KILISUN CARE AND KILIMANJARO SUNSCREEN PRODUCTION UNIT

Annual Report 2017

Prepared by: *Kilisun Care*

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INDEX OF CONTENTS:

1. KILISUN CARE AND THE KSPU: BACKGROUND……page 3
2. ACTIVITIES CONDUCTED AT KSPU……page 4

   2.1 PRODUCTION AT THE KSPU

   2.2 DISTRIBUTIONS OF KILIMANJARO SUNCARE SUNSCREEN

   2.3 SATISFACTION OF BENEFICIARIES WITH KILISUN SERVICES

3. DEVELOPMENT AND DESIGN OF IMPACT STUDY ……page 8

4. DEVELOPMENT OF NEW FORMULA IN COLLABORATION WITH FIRST LINE COSMETICS LABORATORIES ……page 8

5. COMPLETION OF A FEASIBILITY STUDY FOR SCALING KILISUN CARE ACTIONS TO A SECOND SUB-SAHARAN COUNTRY……page 8
6. MILESTONES OF KILISUN CARE IN 2017 ……page 10
7. APPENDIXES ……page 11

   7.1 Appendix I: Conclusions and recommendations of the Final report on the *"Assessment of the situation of the accessibility and availability of sunscreens among Persons with Albinism in Malawi*"

   7.2 Appendix II: Theory of Change Kilisun Care Programme

KILISUN CARE AND THE KILIMANJARO SUNSCREEN PRODUCTION UNIT

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1. KILISUN CARE AND THE KSPU: BACKGROUND

In Sub-Saharan Africa there are more than 200,000 Persons with Albinism (PWA) without access to appropriate sun protection. The **risk of developing skin cancer** in PWA is up **to 1000-fold higher** than in the rest of African population. In Tanzania, where stigma is "rife" **only 1 out of 10 PWA live beyond the age of 30. Sunscreen provision** is alarmingly **poor across Africa**, most health facilities do not have sunscreens, nor offer advice on sun protection to PWA, nor is albinism included in health programs. The access to sunscreens is poor and usually limited to importation of cosmetic products of unaffordable prices and sporadic donations that in many occasions arrive expired or are retained due to customs complications.

Kilisun Care (KC) is a non-for profit organization with base in Spain, currently operating in Tanzania and on the way to expand the services to Uganda, Malawi and Rwanda. Kilisun Care is a leading organization in the provision of **sun-protection tailored to Persons with Albinism of Sub-Saharan Africa**. KC's **mission** is to improve the quality of life of PWA ensuring that they have access to high quality sun protection through a quadruple intervention: Locally producing a sunscreen specially designed for their needs, distributing the sunscreen free of cost to the users, providing education and sensitization to the users and their families and promoting their insertion in society through a dignifying care that help to raise their self-esteem and stand on their own.

KC is behind the production and distribution of the **first sunscreen specially designed for** the **prevention of skin cancer in PWA in Sub-Saharan Africa**. The formulation has been carefully designed by first line cosmetic and chemical companies and adapted to the type of skin and reality of this vulnerable collective. It's the first sunscreen locally produced and distributed at no cost to its users, removing reliance on sporadic foreign donations and enabling a steady and sustainable supply of this life-saving product. Kilisun is not a product but a holistic service, the "**Kilisun package**" comprises:

- **Production** of a high protection sunscreen in a laboratory in Tanzania that employs PWA.
- Free **distribution** across all Tanzanian geography through community dermatologists, mobile clinics, schools, international NGOs and other local platforms.
- **Education** on sun protection and albinism to PWA and families promoting **social inclusion**.
- **Follow up** the compliance and **measurement** of its **impact**

In 2013 the first production center, the **Kilimanjaro Sunscreen Production Unit (KSPU)**, was pioneered at the **Regional Dermatology Training Centre**, dermatology department of the Kilimanjaro Christian Medical Centre, under the guidance of Kilisun Care's CEO and with the mission to reduce the prevalence of skin cancer and improve the quality of life of PWA in Tanzania. In 2013 BASF (Germany) joined this endeavor by providing sunscreen ingredients, as well as technical, scientific and regulatory background support for the development and manufacture of sunscreens. In 2017 Kilisun Care guided the operations and has been the main source of funding of the KSPU. The RDTC is currently advocating with the Ministry of Health and Social Welfare for the inclusion of the KSPU in their budgets thus making the initiative sustainable and able to cover all PWA nationwide.

2. ACTIVITIES CONDUCTED AT THE KILIMANJARO SUNSCREEN PRODUCTION UNIT (KSPU) IN 2017

2.1 PRODUCTION AT THE KSPU

The KSPU produces Kilimanjaro Suncare Sunscreen, a water-in-oil emulsion with a sun protection factor of 30+ (High SPF) specially designed for Persons with albinism of East Africa. 55% of its composition are ingredients are provided by BASF and Granula, the rest are procured from Spanish suppliers.

