, 3 items explicitly mention ritual killings. 15 items refer to PWA as potential victims of other forms of physical violence, persecution, or crimes. Of these 15, 7 items make explicit reference to the higher risk of women and girls to experience violence (GBV) (5 items), such as rape, domestic violence, and a higher incidence of persecution and displacement (2 items). 8 items refer to forms of crimes, violence, persecution and lack of security and protection other than gender specific forms of violence.

10 items mention challenges of myths and superstitions without making explicit reference to the consequences for the physical integrity of PWA.

3.2.2   Health

The health category comprises a total of 67 items: 35 relating to the general availability and access to adequate treatments, 20 to problems of sun exposure and/or skin cancer. 5 mention problems of diagnosis and 5 items refer to the problem of cost/affordability of treatments. 2 items make specific reference to challenges related to HPS (Hermansky-Pudlak Syndrome). 3 items mention geographical /regional differences in the accessibility of medical care.

3.2.3   Education

Challenges regarding the sector of education are mentioned repeatedly throughout the many responses collected. The Education category comprises 43 items, of which 36 refer to the cluster general educational challenges, 2 refer to illiteracy, 3 refer to school dropouts.

Additionally, 2 items mention [lack of] "training", without further specifying the type of training.

3.2.4   Socioeconomic Challenges: Employment and Poverty

Similarly, challenges regarding employment and poverty are observed in a high number of answers. The Employment cluster includes 22 items, of which 20 refer to general challenges in employment and 2 items to other specific work-related challenges. Apart from this, poverty is mentioned in 16 items, and 5 items relate to a lack of funding.

3.2.5   Social interaction and inclusion

Stigma and discrimination, as well as lack of understanding, can be observed as an overarching challenge, mentioned in a variety of contexts.

The discrimination cluster comprises 95 items: 76 regard general discrimination and stigmatization in a broad sense, 10 refer to specific contexts of school and work and 9 items specifically to isolation or banishment. 5 items refer to difficulties in forming specific social relationships, such as finding partners, friends or marrying.

3.2.6   Lack of information and awareness

This category describes the challenge of the general lack of knowledge, understanding, data, information, and awareness observed in many relevant social sectors and groups (i.e.

among the general public, state/institutions, medical staff, educational staff, parents, and PWA themselves). It includes a total of 40 items.

3.2.7   Low vision, disability, and accommodation

The notion of "disability" (8 items) and of "visual impairment" or similar (7 items) is mentioned as a main challenge for people with albinism in several cases. Others frame the need for adaptation and accommodation in transport (4 items) and education and employment settings (8 items).

3.2.8   Sociopolitical, cultural, and environmental conditions

The cluster of political and legal conditions includes 41 items referring to general challenges regarding lack of adequate public policies, laws addressing needs of PWA or the general political framework, 3 additional items address the lack of specific social policies and services. 2 items name the concept of "invisibility" of PWA in the social and political sphere.

7 items refer to challenges regarding albinism organizations/support groups, i.e., lack of funding, cooperation between them or a general lack of available support groups for PWA or a lack of awareness about them on behalf of the PWA.

14 items mention the lack of access to (equal) opportunities and inclusion as a general challenge.

4 items mention general human rights abuses, injustice, or vulnerability as challenges for people with albinism.

Finally, according to 6 items, there are no (severe) human rights violations in their country, or the question is not considered applicable.

3.2.9   Gender-specific challenges

A total of 20 items include references to the aforementioned forms of gender-based violence, and gender-specific challenges. Gender specific challenges include difficulties and discrimination in marriage and relationships, the isolation of mothers of PWA, an increased risk of poverty, vulnerability and insecurity, and generally higher difficulties in livelihood, equity, and empowerment in women with albinism. Human rights violations and challenges regarding sexual and reproductive health are also listed.

3.3   Challenges - Other observations

3.3.1   Limits to Analysis and Interpretation of Challenges

Very few respondents cite quantitative sources with regards to the challenges faced by people with albinism (i.e. low availability of data / survey is mentioned, as well as the fact that responses are based solely on experience). This limitation of quantitative sources and data availability, with answers generally based on estimations and experience, can be considered an overarching difficulty when interpreting the results and drawing conclusions about the exact challenges PWA are facing in their diverse respective contexts. However, the vast number of items identified allow for the conclusion that the answers received to question 24 confirm the findings of the UN Independent expert on the enjoyment of human rights by persons with albinism shared through the many reports released throughout the two terms of her mandate (2015-2018 and 2018-2021). PWA worldwide face many challenges preventing them from fully enjoying their human rights. Regardless of the many positive

impacts that this mandate has had, our survey highlights the fact that there is still a lot to do today.

Answers to questions 24 and 25 were shared with the UN Independent Expert at her request.

