



**KILISUN:**

**Improving the quality of life of Persons with Albinism in Africa**



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# ALBINISM IN AFRICA



More than **200.000** persons have **albinism**

# ALBINISM IN AFRICA: SOCIAL PROBLEMS

- Persons with Albinism (PWA) are victims of **stigma and discrimination**
- Only **10%** have access to **Secondary Education**.
- **522 attacks** to PWA have been reported in Sub-Saharan Africa since 2006. In **Tanzania 77** have been **killed** and other 94 attacked.



*“My teacher always said that when a person with albinism dies the body vanishes. So I was surprised that nothing happened here, we buried Mariam as any other person. Her body did not vanish, we did her a normal funeral”*

Uncle of Mariam Emmanuel, murdered on January 21, 2008



# TANZANIA

Tanzania occupies 151 of a total of 188 countries in the 2014 PNUD ranking (Human Development Index).

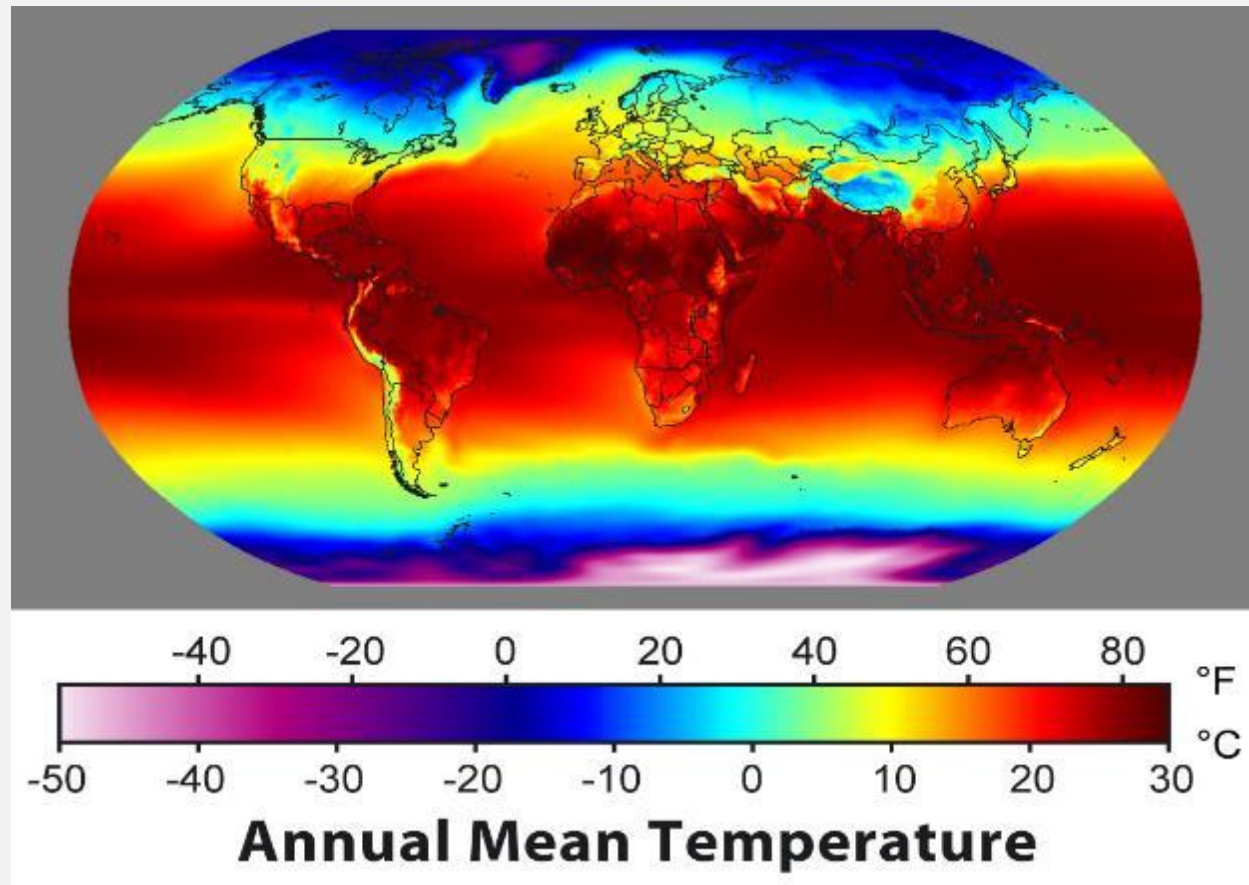


SOCIOECONOMIC INDICATORS	TANZANIA	SPAIN
Surface (km2)	945.090	504.645
Maternity mortality rate (2010)	950	4
Doctors (for 100, 000 inhabitants)	5	380
Malnutrition incidence(% total population)	38	...
Mortality index in under five children (for 10,000 born alive)	1.040	40
Population that lives with less that 1.25 USD/day (%), 2000-2008	88,5	0

# ALBINISM IN AFRICA: ADVERSE EFFECTS OF SUN EXPOSURE IN THE SKIN

Their lifestyle, environment and social challenges make PWA specially vulnerable and exposed to sun damage