The KSPU manufactured a total of **9,651 Kilisun** sunscreen jars for adults and **3,245 Kilisun** jars for *watoto* (children under 7 years old).

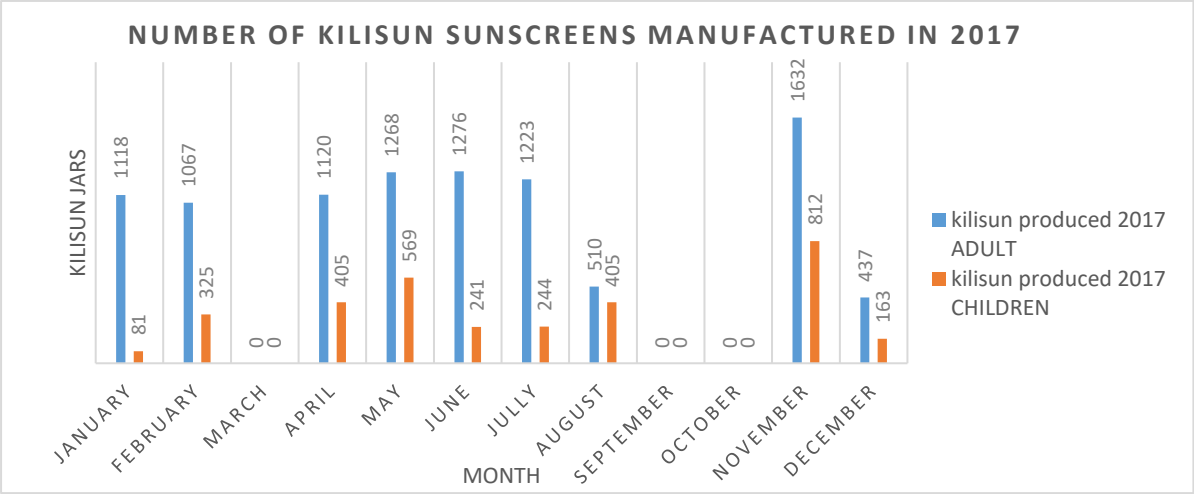


Table 1. Number of Kilisun jars manufactured in 2017

2.2 DISTRIBUTIONS OF KILIMANJARO SUNCARE SUNSCREEN

In 2017 Kilisun was distributed among PWA living in 21 regions across Tanzania covering around **80.8%** of all regions in mainland Tanzania, increasing in a 23.3% from last year.

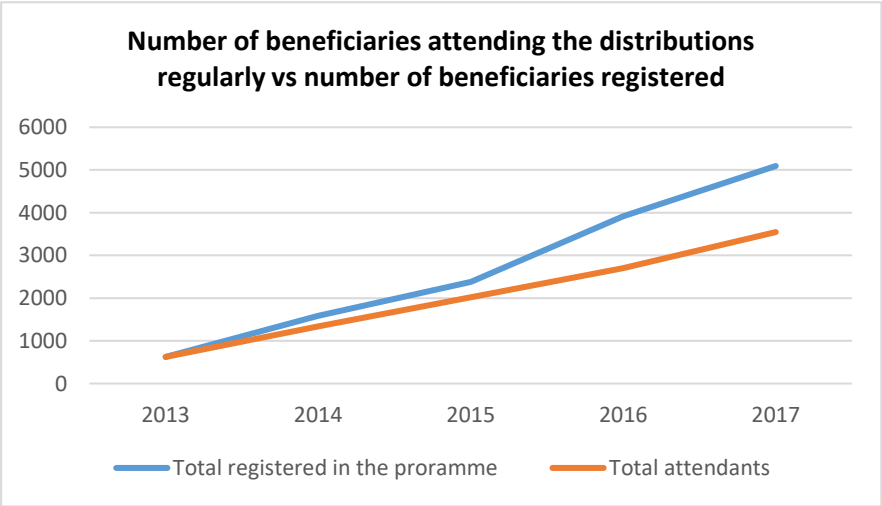


Table 2. Number of attending beneficiaries vs number of registered beneficiaries

The KSPU regularly distributes Kilisun to the most remote areas of the country through mobile clinics, schools and other local platforms. We emphasize the importance of sensitization education on sun protection not only addressing the beneficiaries but their families, caretakers, dermatologists, health workers, teachers and the whole community. Other channel of distribution are the community dermatologists that are running clinics in stablished programmes (Standing Voice) and at their working stations as well as NGOs and local platforms such as Under the Same Sun in Dar es Salaam.