No definition was provided to the survey respondents of what a challenge is. As a matter of fact, among the many responses received, there appear to be differences in the perception of what actual challenges and impacts on human rights enjoyment are, as opposed to minor or non-human rights problems. In a few cases gathered in the cluster "None/not human rights related" (6 items), the answer suggests that the question of challenges for human rights enjoyment are not perceived as applicable for their context. It is also worth noting the comment made by one of the European organizations in the free comment field included at the end of the questionnaire: "Human rights must not be neglected but is only highly relevant in some parts of the world. If you focus too little on other topics you lose focus on the challenges that exist in many of the European countries."

This clearly suggests that a further study should be done by the leaders of the Pilot Alliance to clarify

- the degree of knowledge of the concept of human rights among albinism organization leaders in the different regions of the world,
- the potential existence of other categories of challenges not human rights related.

3.3.2 Regional Challenges Variations

Most categories of challenges faced by persons with albinism occur to some extent in all regions of the world. However, extreme challenges seem to be limited to only a few regions, Sub-Saharan Africa above all. Direct physical violence including GBV, persecution and killings of PWA, appear in a considerable, although limited number of answers. A substantial number of items refer to gender-specific challenges, stating an increased vulnerability of women with albinism to human rights violations.

In a very few cases, "no challenges" regarding the enjoyment of human rights are perceived in the answers. It seems reasonable to think that this might be the illustration of a wider phenomenon, which is the limited understanding among albinism organizations leaders of the concept of human rights (cf. comment made above in §3.3.1 "Limits to Analysis and Interpretation of Challenges").

3.3.3 Causal links

In several cases, patterns of attributions of linked cause-effect relationships can be observed regarding challenges:

- Lack of understanding → discrimination, persecution, killings, GBV
- Lack of information /educational challenges → unemployment or inadequate working conditions
- Lack of understanding → lack of adaptation in school and workplace → lack of education → lack of employment
- Discrimination → mental health impairment / lack of self esteem

The general lack of information and understanding of albinism appears as an underlying factor for several chains of consequent negative impacts on the quality of life and human rights enjoyment in several descriptions.

4.   Best Practices

Question 25 was: *"What best practices exist in your country to enable persons with albinism to thrive and fulfill their human rights?"*

The answers to this question varied greatly in length and detail. An analysis and summary of the answers is not included here because of a lack of resources to conduct a proper content analysis. This valuable data should be used by the future alliance to facilitate sharing best practices among albinism organizations.

5.   Additional Comments

Question 26 was: *"Please add any additional comments you might have about your organization or about the questions discussed in this survey."*

An analysis and summary of the answers to this question is not included here because of a lack of resources to conduct a proper content analysis. Although when the information provided was related in any manner to any other question of the survey, the information was considered in the analysis of that question.

More generally, the data provided should be considered when planning the structure, mission, and functions of the future alliance.

Chapter VI   Observations, Analysis and Recommendation for the Future Alliance

The data compiled via the worldwide survey is the most comprehensive description of albinism organizations ever done. Careful consideration and analysis of the information gathered in the worldwide consultation is essential to the efforts to build a global albinism alliance.

This chapter makes observations relative to the survey data, provides analysis intended to inform the leaders of the future alliance as they move to the next phase of the creation of the organization and makes recommendations for next steps.

1.   General Observations

1. The Pilot team gained valuable experience while conducting the survey. This experience should be very useful to the alliance as conducting global survey-based studies on albinism is anticipated to be among the activities of the organization.

2. The albinism organization database managed by the Pilot Alliance was brought up to date by making connections with both known and new organizations.

3. The worldwide survey received an extraordinarily high rate of response among known albinism organizations that could be reached (68%). Out of 145 complete responses, 16 came from new organizations (i.e. not listed in the Pilot GAA database). This illustrates the fact that there was obviously no significant lack of communication and that whoever wanted to and could respond to the survey did respond.

4. The high response rate ensures that the data collected is sufficient to draw reliable and meaningful conclusions about the future alliance. However, collection of additional information might be necessary to determine more precisely the characteristics of this future alliance such as the membership, the structure, and the mission of the organization.

5. Following the significant growth of albinism organizations in recent years (83 organizations starting operations since 2011) all regions of the world have at least one albinism organization operating. Several regions such as West, Central, East and South Africa, North and South America and Western Europe have albinism organizations in most of their countries, but others are still sparsely covered. The leaders of the future alliance should consider doing outreach to countries without organizations to determine if help is needed to get them started.

6. In addition, the data reported in Chapter III clearly shows significant regional differences including variation, not only in density of coverage by albinism organizations, but also length of operation, registration status, budget and staffing of these organizations.

7. Several additional questions came to light while compiling and analyzing the survey results. These questions, that could bring useful input to the leaders of the alliance, are listed in Appendix 3.

8. While reviewing the data and compiling the results, the Pilot Team identified some limitations to the survey. These will be noted in the analysis and recommendations below.

