

Science, Art, Community

Building Interactive Understanding of Albinism in Tanzania

# Evaluation Report



**“it is by chance they are who they are,  
and we are who we are, not by choice”**

‘Creative advocacy brought us together [...] to learn and to understand the issues around albinism, and the challenges people with albinism encounter each day of their lives. We collectively explored and discussed possible means and ways to address those challenges [and...] intervene [against socially] constructed myths [...] it was a wonderful avenue [...] to strive for inclusion, for people to understand albinism and genetics, and [for the empowerment of] our fellow Tanzanians to speak up, advocate for change, and edify community aggressors through creative performances, debates and conversations. [It] is by chance they are who they are, and we are who we are, not by choice [...] thus people with albinism need to be respected, loved, protected and included.

Thank you to the Wellcome Trust, Standing Voice,  
TaSUBa, the Ukerewe Albinism Society.

Together we will overcome! Asante Sana.’



## INTRODUCTION

Albinism is a genetic condition poorly understood in many African societies. People with albinism face particular persecution in Tanzania, where myths about the condition are rife. Using the science of genetics, this project sought to fight ignorance and generate better understanding of albinism as a genetically heritable condition.

Bringing together scientists and artists from across the UK and Africa, the project explored the biomedical facts of albinism and the best strategies for communicating these to the Tanzanian public through interactive cultural forms. Recognising and harnessing the particular prevalence of oral traditions within many African societies—storytelling as a way not only to record history, but also to broker solutions to social problems—this project used indigenous cultural practices to spark public dialogue around science.

Renowned musicians with albinism from Tanzania, Uganda and Zambia travelled to Bagamoyo and Ukerewe Island in Tanzania to work alongside artists from the Bagamoyo Creative Arts Institute (TaSUBa) and students from the African Institute for Mathematical Sciences (AIMS) Tanzania. Art, music, dance and theatre were employed to articulate the scientific coordinates of albinism in interactive and socially accessible ways. In all, three workshops and 15 public engagement events were held, with a direct primary audience of 3,250 and an online secondary audience of 33,444.



Project implementation was a demonstration of what can be achieved when stakeholders from different realms of expertise combine forces. This project aimed to use science to fight ignorance in local communities and generate an improved understanding of albinism as a genetically heritable condition. Crucially the project brought together African scientists, performance artists, fine artists, filmmakers, audio specialists and albinism association representatives to achieve this aim. By exposing these actors to the scientific origins of albinism while mobilising their respective forms of disciplinary expertise, the project was able to situate these civil society actors as change-makers capable of triggering shifts in community perceptions of albinism. In essence, the project trained and activated the most able engagers in society to tackle their own society's ignorance.

## IMPLEMENTATION

Implementation involved the following actions:

### 1. The formation of a diverse and experienced public engagement team

Name	Institution/organisation	Role
Jon Beale	Standing Voice UK	Project Manager
Harry Freeland		Creative Director
Sam Clarke		Project Communications Manager
Alex Magaga	Standing Voice Tanzania	Local coordination
Dr Patricia Lund	Coventry University	Lead Bio-Scientist: expert leadership on performance content relating to genetic inheritance
John Sagatti	TaSUBa	Performance management and script development
Melkiades Banyanka		
Mark Roberts	AIMS Tanzania	AIMS Tanzania Coordinator: expert leadership in on performance content relating to mathematical chance
Naomi Kollenge	AIMS Tanzania	Performance content relating to mathematical chance
Laurette Mhianga		
Alexis Arakaza		
Peter Nabutanyi		
Christian Mganga	TaSUBa	Filming and editing team
Baraka Mtoheve	TaSUBa	Filming team
Rodney Machange		
Daines Mwangamila	TaSUBa	Audio team
Edger Msyani		
William Mseti	TaSUBa	Drama/Music
Dorice Ahmed	TaSUBa	Drama
Colimba Malecela		
Chiku Robert	TaSUBa	Drama / dance
Theophil Reginald	TaSUBa	Fine art
Sixmond Mdeka	Independent musician – Tanzania	Drama / music
John Chiti	Independent musician – Zambia / Albino Foundation of Zambia	Drama / music