As indicated in the following tables at the end of 2016 **5,093 PWA** are enrolled in Kilisun. **54% of them are children** (minors <18 years old), important data as sun protection must start in early stages of life. 49% are male and and 51% are female.

	PWA ENROLLED IN KILISUN IN 2016					
	REGION	**TOTALS 2017**	**ADULTS**	**CHILDREN ≤18**	**MALE**	**FEMALE**
1	SHINYANGA	578	211	367	327	251
2	SIMIYU	139	54	85	72	67
3	MARA	312	116	196	144	168
4	KAGERA	169	74	95	81	88
5	TABORA	225	68	157	94	131
6	GEITA	224	95	129	121	103
7	MWANZA	661	249	412	326	335
8	KIGOMA	161	50	111	78	83
9	MBEYA	140	92	48	78	62
10	IRINGA	185	94	91	66	119
11	NJOMBE	44	31	13	24	20
12	ARUSHA	242	142	100	98	144
13	KILIMANJARO	534	268	266	409	125
14	TANGA	494	260	234	231	263
15	MANYARA	53	27	26	25	28
16	DODOMA	155	75	80	76	79
17	SINGIDA	72	43	29	23	51
18	MOROGORO	93	27	66	44	50
19	DAR ES SALAAM	354	258	96	158	193
20	RUVUMA	136	63	73	60	76
21	PWANI	122	54	68	61	61
TOTALS		**5,093**	**2,351**	**2,742**	**2.596**	**2,497**

Table 3. Number of PWA enrolled in Kilisun in 2017 by region

70% of the total number of beneficiaries registered in Kilisun programme attended the distributions in 2017, making a total of **3,546**, 767 more than in 2016. Out of this total 44% attended the distributions more than once. In addition 79% of the beneficiaries that received the services in 2016 returned in 2017.

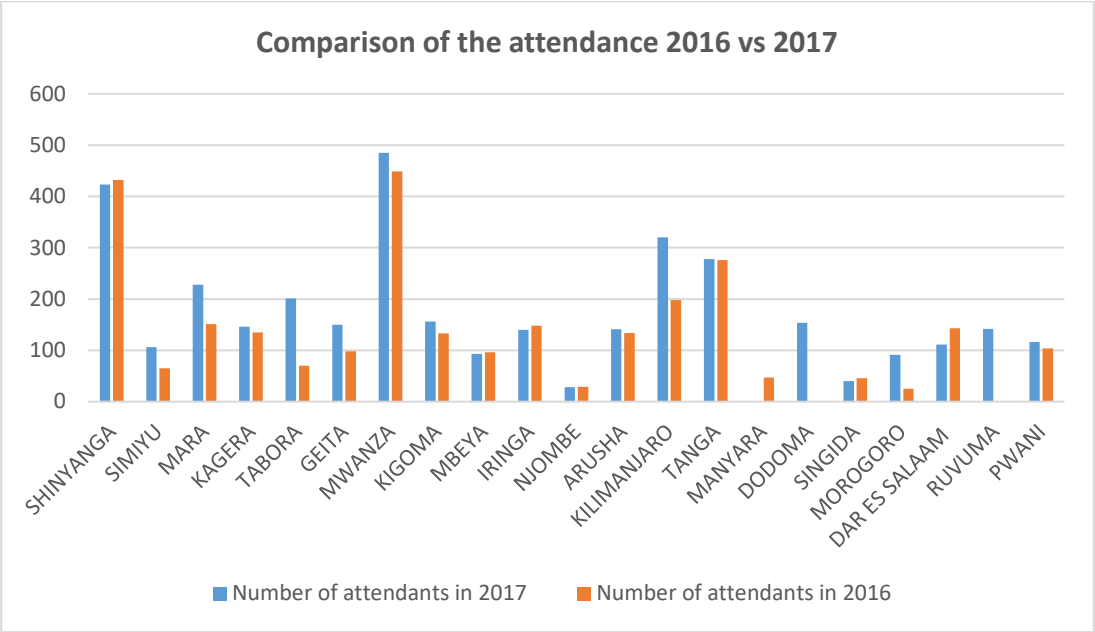


Table 4. Comparison of the attendance by Region in 2017 vs 2016

An average of **30 % of the empty containers were returned** by the beneficiaries for recycling in 2017. The figure is increasing (24% in 2016) and hope that it will continue improving as that is an indicator of the compliance and proper use of the sunscreen, it indicates the quantity of cream used in a specific period of time.