2.   Factors in Support of a Global Albinism Alliance

1. There is strong support for the creation of a Global Albinism Alliance. The unanimous vote of the delegates to the Paris meeting to embark on a pilot to form a Global Alliance (cf. introduction) is strongly supported by the worldwide albinism community, with 97% of survey respondents saying that they either support or strongly support the development of such an alliance. Only 3% of respondents took no position for or against forming an alliance. No respondent opposed the alliance. It is, however, important to note, with respect to the question concerning the degree of support for the alliance, that no description of the potential future role of the alliance was given while asking this question.

2. The high percentage of registered organizations and the significant number of organizations having an operating budget are positive indications that many groups should be sustainable. There is therefore a great potential for success of the future alliance given a large cohort of stable functioning albinism organizations.

3. The rapid increase in the number of albinism organizations starting operations recently and the total number of existing organizations around the world shows conclusively that the activity of the global albinism community is growing and not diminishing. The data collected in the survey supports the proposition that this is an appropriate time to form a global alliance. Note that this is the third attempt to form a global alliance of albinism organizations (see Chapter I). As stated in #5 above, over 83 new albinism organizations have started operations since around the time that the World Albinism Alliance was formed. This is a growth of 131%.

4. Data reported in Chapter III shows a direct correlation between organizations having an annual budget and the length of operations.

   Of 63 organizations which started operations before 2010:

   - 56 are registered
   - 46 are registered and have a budget
   - 24 are registered, have a budget, and have paid staff

   Of 83 organizations which started operations from 2011 to 2020:

   - 55 are registered
   - 31 are registered and have a budget
   - 18 are registered, have a budget, and have paid staff

These statistics make clear that the number and level of maturity of albinism organizations has grown significantly in the last ten years. It is reasonable to assume that albinism organizations will continue to grow and develop. Collaboration and coordination between albinism organizations by the future alliance will increase the capacity of members to serve people with albinism.

3. Recommendations – Membership of the Future Alliance

1. The survey data indicates that it is likely that about 75% of future member organizations will be national groups and the other 25% will consist of regional groups and other types. Because different parts of the world face different challenges, and because the development of albinism organizations hasn't followed the same curve in the different regions of the world, the Pilot Team recommends conducting a specific study dedicated to regional federations to determine their proper role in the future alliance.

2. It is imperative that the leaders of the future alliance take into consideration that their members will differ by:

   - Type
   - Mission
   - Registration status
   - Budget
   - Staffing

   The Pilot Team recommends that these organizational differences be considered particularly when defining membership in the future alliance.

3. When designing the survey, the Pilot Team spent a considerable amount of time trying to come up with a question or questions that would provide an indication of the size of albinism organizations. It was unclear how to accurately evaluate this characteristic. The measures considered were the number of persons served by an organization, number of contacts in a database and or number of members. Because no question leading to a set of answers that would be easy to compare and analyze was identified, the Pilot Team purposely did not include any question(s) about organization size. The Pilot Team recommends that alliance leaders collect additional information to measure the size of potential future member organizations. Such data could be especially useful when making decisions on membership for the alliance.

4. The future alliance will need to consider that organizations will vary in their level of development and professionalism. It is imperative that the leaders of the alliance keep in mind the diversity among the potential members with respect to their:

   - Experience
   - Stage of development
   - Organizational needs
   - Human and financial resources
   - Capacity to dedicate time to participate in the activities of the future alliance

4. Recommendations – Functions and Mission of the Future Alliance

1. The fact that about 40% of respondents do not have operating budgets shows that a significant number of potential future members of the alliance would likely benefit from peer support to help move them towards sustainability by establishing operating budgets among other things. It is interesting to note that over 80% of organizations

from Western & Central Africa have operating budgets (38/46). This suggests that some more developed organizations have knowledge to share with other less advanced organizations.

The future alliance should facilitate programs that provide albinism organizations with tools to become more sustainable.

2. The answers to question 25 concerning best practices indicates that organizations possess valuable knowledge and experience regarding ways to serve people with albinism.

    The future alliance should conduct further studies about programming and facilitate the sharing of best practices among albinism organizations worldwide. The Pilot Team recommends that the future alliance facilitate sharing of information between organizations with greater experience and resources with those with less.

3. With respect to the data collected concerning the challenges faced by people with albinism, it is important to note that recurring cross-cutting themes (see Chapter V-§3), such as, the lack of information, the problem of discrimination, as well as the described cause-and effect chains, relate to the answers regarding the most important functions of the global alliance.

    When taken together, "promoting and spreading accurate information on albinism worldwide" and "developing and implementing programs of public awareness and education on albinism" were the most selected functions for the future alliance. This closely reflects the need for a comprehensive multidimensional rather than sectoral approach when determining the functions of the future alliance.

