



*Science, Art, Community: Building
Interactive Understanding of
Albinism in Tanzania*

Funded by



MAZOEZI YAKAPAMBA MOTO, TIMU YA
WASANII IKAANZA KUJIFUA VILIVYO....

MMH
UNACH-
EZA VIZU-
RIII...

PIGA
NGOMA
AAAA



NDIOOOO,SAFI KABISA...LAZIMA
TUWAELEMISHE WATU KUA BINADA-
MU WOTE NI SAWA.....

Funded by The Wellcome
Trust UK

Project Lead:

Standing Voice

Lead Partner: Coventry
University, UK

Co-Partners: Bagamoyo
Creative Arts Institute
(TaSUBa); African
Institute for
Mathematical Sciences
(AIMS) Tanzania



Facts on albinism in Tanzania

- 16,477 people with albinism live in Tanzania
- SV research on Ukerewe Island [2016] demonstrated average monthly income of \$41 a month [national average: \$76]
- SV skin cancer data reveals a 23% presentation of skin cancer amongst PWA in some locations of Tanzania
- 76 murders reported since 2006, 72 survivors, 1 abduction, 21 grave violations (160 reports in total)
- No specific legislation targeting the protection of persons with albinism

‘Science, Art, Community’

KEY ACTIVITY: artistic interactive community engagement performances *grounded in scientific fact on the genetic inheritance of albinism.*

2 KEY OUTCOMES:

- **OUTCOME 1:** Engagement of civil society in dialogue, which uses scientific fact to challenge and change damaging stereotypes and stigma
- **OUTCOME 2:** A shift in community engagement techniques towards interactive engagement grounded in science



Burundi

Tanzania

Mombasa

Dar es Salaam

Maswa Game Reserve

Kigosi Game Reserve

Moyowosi Game Reserve

Ugalla River Game Reserve

Katavi National Park

Kizigo Game Reserve

Rungwa Game Reserve

Usungu Game Reserve

Ruaha National Park

Mikumi National Park

Kigoma

Kazuramimba

Kalemie

Kirungu

Kasenga

Pepa

Kaputa

Mporokoso

Mpanda

Namanyere

Chala

Sumbawanga

Kizwete

Mtai

Mbala

Tabora

Sikonge

Itigi Manyoni

Dodoma

Mpwapwa

Kilosa

Morogoro

Mikumi

Iringa

Ilula

Ifakara

Rujewa

Makambako

Mlimba

Arusha

Karatu

Marangu

Voi

Usangi

Samburu

Lushoto

Korogwe

Tanga

Zanzibar Town

Bagamoyo

Malindi

Watamu

Kilindini

Kilwa Masoko

6



Rwanda

Burundi

Tanzania

Ruaha National Park



Activities implemented in Bagamoyo and Ukerewe

- 2 workshops (Bagamoyo & Ukerewe) for scientists and creative artists on genetic origins of albinism & interactive performance ideas
- ‘Spontaneous acts of culture’ - interactive play performances and call-and-response songs performed without warning in communities where stigma is known to be high
- Play involved the ‘game of chance’ – juggling black and white balls to demonstrate genetic chance

The approach to change:

1. **OUTCOME 1: Engagement of civil society in dialogue**



- interactive performances



- Engagement of the engagers: a cross-fertilisation of expertise between scientists and performance

2. OUTCOME 2: Shift in community engagement techniques

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- partners model their own initiatives on this project, based on the project's founding principle that

↑

- partners value and learn the methods used in this project

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- partners develop a new awareness of: the genetics of albinism, inheritance patterns, the experiences of people with albinism

Who are these partners?:

- **Tanzanian/Ugandan/Zambian performance artists (musicians, actors/actresses, dancers)** [performed in communities]
- **Tanzanian fine artists** [recorded activities]
- **Tanzanian film makers** [recorded activities]
- **Tanzanian audio-recorders** [recorded activities]
- **Albinism association leaders** [hosted the team]
- **Scientists** [provided scientific training to engagers]
- **Partner organisations** [engaged with activities]

COMMUNITY ENGAGEMENT – THE RISKS



ONESHU LIKAANZA KWA NGUVU ZOTE. MSANII RAS SIX AKAPANZA KUONESHA CHECHE ZAKE HUKU AKIIMBA.....