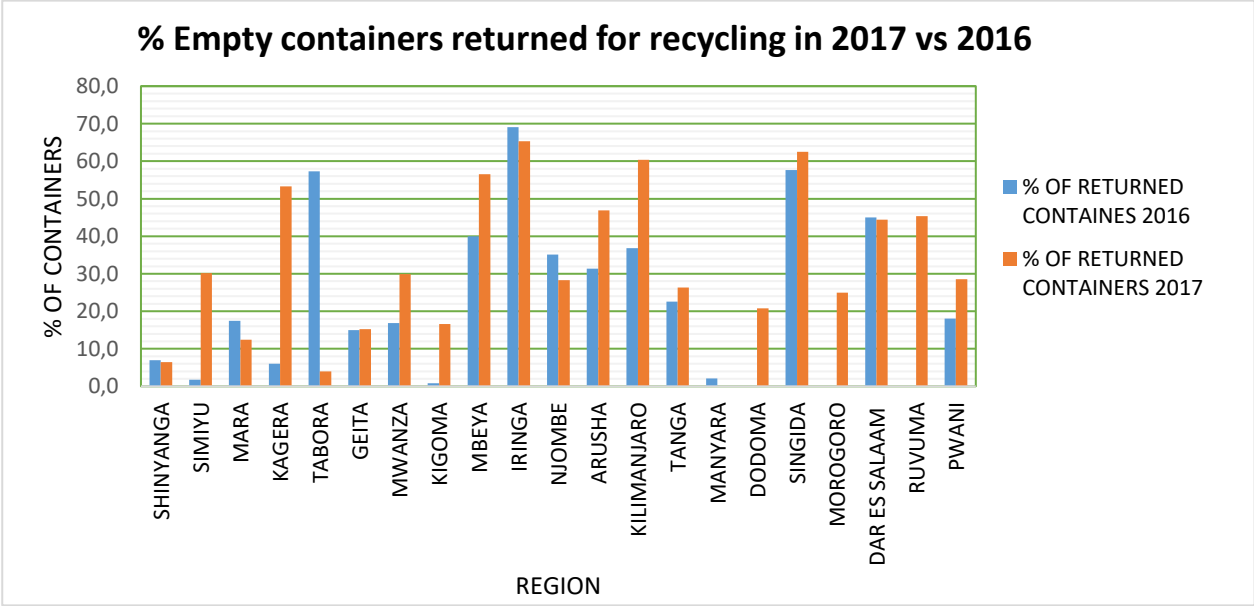


Table 5. Returning of used containers for recycling

2.3 SATISFACTION OF BENEFICIARIES WITH KILISUN SERVICES

A surveillance on 10% of the total number of regular beneficiaries showed that more than **95% of them would recommend Kilisun services** and confirm that their **skin looks better** after starting using Kilisun sunscreen.
In terms of psychosocial impact, more than **95%** of the interviewed PWA report that they feel **more confident** as a result of the treatment and are less afraid of the skin condition getting worse.