    Starting with the promotion of awareness and information on albinism is a key underlying factor for consequent challenges. Raising awareness about albinism, combating myths and misconceptions, and fighting stigma are necessary first steps to address the wide range of challenges faced by people with albinism. The future alliance should become the world's foremost authoritative source for information related to albinism.

4. When taken together, the answers to questions concerning the most important function of the future alliance and the challenges negatively impacting the quality of life and the things preventing people with albinism from enjoying human rights can provide important insights that can be used to guide the leaders of the future alliance. However, an objective analysis reveals some limitations to the value of the information included in the answers to these questions. The amount of data provided through the answers to questions as well as the degree of detail and the clarity of the information vary greatly. Some answers include a lot of information, while others are noticeably short.

    A key role that could be played by a global alliance would be to collect data and promote research programs aiming at reaching a more detailed, accurate and exhaustive understanding of the variety of situations faced by persons with albinism around the world.

5. It is important to note that the answers received to the questions concerning challenges to persons with albinism and organizational best practices show that a significant amount of expertise and best practices has been developed among albinism organization leaders in many countries. The many detailed answers to these

questions received from African organizations tend to confirm that there is a good understanding of the concept of human rights among them. In contrast, it is not clear whether albinism leaders in other regions of the world have similar expertise. Several answers tend to suggest that a certain range of albinism organization leaders would benefit from human rights capacity-building training. Organizing and providing such training could certainly fall into the future activities of the alliance.

Further, several specific human rights and social science studies appear clearly necessary to build a more comprehensive portrayal of the situation and assess more precisely the degree of importance of each challenge faced by PWA in the different regions and countries of the world. By accessing more comprehensive and reliable data, the future alliance, as well as each albinism organization would certainly be more efficient when advocating for the communities they represent.

6. The varying degrees and severity of challenges faced by persons with albinism around the world will make it difficult for the future alliance to prioritize goals. The challenge for the future alliance will be to carefully select the functions it will perform, to set priorities for the selected functions and to find the resources to carry out what is likely to be an extensive range of functions.

7. The future alliance will need to figure out what its mission will be. This decision will need to consider how the alliance will support types of groups including local, national, and regional organizations as well organizations that do not fit into these categories.

It will be necessary for leaders to do more consultation with stakeholders and/or to use the data compiled from this survey to determine a viable mission. If the latter is chosen, great care will need to be taken to build support and possibly refine the proposal to gain sufficient consensus to move forward.

5. Next Steps

The rich data compiled via the worldwide survey combined with the analysis found in this chapter provides much information to inform and guide leaders as they endeavor to build the future alliance. This never-before compiled information and analysis along with some additional data collection and considerations noted above should be used when planning the future alliance membership, structure, and mission during the next phase of the pilot.

BEFORE YOU START

Please note that this survey is also available in <u>French</u>, <u>Spanish</u> and <u>Portuguese</u>. **This survey is**
one of the goals of the pilot phase of the Global Albinism Alliance. It was created and is
managed by the Pilot Alliance Secretariat under the oversight of its Technical Team.
It has been endorsed by the UN Independent Expert on Albinism, Ikponwosa Ero.
This survey is open to all albinism organizations worldwide, registered or not, community-
based, local, national or international. The term "organization" used in this questionnaire is defined
broadly and refers to all groups whose sole or primary purpose is to promote the well-being of
persons with albinism.
This questionnaire is not made for individuals and should be filled out ONLY by
representatives of albinism organizations.
The two main objectives of this survey are to hear about:
- your organization and its leadership,
- the level of interest and support for the creation of a global albinism alliance within the global
albinism community.
While many of us are feeling positive about the Global Albinism Alliance and its aims, **WITHOUT**
YOUR VOICE in this questionnaire we cannot fully be called "global", so your early,
honest and full response is requested.
Feel free to contact us at <u>albinismalliance.pilot@gmail.com</u> or your Regional Contact Point if you have
any questions.
All your information will be used only for the needs of the Pilot Global Albinism Alliance and only by
members of the management team.

* 1. What is your email address?

1

About your organization

The information gathered in this section will **help us enrich and update our database of ⬜⬜lbinism support groups**. Please make sure to share with us the most up-to-date and detailed data.

* 2. Please indicate the name of your organization.

[   ]

3. If you use an acronym, please list it here.

[   ]

* 4. Email address of the organization

[   ]

* 5. Please indicate the country where your organization is based or <u>headquartered.</u>

[▲▼]

[   ]

* 6. Please indicate the country or countries in which your organization operates. (Check as many as apply.)