Name	Institution/organisation	Role
Peter Ogik	Independent musician – Uganda / Source of the Nile Union of Persons with Albinism	Drama / music
Ramadhan Khalfan	Ukerewe Albinism Society (UAS)	Local coordination and community engagement
Theresa Phinias	Ukerewe Albinism Society (UAS)	Drama / music / local community engagement
Elias Sostenes		
Charles Kalilo		
Paschal Merumba		
Vedastus Zangule		
Avelina Zangule		
Sospeter Zacharia		
Ezekiel Zacharia		
Neema Kajanja		
Alphonse Kajanja		
Riziki Julius		
Chihiro Tagata Fujii	Photographer - Japan	Photography
Josh Beattie	Independent filmmaker – UK	Filming team

Much of the success of this project can be derived from the geographical and disciplinary diversity of this team, which saw a coalition of specialists collaborating to develop and invest in African capacity and expertise.

2. Three public engagement workshops held in Tanzania for project team members to explore the biomedical facts of albinism, and strategies for engaging the public in dialogue around those facts through interactive artistic forms

Taking place in Bagamoyo in June 2016, and on Ukerewe Island in November 2016 and June 2017, workshops focused on the following:

- The genetic origins of albinism (led by Dr Patricia Lund of Coventry University)
- Theory of mathematical chance (led by AIMS students)
- Dramatic techniques for illustrating the genetic origins of albinism and theory of chance inheritance (led by John Sagatti of TaSUBa)
- Composition of an interactive performance narrative (led by John Sagatti of TaSUBa)
- Composition of interactive songs (led by John Sagatti of TaSUBa)
- Artistic methods of recording the project – film, fine art and Photography (led by SV)

3. Interactive community performances

Interactive community performances were developed and implemented in three phases:

- I. Training (June 2016)
- II. Delivery of comprehensive interactive narrative (November 2016)
- III. Further development for scale-up (June 2017)



## PHASE I: TRAINING

Phase I was implemented in Bagamoyo in June 2016. This involved the introduction of new concepts of genetic inheritance to the project team in a week of workshop sessions held at TaSUBa. The sessions, conducted both in English and Swahili, focused on explaining how albinism is genetically inherited, then exploring narrative options to convey this information in a way that invites audience response. The team then tested the performance in a bustling Bagamoyo fish market: the aim was to practise delivering a spontaneous community performance, using call-and-response techniques to promote audience interaction and shared control over the narrative conclusion. This also gave our team's artist a chance to test his recording of the community engagement in pictorial form, and our audio team a chance to test their audio recording and participant interview approach. These forms of documentation were conveniently 'low-profile' for an early test performance of this kind, enabling us to preserve spontaneity and generate an impression of real events unfolding, thereby providing an unfiltered window into community attitudes and an exciting glimpse of the constructive possibilities afforded by immersive theatre. (This 'guerrilla-style' spontaneity bore the additional benefit of enabling performances to take place without extensive logistical planning, and at low cost. Later on in the project lifecycle—once the strategy of spontaneity had been established among performers—we selected specific opportunities to document delivery further through still photography and film).





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## PHASE II: DELIVERY OF INTERACTIVE NARRATIVE

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Phase II involved comprehensive implementation of interactive community performances on Ukerewe Island in Mwanza Region. This still required the provision of a workshop to fine-tune the narrative and performance strategy that had been developed in Phase I. The performances on Ukerewe typically began with a scene that appeared real, to attract a large audience and invite audience participation. This usually involved a confrontation between two characters. This proved highly effective in eliciting unrestrained community engagement and response, which was recorded with audio equipment and captured in sketches by the team's fine artist. In each performance, an actor stepped into the scene to play the role of MC, leading the audience through a story that explored the genetic origins of albinism. The narrative used in each performance charted the life of a man with albinism wishing to have a relationship with a black woman, and the rejection of that man by the woman's father. In each performance, the man with albinism used the fact that both his parents were black to demonstrate how albinism is a recessive gene. This part of the narrative was delicate to construct, and here is where Dr Patricia Lund's expertise was essential, as were the contributions of representatives from AIMS Tanzania. The team worked to ensure the narrative conveyed genetic inheritance and the concept of chance in a comprehensible way. This was ultimately achieved using 'the game of chance', where black and white balls representing genes were juggled and combined in different formations to illustrate how one may be a carrier of the albinism gene but not have albinism oneself.