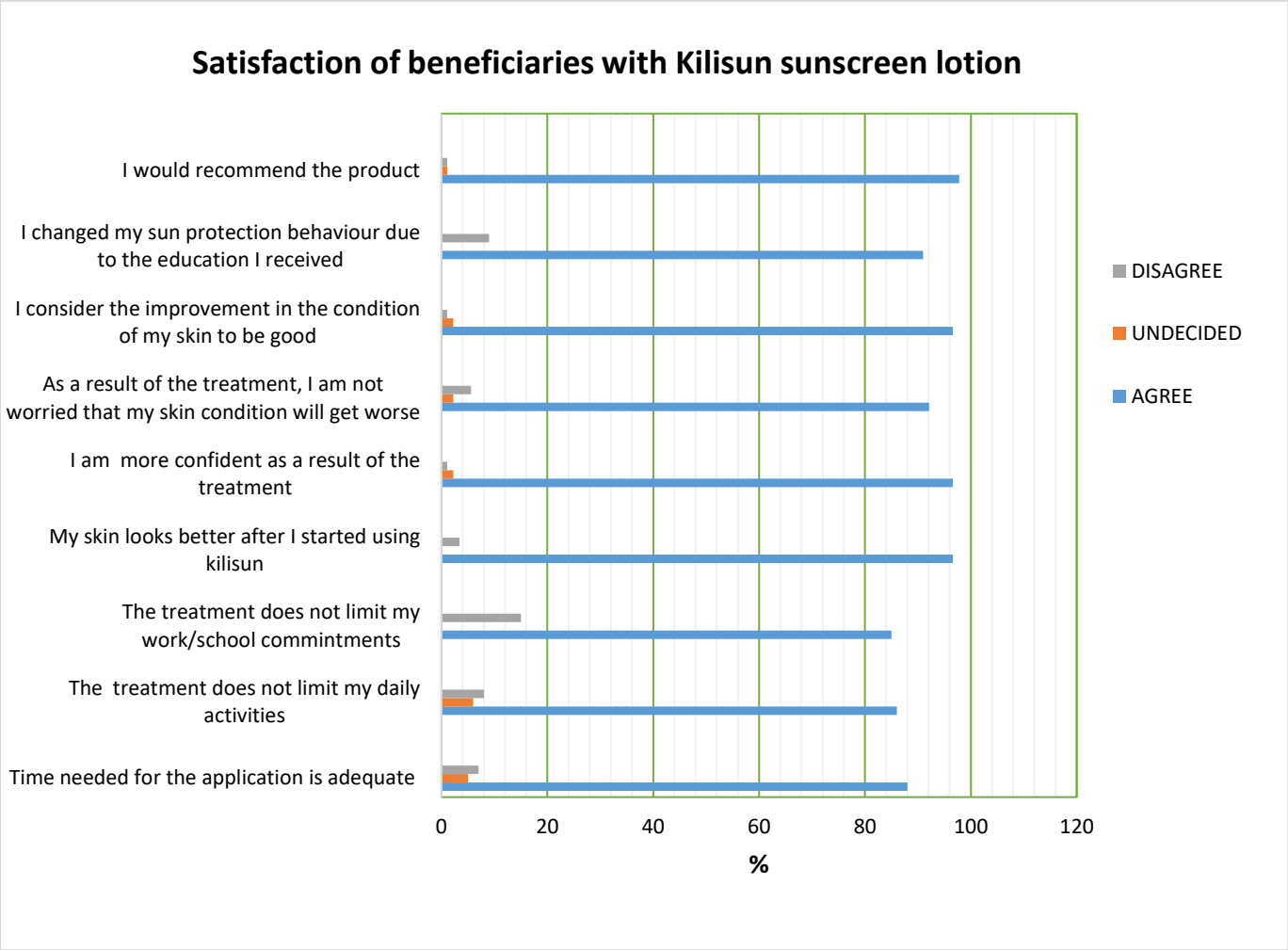


Table 6. Satisfaction of beneficiaries with Kilisun in Arusha and Kilimanjaro regions

In Arusha and Kilimanjaro, 2 of the regions that represent 10% of the total beneficiaries, out of the total number of **new beneficiaries** enrolling in the services in 2017 there was an **80% decrease in the presentation of erythema**

The KSPU team is evaluating the impact of the education provided during the distributions by the medical and KSPU personnel. The education is structured in 3 blocks: Education on General Understanding of Albinism, Photo protection and Kilisun (keeping, use, application, etc.).

Out of the total beneficiaries interviewed in Kilimanjaro and Arusha, **67.4%** consider the education on **General Understanding of Albinism** useful, **82.9%** consider the education on **photo protection** useful and **96.4%** consider the education about **Kilisun use** and management helpful.

EDUCATION BLOCKS	HELPFUL	INDIFFERENT	NOT HELPFUL
Albinism	67.4%	1.8%	30.8%
Photo Protection	82.9%	3.9%	13.2%
Kilisun	96.4%	1.4%	2.5%

Table 7. Satisfaction of beneficiaries with Kilisun in Arusha and Kilimanjaro regions

3. DEVELOPMENT AND DESIGN OF IMPACT STUDY

By November 2017 **Kilisun Care completed the design of a 4 years impact** study in partnership with Standing Voice (UK), the support of Pierre Fabre Foundation (France) and the expertise of Roots for Sustainability (Spain), a B Corp company specialized in **projects and organizations social impact measurement, inclusive business development** and **social innovation programs creation.** The design is being adapted to be implemented in Malawi as well and launched in the first semester of 2018. *See enclosed in Appendix II the Theory of Change of the Intervention.*

4. DEVELOPMENT OF NEW FORMULA IN COLLABORATION WITH FIRST LINE COSMETICS LABORATORIES

In 2016 eight sunscreen cream prototypes developed in collaboration with BASF expertise, were assessed at the KSPU for sensory preference. Selected prototypes underwent stability test in BASF Suncare labs and the one with best results was sent for performance assessment.

In 2017 *Dermscan labs* conducted the evaluation of the sun protection factor and water resistance concluding that **KILISUN MAX**, the new formulation, has an average **SPF of 64.4** (invivo). In addition it could support the claim "water resistant" because the value [mean %wrr] is greater than 50% of the SPF without immersion. **KILISUN MAX will be launched in Malawi and Rwanda** in in 2018.

More technical data about the new formula (ex. Performance, technical information, etc.) is detailed in the enclosed presentation of the report *"**Assessment of the situation of the accessibility and availability of sunscreens among Persons with Albinism in Malawi**"*.