☐ Algeria

☐ Angola

☐ Argentina

☐ Australia

☐ Belgium

☐ Benin

☐ Botswana

☐ Brazil

☐ Burkina Faso

☐ Burundi

☐ Cameroon

2

- [ ] Canada
- [ ] Central African Republic
- [ ] Chad
- [ ] Chile
- [ ] China
- [ ] Colombia
- [ ] Congo
- [ ] Czech Republic
- [ ] Denmark
- [ ] DR Congo
- [ ] Ecuador
- [ ] Eswatini (Swaziland)
- [ ] Ethiopia
- [ ] Fiji
- [ ] Finland
- [ ] France
- [ ] Gabon
- [ ] Gambia
- [ ] Germany
- [ ] Ghana
- [ ] Guatemala
- [ ] Guinea
- [ ] Guinea- Bissau
- [ ] Haiti
- [ ] India
- [ ] Iran
- [ ] Ireland
- [ ] Israel
- [ ] Italy
- [ ] Ivory Coast
- [ ] Japan
- [ ] Jordan

3

- [ ] Kenya
- [ ] Liberia
- [ ] Malawi
- [ ] Malaysia
- [ ] Mali
- [ ] Mauritania
- [ ] Mexico
- [ ] Monaco
- [ ] Morocco
- [ ] Mozambique
- [ ] Namibia
- [ ] Nepal
- [ ] New Zealand
- [ ] Niger
- [ ] Nigeria
- [ ] Norway
- [ ] Pakistan
- [ ] Panama
- [ ] Paraguay
- [ ] Perù
- [ ] Philippines
- [ ] Poland
- [ ] Romania
- [ ] Rwanda
- [ ] Samoa
- [ ] Senegal
- [ ] Sierra Leone
- [ ] Somalia
- [ ] South Africa
- [ ] Spain
- [ ] Sweden
- [ ] Switzerland

4

☐ Taiwan

☐ Tanzania

☐ The Netherlands

☐ Togo

☐ Trinidad and Tobago

☐ Turkey

☐ Uganda

☐ United Kingdom

☐ Unites States

☐ Uruguay

☐ Venezuela

☐ Vietnam

☐ Zambia

☐ Zimbabwe

☐ Other (please specify)

[   ]

* 7. Is your organization registered? Registered means that a governmental or civic organization has given a formal written approval that makes your group a legal entity with full legal capacity.

◯ Yes

◯ No

◯ Registration in process

* 8. In what year did your organization begin operating ? (Check one.)

◯ Pre-1990

◯ 1991-2000

◯ 2001-2010

◯ 2011-2016

◯ 2017-2020

* 9. Do you have an annual operating budget?

◯ Yes

◯ No

5

10. If so, what is the total amount of your latest annual budget? (in local currency)

[   ]

11. Do you have paid staff?

○ Yes

○ No

* 12. Of the following, which <u>best describes</u> your organization? (Please check only one.)

○ Local organization

○ National organization

○ Regional federation (several countries within a continent)

○ Other (please specify)

[   ]

* 13. Of the following widely spoken languages, which would you be comfortable using when communicating with the Global Albinism Alliance? (Select up to two.)

☐ English

☐ French

☐ Spanish

☐ Portuguese

☐ None

6

Survey on Global Albinism Alliance

Please provide us with information about the head of your organization.

* 14. Title

- ◯ Mrs.
- ◯ Mr.
- ◯ Ms.
- ◯ Other

* 15. First Name

[   ]

* 16. Surname

[   ]

* 17. What is the best email address to reach her/him?

[   ]

* 18. Phone Number (Please use international format with country code.)

[   ]

19. What is her/his age?

- ◯ Under 18 years
- ◯ From 18 to 24 years
- ◯ From 25 to 39 years
- ◯ From 40 to 59 years
- ◯ 60 years or older

* 20. How long has she/he served as head of the organization?

◯ Less than 2 years

◯ 2 years to 5 years

◯ 6 years to 10 years

◯ More than 10 years

* 21. What is her or his primary relationship to albinism? (Choose one answer)

◯ Person with albinism

◯ Parent of a person with albinism

◯ Grandparent of a person with albinism

◯ Sibling of a person with albinism

◯ Child of a person with albinism

◯ Spouse of a person with albinism

◯ Friend of a person with albinism

◯ Health care provider

◯ Human rights expert

◯ Researcher

8

Survey on Global Albinism Alliance

* 22. How supportive are you of the development of a formal international alliance on albinism? (Choose one answer)

○ Strongly supportive

○ Support

○ Neither supportive or not supportive

○ Unsupportive

○ Strongly unsupportive

* 23. In your opinion, what are the most important functions of a Global Albinism Alliance? (Check the three most important.)

☐ Promote and spread accurate information on albinism worldwide.

☐ Develop a global strategy and action plan on albinism.

☐ Develop and implement programs of public awareness and education on albinism.

☐ Support the founding and development of new national albinism groups.

☐ Promote the work of albinism groups around the world.

☐ Facilitate knowledge and skill development of albinism groups worldwide.

☐ Support the founding of new regional albinism groups as well as the implementation of regional plans and initiatives on albinism.