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### PHASE III: FURTHER DEVELOPMENT FOR SCALE-UP

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Phase III took implementation to the next level by using the trained project team to in turn train community members in performance-based public engagement, with the genetic inheritance of albinism as a central concept. People with albinism and their friends and families—ordinary villagers from across Ukerewe Island—became the deliverers of engagement, using their own experiences as a foundation for performance development. What ensued was a widening (and deepening) of our source material to encompass real stories and situations inspired by the lives of our contributors. Training villagers to understand the science of albinism, and to engage their own communities in productive exploration of that science, moreover helped to produce a trail of change-makers across Ukerewe Island itself. By decentralising the very action of advocacy, Phase III extended beneficiary ownership of the project and shifted the centre of gravity away from specialists in favour grassroots advocates and mobilisers: a promising stride toward sustainability and encouraging evidence of this pilot’s scalability.



4. Production of filmed and audio-recorded outputs for dissemination to all four audience tiers for further dialogue

The project team has produced the following artistic outputs, which explore the genetic origins of albinism:

- Drawings based on the community performances
- A short film produced by the TaSUBa student film team
- A short project film produced by our UK editor
- A community performance narrative complete with composed songs
- Audio recordings of community performances
- Photographs of implementation



## METHODOLOGY

Our evaluation plan was developed in line with the project Theory of Change, which determines the ultimate intended outcome this project sought to achieve, specific outcomes achievable within the project timeframe, and necessary steps to achieve these specific outcomes.

Our evaluation tools sought to ascertain the impact of our project on each of our audience tiers, and to determine if and how those impacts facilitated achievement of project outcomes featured in the Theory of Change. These tools included interview questions designed to measure changes in participants' knowledge and attitudes following project implementation; observational sketches of project performances; film footage of rehearsal and performance development; audio recordings of all aspects of implementation including community interviews; questionnaires inviting participant reflection 18 months after the first phase of implementation; and online metrics to calculate global reach.

Our evaluation tools were intended to measure impact on each of our audience tiers:

- A. Individuals with a foundation of scientific or medical knowledge, who may not be well informed about albinism
- B. Formally educated professionals with no specific biological or scientific training
- C. Members of the public with limited formal education
- D. Global audience

Our methods of evaluation corresponded to particular audience tiers:

- Analysis of interviews before and after implementation (Tiers A, B, and C)
- Analysis of pictorial, audio and video representations of implementation (Tiers A, B, and C)
- Analysis of performance outputs (Tiers A, B, and C)
- Analysis of team questionnaires (Tiers A, B, and C)
- Analysis of global/online dissemination responses (Tier D)