NINA ALBINISM....
NILIPATA KWA BABA
NILIPATA KWA MAMAA

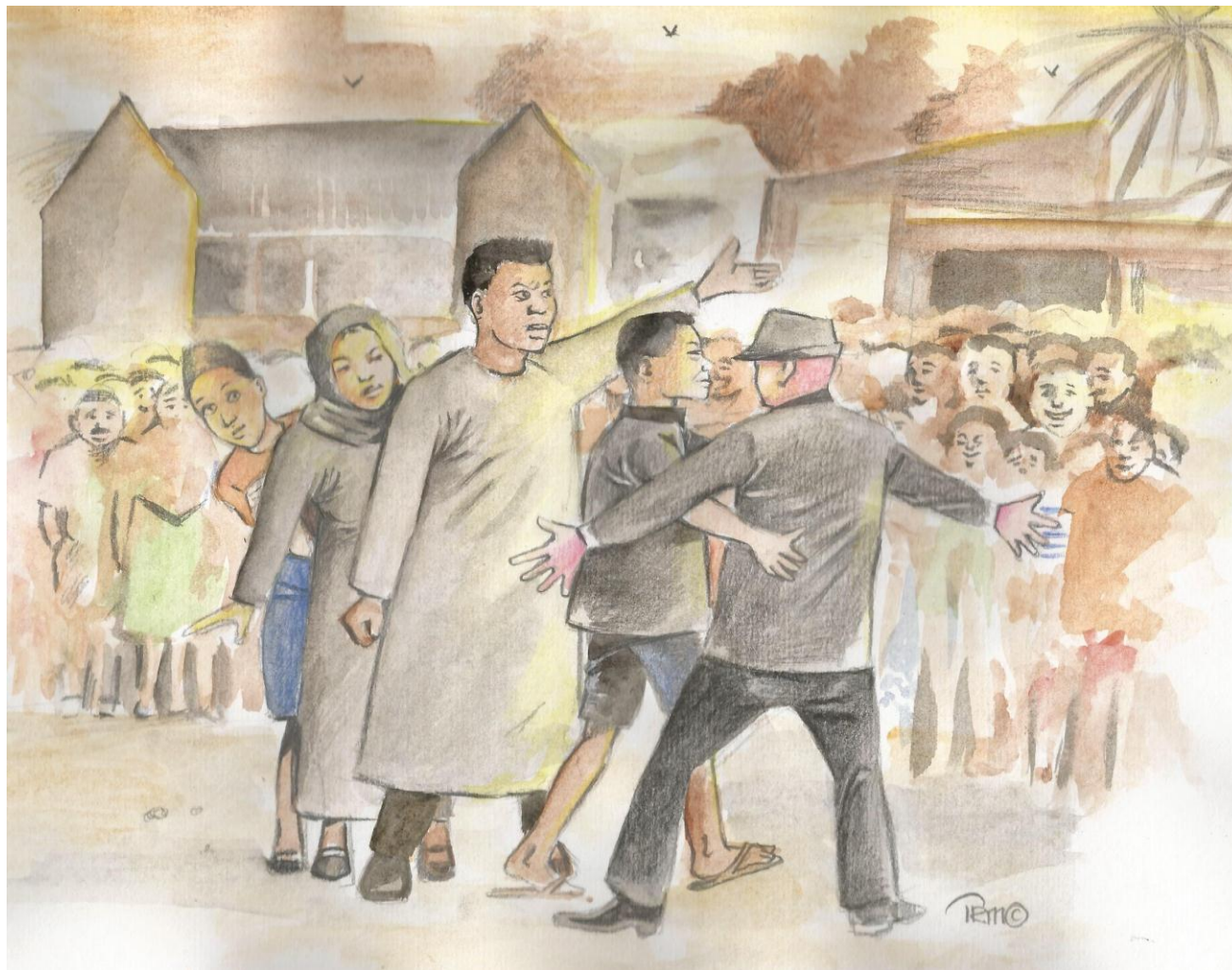
NINA
ALBINISM
.....

NILIPATA KWA BABA
NILIPATA KWA MAMAA



Actor sings: *'I have albinism, from my father and mother...'*

Audience in response to song: *'I have albinism'*



Audience member: *'The Albino wants to rape her'*

LAKINI HALI ILIKUJA KUBA-
DIRIKA BAADA YA MKE
KUJIFUNGUA MTOTO MWE-
HALI YA UALBINO.....HEBU
TUONE ILIKUAJE.....



Scene from the engagement play:

*Husband abandons wife for having a
child with albinism*

Audience: 'Wow, that's not right!'

BABA AKAWA MKALI NA
AKAMFUKUZA MKE.....

MH!

SIO
HAKI

NASEMA
ONDOKA
MIE SIWEZI
KUZAA ZE-
RU ZERU

LAKINI
MUME
WANGU
HUYU NI
MWANAO



SOME KEY FINDINGS

- **Engaging the engagers proved effective** – artists (performers as well as recorders of the activities – became engagers of their society
- **Clear and simple** concepts worked best (e.g. ‘the game of chance’)
- **Interaction** was key and resulted in:
 - A. positive testimony from audience
 - B. Follow on discussions amongst and with the community following the engagement
- Collaborations between artists and scientists **require time for knowledge transfers** – confusion did arise in preparation phase
- Making the engagement **entertaining** worked – dancing and music after the engagement

Work showcased in this presentation was provided by:

- ARTIST: Theophil Reginald - theofeelme@gmail.com
- FILM MAKER: Christian Maganga - drchristianmaganga@gmail.com

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- Dr Patricia Lund of Coventry University (lead partner)
- Mr. Melkiades Banyanka, music teacher and administration coordinator at TaSUBa and co-lead performance director
- Mr. John Sagatti, drama and music instructor at TaSUBa and co-lead performance director
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- TaSUBa performance arts students
- AIMS students
- Tanzania Albinism Society
- Prime Minister's Office of the United Republic of Tanzania