☐ Facilitate collaboration among albinism groups and other stakeholders working on albinism.

☐ Promote research on albinism and life science (medical research).

☐ Promote research on albinism and social science.

☐ Promote research on albinism and human rights.

* 24. In your country, what challenges negatively affect the quality of life for persons with albinism, or prevent them from exercising their human rights?

```

```

9

* 25. What best practices exist in your country to enable persons with albinism to thrive and fulfill their human rights?

26. Please add any additional comments you might have about your organization or about the questions discussed in this survey.
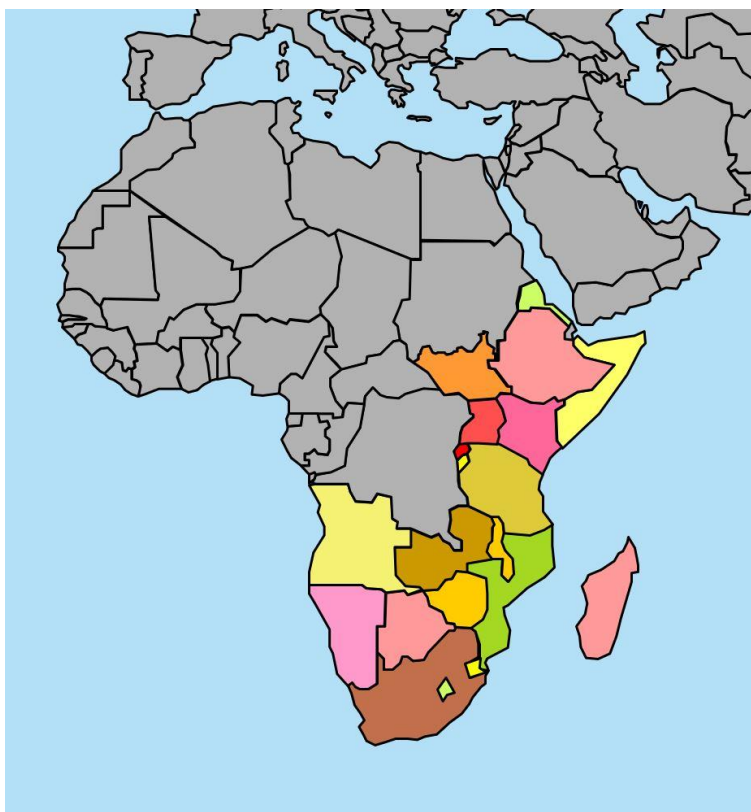
10

Appendix 2: Maps of the regions as considered in our response analysis
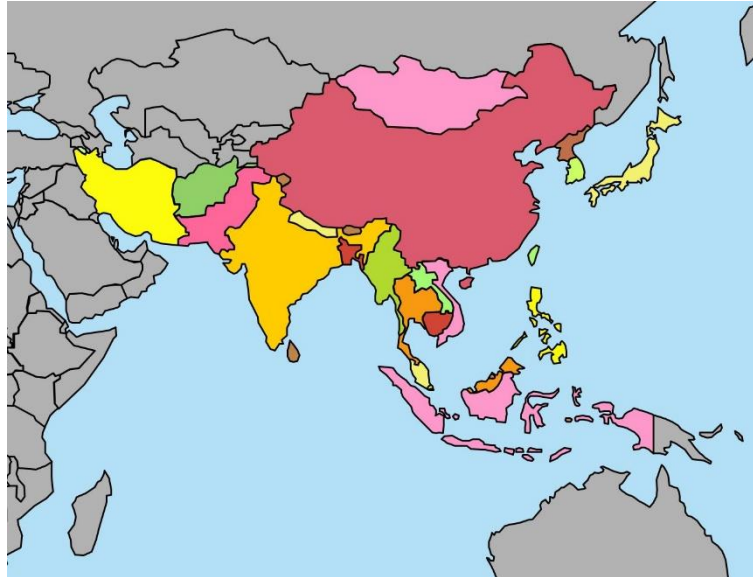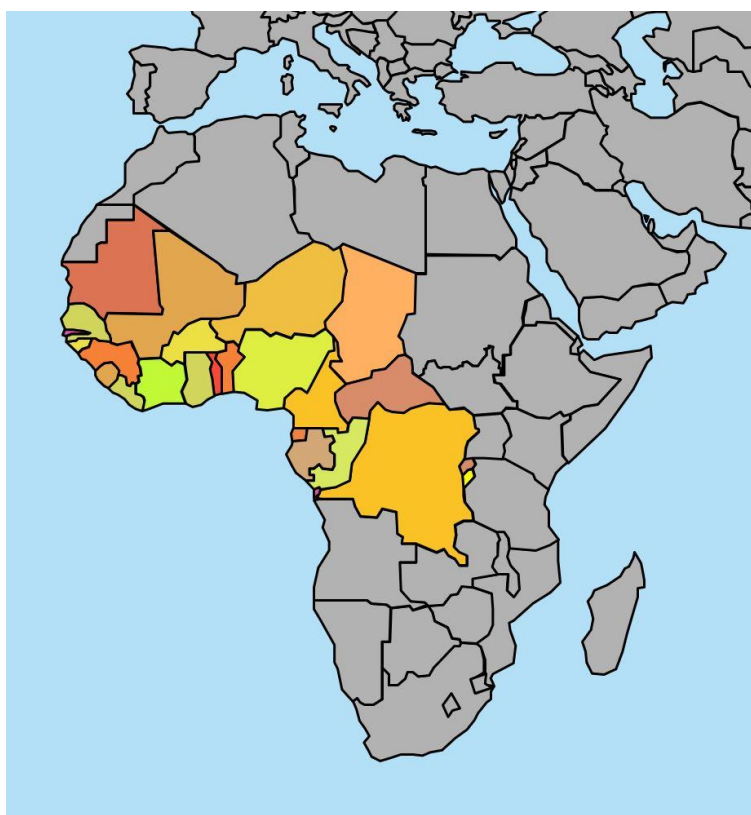