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# ALBINISM IN AFRICA: ADVERSE EFFECTS OF SUN EXPOSURE IN THE SKIN

Only **1 out of 10** PWA live beyond **30 years**



Sunburn

Actinic Keratoses

Skin Cancer (NMSC)

**PREVENTION**

# THE «SUN PROTECTION PACKAGE»

## EDUCATION

Awareness, sensitization

Sun safe practices



Protective Gears



Sunscreens





# KILISUN



Adapted to **THEIR reality** and needs

SPF 30+, UVA/UVB coverage

**Locally manufactured** in own laboratory in Moshi (Tanzania)

Support of **BASF Sun Care**



# The long way towards the ideal sunscreen....

Publication in PPS in 2010

## The long way towards the ideal sunscreen—where we stand and what still needs to be done

Uli Osterwalder<sup>a</sup> and Bernd Herzog<sup>b</sup>

Received 30th November 2009, Accepted 4th December 2009

First published as an Advance Article on the web 1st March 2010

DOI: 10.1039/b9pp00178f

The magnitude and quality of UV protection provided by top considerably over the past three decades. As our knowledge and requirements increases, product and testing technologies advance and new technologies become available. The biannual London Sun Protection development over the last two decades. The 2009 edition of the “Perfection of Protection”. This paper, based on our talk, gives a question about the “ideal sunscreen” and explores four key requirements regarding where we stand on a ranking scale between poor and perfect. Technology is leading with a rating of 80%, Assessment/measurement around 50% and Compliance ranks only around 30% between poor and perfect. UV