5. COMPLETION OF A FEASIBILITY STUDY FOR SCALING KILISUN CARE ACTIONS TO A SECOND SUB-SAHARAN COUNTRY

MALAWI:

Kilisun Care will **focus on the expansion to Malawi in 2018-2020**, where we plan to launch the initiative at National level in **partnership with the Albinism Society of Malawi (APAM)**. In May 2017 Kilisun conducted an **assessment exercise** with the support of United Nations and Ministry of Health of Malawi to evaluate the situation in the country regarding the access to sun protective services for PWA for a potential launching of Kilisun. During the visit the team mapped the whole

country, decided the site where to establish the potential production unit, design the distributions plan and worked on the way forward. The assessment also evidenced the need of decentralizing the service provision of sun protection so that it reaches all PWA, most of them living in rural areas, as well as the urgency of improving the efficacy of the available sunscreens in the country and the awareness about sun protection and sunscreen use.

* The full conclusions and recommendations of the Assessment Report can be found in Appendix I and the enclosed presentation: ***"Assessment of the situation of the accessibility and availability of sunscreens among Persons with Albinism in Malawi"***.
The strategy in Malawi is to launch a 3 year program, divided in 3 main actions:

a. Piloting Kilisun model (2018-2019):

- Running a **Pilot project in 9 of the 28 districts** of the country. These districts, 3 by region, where those where the assessment study was conducted in 2017; the data collected during the assessment will be used as baseline information.
- The sunscreens will be labeled in Chichewa, imported and distributed by the **Central Medical Stores Trust**, Governmental supply machinery, ensuring that arrive to the dispensaries and Health Centres. Kilisun Care and APAM will be behind the supply and PWA mobilization. **Health Personal at health centers and members of APAM will be trained** on the provision of the Kilisun package and data collection. **Data will be exhaustively analyzed and impact measured**; for this endeavor we count with the collaboration of the Mc. Biostatistics of the Universidad Complutense de Madrid and the Social Impact expert company Roots for Sustainability.
- In addition of **evidencing the impact of Kilisun the pilot** aims to assess the challenges existing in terms of service provision to PW in the country and will **identify areas of potential development of the services and further inclusion of other elements of health care for PWA** (Ex. Dermatological services, training on Dermato-surgery to local clinicians, referral system for PWAs that need further management, etc.).
- Results will be shared with the Government, UN offices, local and international partners and stakeholders.
- Number of beneficiaries: **2.500** –including 1.500 direct beneficiaries (PWA) and 1000 indirect beneficiaries (caretakers, APAM and health personnel)-.

b. Establishment of the Sunscreen Manufacturing Unit (2019):

- **Building, equipping the laboratory** and identifying the **staff**
- Registering the sunscreen formulation and the facilities in the **Malawian Regulatory Boards**.
- Formalizing agreements with the Ministry of Health and the Central Medical Stores Trust (CMST) for the future procurement of the products manufactured in the unit.
- Continuation with the Kilisun provision in the 9districts of the districts.

- Number of beneficiaries: **2.500** –including 1.500 direct beneficiaries (PWA) and 1000 indirect beneficiaries (caretakers, APAM and health personnel)-.

c. Launching Kilisun package at National level (2020):

- Training health workers and APAM member is the remaining 19 districts of the country.
- **Launching Kilisun production and distribution ops an National level**
- Formalizing **contractual agreements** with partners and stakeholders for **future procurement of the sunscreen by the CMST**
- Number of beneficiaries: **8.000** –including 5000 direct beneficiaries (PWA) and 3000 indirect beneficiaries (caretakers, APAM and health personnel).

RWANDA:

Kilisun Care has also received demand from different organizations around the globe that would like to procure Kilisun to supply to PWA in their regions. We are currently manufacturing the new formulation (SPF 50+ developed in collaboration with BASF) in Europe so we can launch pilot projects in Africa, scaling in less time and being able to cover all the existing demand.

In Rwanda Kilisun is working with ARIANA to pilot the Kilisun package in a group of PWA in the northwest of the country in the first half on 2018, adapting it to the specific needs of Rwanda. We have submitted a joint concept note to the Minister of Health of Rwanda to explore the scope of their support in a second stage.

6. MILESTONES OF KILISUN CARE IN 2017

- **KILISUN SL and Kilisun Care are constituted** in Spain in 2017. KILISUN SL is the Social Enterprise, developing a business model that enable Kilisun Care to be have financial sustainability and its actions to be scalable to other African countries in need.
- Completion of the development of the **KILISUN MAX, new formulation SPF 50+** in partnership with BASF
- Completion of the design of **Kilisun Impact Study** in partnership with Standing Voice and Roots for Sustainability
- Signing of an agreement with ARIANA for the **launching of Kilisun in Rwanda** in 2018
- Implementation of a National assessment in Malawi in partnership with the Albinism Society of PWA in Malawi "**Assessment of the situation of the accessibility and availability of sunscreens among Persons with Albinism in Malawi**"
- **Partnership with RNB** for the development of a cosmetic social line for Kilisun SL Social Enterprise.