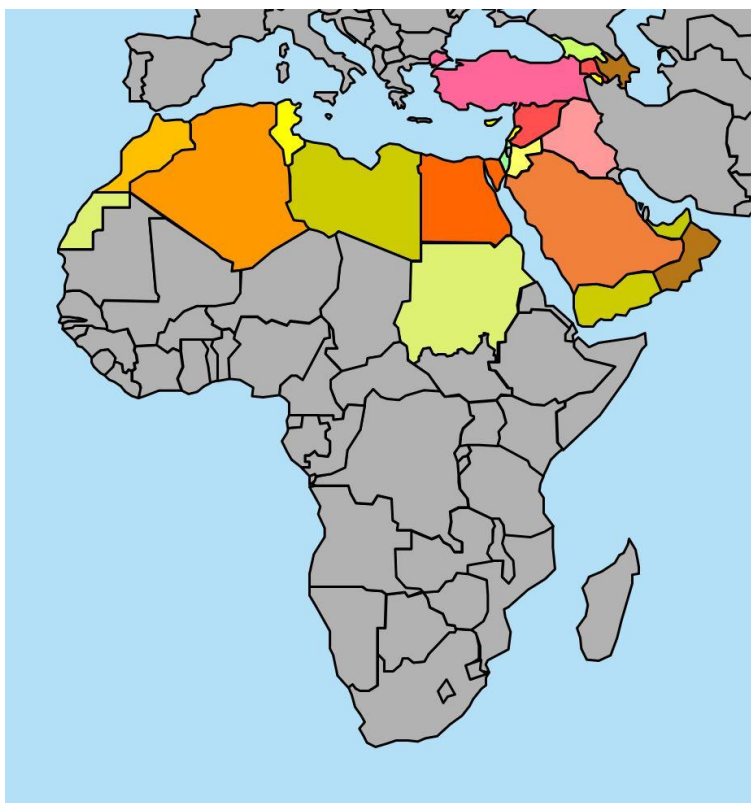*Figure VI-1 - Map of Asia as considered in response analysis*
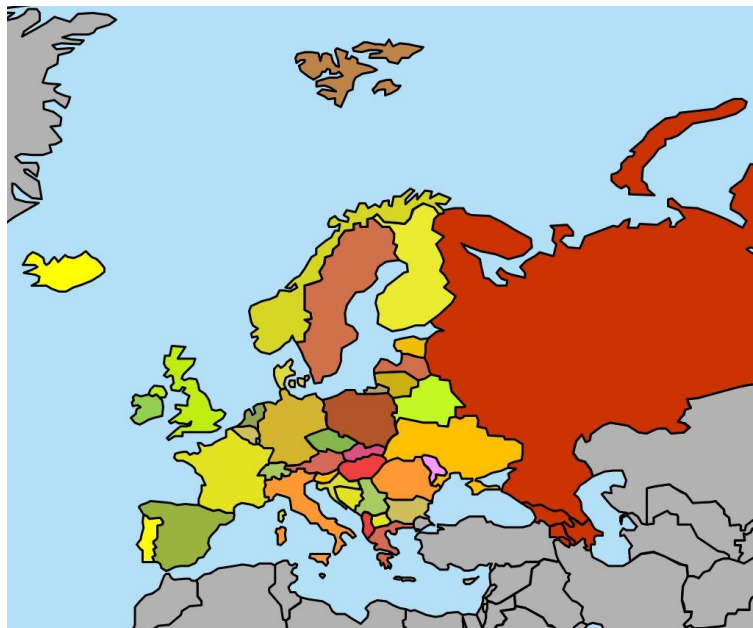
Figure VI-2 - Map of Europe as considered in response analysis