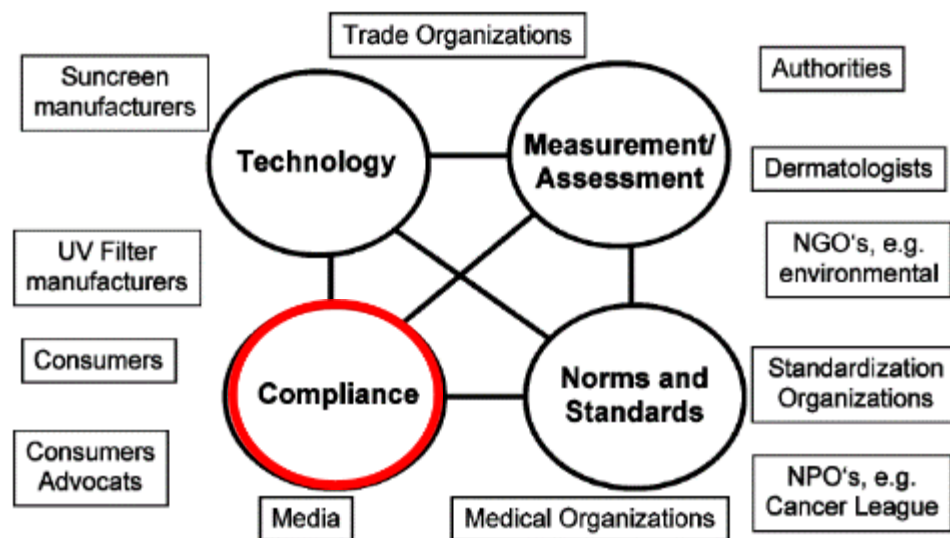
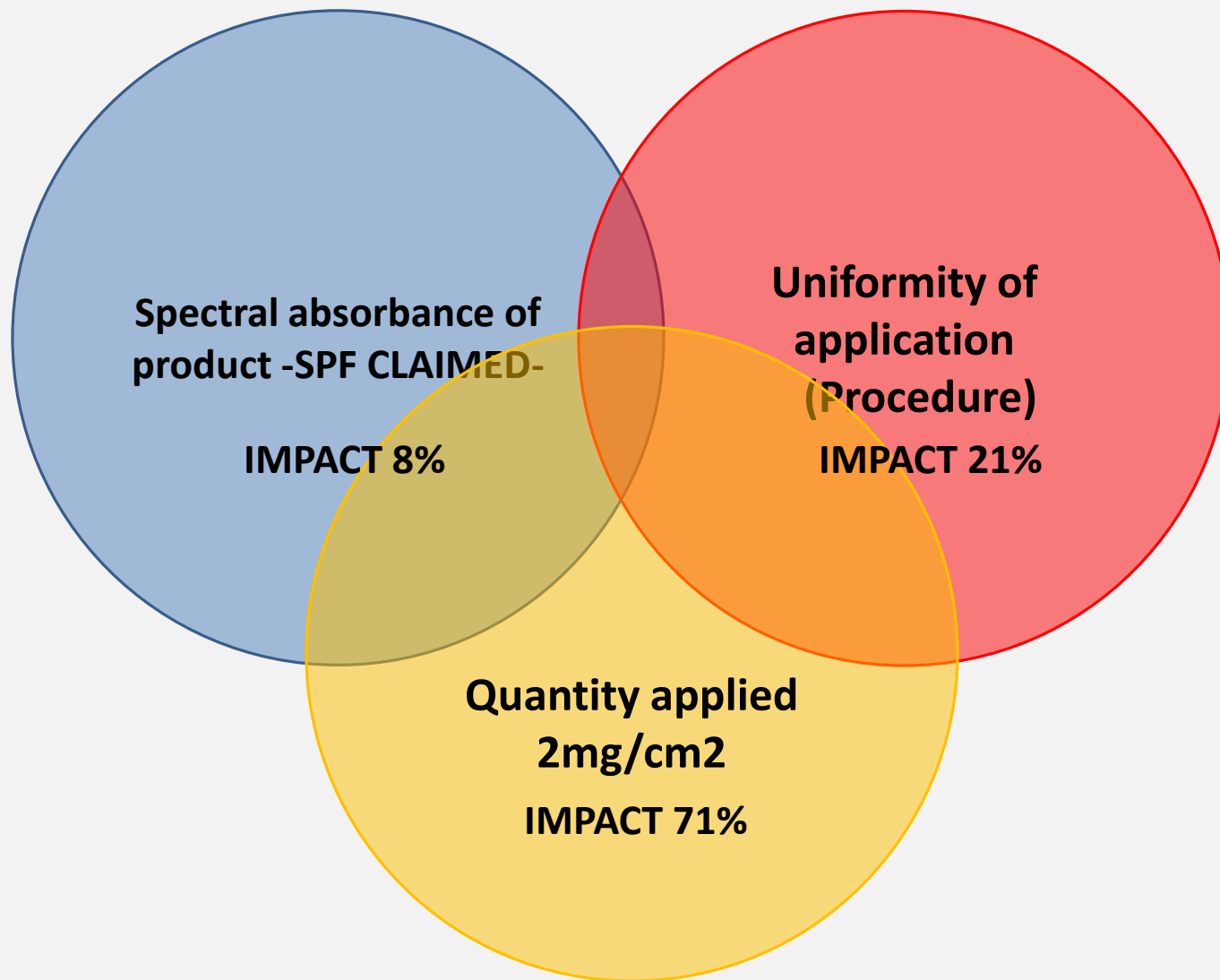