7. APPENDIXES:

7.1 Appendix I: Conclusions and recommendations of the Final report on the *"Assessment of the situation of the accessibility and availability of sunscreens among Persons with Albinism in Malawi"*

Conclusions

It can be concluded that there are so many hindrances in the supply chain of sunscreen to the health facilities that are affecting the accessibility and affordability of this essential product in Malawi.

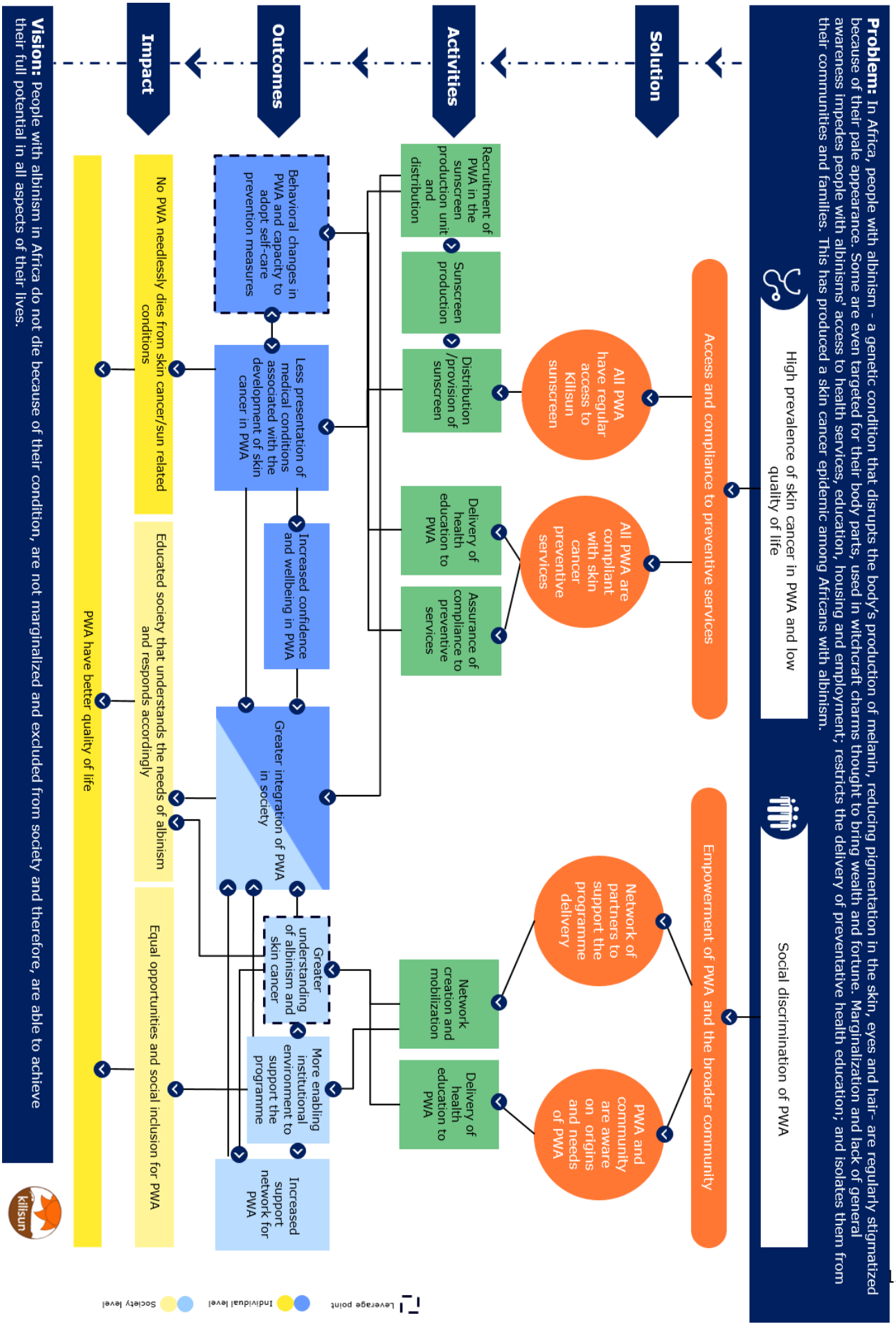
- ***Insufficient supply***:
  - Whilst the assessment reveals that the **quantities** of sunscreens delivered to the districts do not match with the number of persons with albinism registered in those areas, many sunscreens in risk of expiration are accumulating at the stores of the CMST branches due to an inadequate supply chain.
  - Even though the majority of the persons with albinism live in rural settings, sunscreen **distribution is centralized** in district and central hospital. The long distances needed to walk to reach the hospital are an obstacle to ensure good sunscreen use habits due to the high costs of transportation and the lack of security of this exposed and in-risk population. Therefore there is a strong need for a decentralized supply system, strengthening the coordination between health center personnel and members of APAM to ensure that persons with albinism have not only easier access to sunscreens but are also aware of the application habits and are followed up on early identification of skin damage.
  - In addition **sunscreens are imported** from abroad making difficult an agile communication and response between the procurer and the sunscreen supplier thus affecting the stock management, product rotation and management of expired products.
- ***Unaffordability***:
  - In addition to the insufficient number of sunscreens the **elevated costs** limit its accessibility, DHOs do not place sufficient orders due to their high prices and patients do not attend the health facility to collect them due to high transport associated expenditures.
- ***Inadequate efficacy of the available products***:
  - The chemical analysis shows that the sunscreens available in the market and at CMST fall **short of the specifications needed** to provide the **ideal sun protection** to persons with albinism who are recommended to use SPF 50+, broad spectrum coverage and high viscosity products to ensure maximum skin coverage. In addition, some of the sunscreens in circulation have shown not be safe and stable, SPF 50+ sunscreens available in the local shops are very expensive and not affordable to many persons with albinism. Therefore, the **cost-effectiveness ratio** of the existing services is far from being ideal.
- ***Lack of awareness about sun protection and sunscreen use***:
  - On the other hand the in charge of skin departments at district level are not always trained on dermatology nor in specific health and clinical issues related to albinism. There is a **need to build the capacity of the in charge of dermatology at district level,** both in terms of skills and knowledge.
  - The lack of a coordinated health program targeting persons with albinism in Malawi has led to poor communication channels between hospitals and persons with albinism in the community regarding the availability of sunscreen, health education on albinism and