Figure VI-3 - Map of Eastern & Southern Africa as considered in response analysis

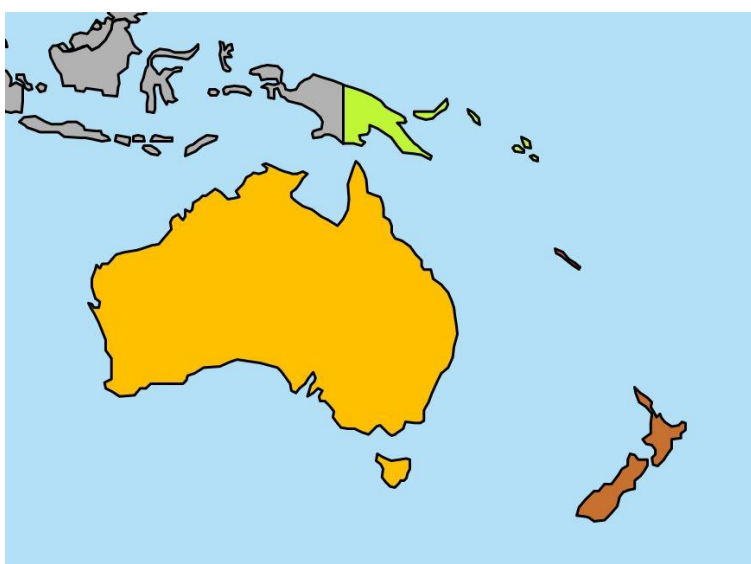*Figure VI-4 - Map of Western & Central Africa as considered in response analysis*

Figure VI-5 - Map of Western Asia & North Africa as considered in response analysis

Figure VI-6 - Map of Latin America & Caribbean as considered in response analysis

Figure VI-7 - Map of North America as considered in response analysis

Figure VI-8 - Map of Oceania as considered in response analysis

Appendix 3: Needs identified for Further Study

Several needs for further study were identified throughout this report. The following list is a compilation of these needs presented in a synthetic and ordered manner. These needs are to be seen as suggestions made to the leaders of the future alliance, who will be free to follow all or only part of them, according to their priorities, to the resources available, and to their own expertise and knowledge in the various areas addressed by these potential studies.

1. Further effort should be made to contact the 58 organizations listed in our database that could not be contacted directly. It would be beneficial to know if they are still in operation and if so, what should be used to communicate with them.

   A similar approach could make sense with the 32% of the organizations listed in our database that could be contacted directly but who did not take part in the survey.

2. Further study would be needed to get a more comprehensive and exhaustive picture of the variety of types of organizations operating across the world.

3. Further study would be needed to determine if there are subcategories of national organizations.

4. Further study would be needed to understand the reason that multiple national organizations operate in a single country and to understand the implications of this for the future alliance.

5. About 5% (8 of 145) of albinism organizations are led by health-care providers, all except one of these organizations operating in Africa. It would be wise for the Pilot GAA to investigate the structure, missions and mode of operations of these organizations, as well as the factors leading to their creation and how much their experience and best practices could be useful in other countries / parts of the world.

6. Further study will be needed to draw a more accurate map of the geographical area of operation of the different albinism organizations around the world.

7. A few organizations are operating in a country (or countries) different to the one where they are based. They usually identify themselves as "international" organization and operate in Africa. It is interesting to notice that these organizations operate in countries where one or several albinism organizations are already based and operate. It would be wise for the GAA Pilot Team to find out what type of collaboration potentially exist in these countries between the two categories of organizations.

8. It is worth noting that some very big countries (either geographically and/or in terms of population) have only one or two national groups. The future alliance would be well served to determine whether these organizations are facing difficulties in covering their country's entire population, and, if not, how they manage a large population and/or geography. Countries to investigate could be: China, Indonesia, India, Pakistan, USA, Brazil, Nigeria, Russia, Mexico, Canada, Australia.

9. We would recommend conducting a specific study dedicated to regional federations, as this subject could play a major role in the decisions on the structure of the future alliance

10. In a further study, it could be interesting to find out the different sources of funding that albinism organizations manage to access by countries/regions and projects, and, given the obvious budget differences, to collect and share fundraising best practices among organizations.

11. Determining if there is a reason that there is a higher percentage of unregistered organizations in Latin America and Caribbean is an issue of interest.

12. Further study to examine leader retention, turnover rates and succession planning may provide useful information to the leaders of the future alliance.

13. The answers to question 25 regarding best practices in the human rights area varied greatly in length and detail. An analysis and summary of the answers should be done. This data should be used by the future alliance to facilitate sharing best practices among albinism organizations.

14. An additional analysis of the information provided in the answers to question 26 (empty field aimed at providing any additional information and/or to react to the questions discussed in the survey) should be considered when planning the structure, mission, and functions of the future alliance.