Fig. 1 UV protection: four key requirements and influencing stakeholders.

UV

**Lack of Compliance = Problem #1**

# SPF IN VIVO VERITAS EFFICACY



# KILISUN: A COMPREHENSIVE PACKAGE

## DISTRIBUTION



## EDUCATION



## FOLLOW UP THE COMPLIANCE



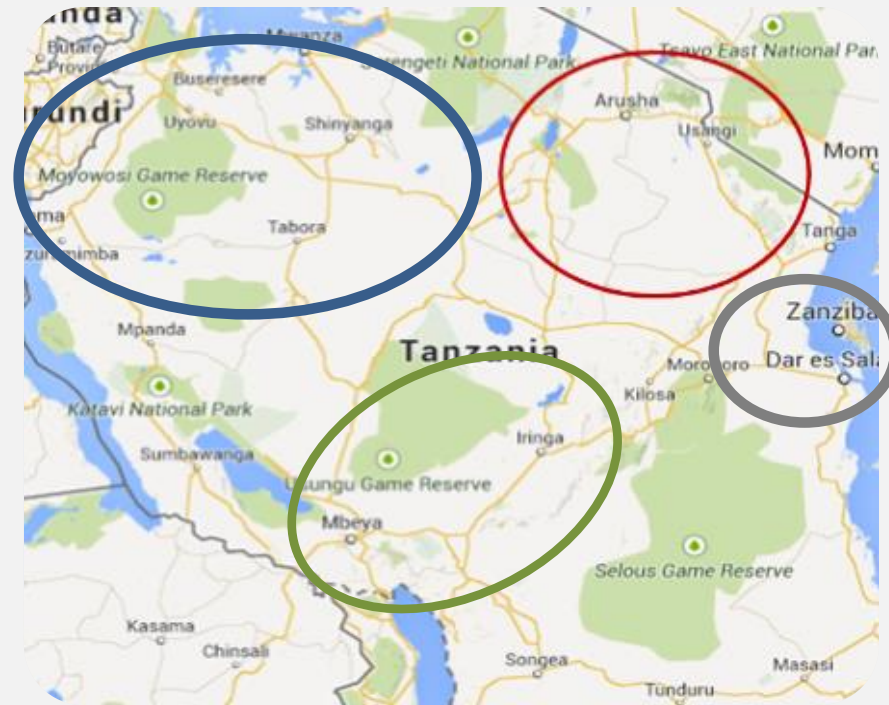
## IMPACT MEASUREMENT



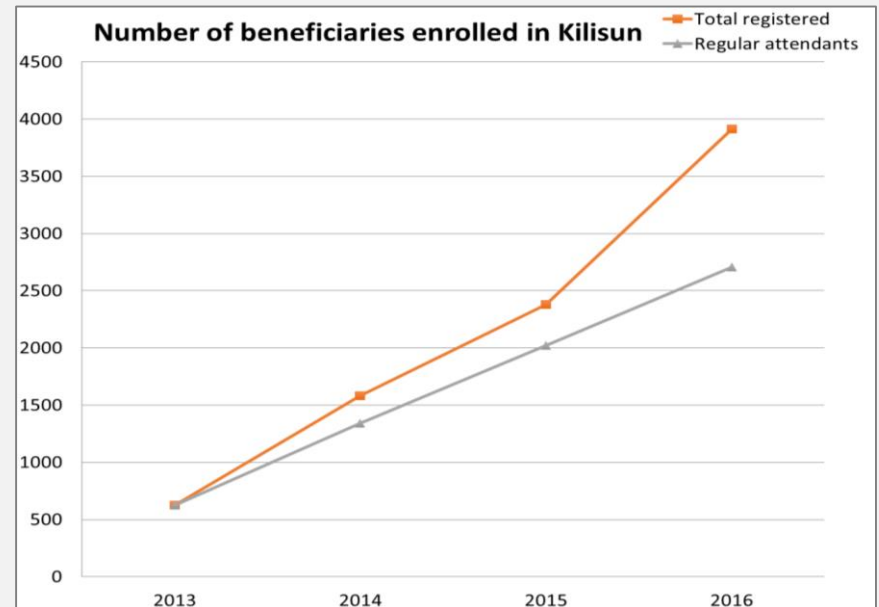




# DISTRIBUTIONS IN 2016



Distribution channels	% Total beneficiaries
Outreach health programmes	75,44
Community Dermatologists	16,09
School and Centres	6,19
NGOs	2,28