counseling on sun protection. In most cases this has contributed to demotivation of persons with albinism to go to the hospitals to obtain the sunscreen and dermatological services. There is a **need for a strategic albinism civic education** and **awareness program** among persons with albinism and their families and health workers at district and health center level so that the intervention is focused more on prevention of skin cancer and changing mindset to realize the value of routine skin checkups. This will help to improve the quality of life of persons with albinism and to save many of them from dying of skin cancer.

Hence, the need for a specific **local production unit** that manufactures a specific, high quality, affordable sunscreen, formulated according to the needs of the persons with albinism of Malawian settings and that is well coordinated with the Ministry of health in order to guarantee an optimal supply chain. This would help to ensure the adequate availability of the needed quantities of sunscreen in the health facilities of Malawi and the distribution through a community based program that stablishes linkages and coordination with persons with albinism.

Kilisun is the package that could be replicated in Malawi to support the Government and APAM to provide such comprehensive program on preventive health services to persons with albinism as it gives an answer to many of the challenges identified in this assessment study.

Recommendations

- Decentralization of services: Persons with albinism should be able to access education on sun protection and sunscreen provision at Health Centre level.
- Ensuring availability of high efficacy sunscreens: Ensure that the sunscreen supplied is adapted to the extremely sensitive skins of the users and local environment, and that they satisfy the recommended specifications for persons with albinism in Malawi (SPF 50+, UVA/UVB coverage, etc.)
- Establishment of a local production unit of a specific sunscreen for persons with albinism following Kilisun model to ensure constant availability, affordability and provision of comprehensive programme that includes follow up of compliance, education, awareness and empowerment of beneficiaries.
- Training of health personnel at Health Centers on understanding albinism and sun protection measurements: Health workers providing care to persons with albinism should be trained and provide education on sun protection and sunscreen use to persons with albinism, especially at the moment of distributing sunscreen lotions. In charge of skin departments at district level should be specifically trained on dermatology.
- Reinforcement of the coordination and communication between APAM and Health Facilities: APAM members and health workers should be coordinated in a way that persons with albinism can easily be aware about where and when to receive the services. APAM should assist in the identification and mobilization of persons with albinism living in the catchment area of a specific Health Centre and coordinate efforts with the HSAs and health personal to ensure that they attend the clinics / distributions and receive the services regularly.
- Follow up the compliance: As albinism is a chronic condition that needs a chronic preventive treatment, measures to follow up the compliance to sunscreen use and sun behavior should be developed and implemented by the Ministry of Health.
- Conduct a census of Persons with Albinism
- Adopting messages on understanding albinism and sun protection measurements in health education and health promotion programs.

7.2 Appendix II: Theory of Change Kilisun Care Programme