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

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Project Lead:
Standing Voice

Lead Partner: Coventry University, UK
Co-Partners: Bagamoyo Creative Arts Insitute (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
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

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   - interactive performances

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   - Engagement of the engagers: a cross-fertilisation of expertise between scientists and performance
2. OUTCOME 2: Shift in community engagement techniques

- 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

- 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
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’
Scene from the engagement play:

*Husband abandons wife for having a child with albinism*

Audience: ‘Wow, that’s not right!’
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)
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