## KILISUN IMPACT



**After using the product**

**3,000** beneficiaries received Kilisun in 2016

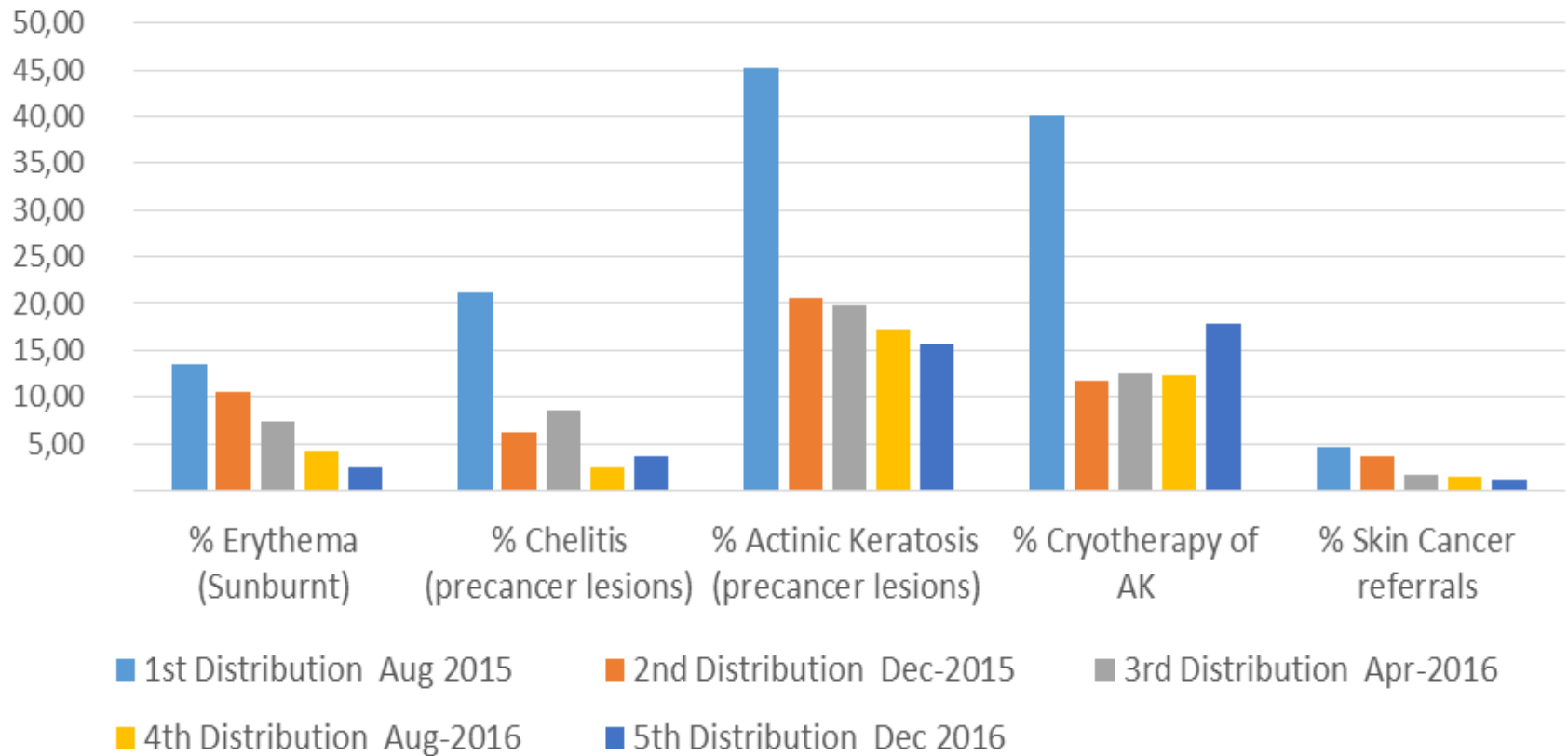
**52%** of them are children

**80%** drop in skin cancer incidence\*



# KILISUN IMPACT

Impact of Kilisun in the skin health of the beneficiaries



# COSTS OF THE PROGRAMME

The annual cost of the Kilisun package in Tanzania is **50 Euro per person**.



The cost includes:

- Price of the cream (including the procurement of packaging, ingredients and production costs)
- Operational costs
- Distribution
- Educational programme
- Impact assessment and follow up of compliance



# KILISUN CARE N.G.O.

**Mission: All Persons with Albinism have access to sunscreens**

- Registered in **Spain**
- Ensures that PWA in Africa have **access to sunscreen**
- **Manages the expansion** of Kilisun services in Africa
- Obtains **resources** (funding)
- Establishes **alliances** with collaborators
- Ensures efficient **operations** in Africa
- Ensures **sustainability** of Kilisun in Africa:
  - Establishing **Public Private Partnerships** with Governments in Africa so the Government cover the costs of Kilisun (production, distribution, education, etc.) maximizing the impact at national level and making the programme sustainable







## KILISUN CARE: THE EXPANSION

**Malawi:** Initial evaluation (May 17) with the *Association of People with Albinism (APAM)*, United Nations and Ministry of Health.

**Objective:** Evaluate the situation in the country regarding sun protective services for PWA for a potential launching of Kilisun.

**Next step:** Presentation of findings and Intro proposal for pilot project in 2018 to MoH&UN (Oct. 17)

**Rwanda:** Piloting the launching of Kilisun in collaboration with HAND IN HAND FOR DEVELOPMENT (HIHD) and Ariana.

**Next step:** Training counterpart and launching of Kilisun services (March 2018)



# ACHIEVEMENTS IN TANZANIA

- International visibility
- **3,000 PWA** receive Kilisun sunscreen regularly
- (51% are children)
- **80% reduce skin cancer incidence**
- We reach **21** of 25 regions in Tanzania

## OUR VALUE

- Pioneers and unique
- Mission
- Social Impact
- Tested model in Tanzania ready to scale
- Trajectory
- Committed team
- International strategic collaborators



# KILISUN IN THE MEDIUM TERM

- **Objective:** Reduce the morbi-mortality due to skin cancer among Persons with Albinism in **Tanzania, Malawi and Rwanda**
- **Implementation period:** **January 2018 – December 2020**
- **Expected results:**
  - **Consolidation** of Kilisun Care and Business model
  - **15,000 beneficiaries** receiving regular KiliSun services
  - Launching a **new SPF 50+ formulation** (“**Kilisun Max**” developed in partnership with **BASF**)
  - Launching an **impact study** and comparative study
  - Launching Kilisun in **two new countries**





# *Penye nia, pana njia*

*Where there is a wish, there is a will*



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**Asanteni sana**