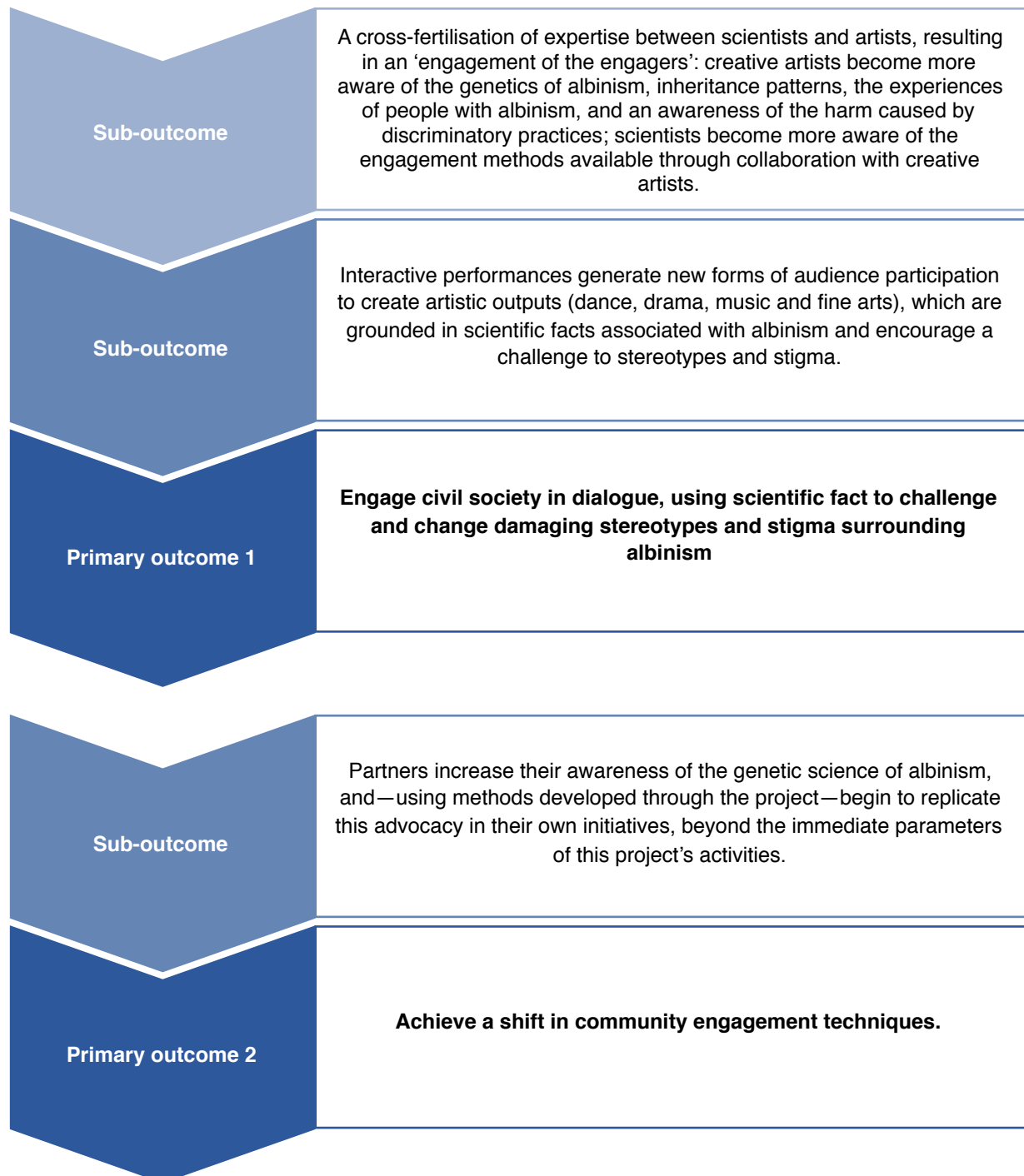




## THEORY OF CHANGE

This project was guided by a theory of change comprising two primary outcomes.

To accomplish these outcomes, the project team identified and sought to realise a chain of causally connected sub-outcomes, which, together, could be deemed preconditions for the achievement of the primary outcomes. This evaluation report uses established success indicators and evidenced findings to explore and examine progress toward these primary and sub-outcomes.







## PRIMARY OUTCOME 1: ENGAGE CIVIL SOCIETY IN DIALOGUE, USING SCIENTIFIC FACT TO CHALLENGE AND CHANGE DAMAGING STEREOTYPES AND STIGMA SURROUNDING ALBINISM

**Sub-outcome 1:** Interactive performances generate new forms of audience participation to create artistic outputs (dance, drama, music and fine arts) that are grounded in scientific facts associated with albinism and encourage a challenge to stereotypes and stigma

### Indicator 1: Audience's existing understanding of albinism and experience of participating in public engagement initiatives

Method	Evidence
Audio-recorded interviews before and after the project actions with audience members to record any change in their understanding and experience, including but not limited to: understanding of the biological aspects of albinism; experience of participating in public engagement initiatives that generate dialogue around albinism by involving the public in the creative process	<p><b>Dehumanising attitudes and ignorance of the genetic origins of albinism:</b>  <i>[Interview with local woman before performances]</i> 'I remember when we were growing up... we didn't believe they were normal people with normal origins. They could disappear at any moment'  <i>[Interview with local Bagamoyo women before performances]</i> 'In our community if you see someone with albinism you spit on yourself like this so you don't get infected'; 'people say albino people do not die they disappear'</p> <p><b>Community realities - Violent abuse resulting from dehumanisation:</b>  <i>[Interview with local Bagamoyo man before performances]</i> 'People chop off their limbs. They say they can be used for mystic rituals, in mines. For example by boiling the body people believe mines will be profitable'</p> <p><b>Positive transformation of these attitudes:</b>  <i>[Interview with Jenson Safina on Ukerewe following performance – MONO-010.wav]</i> '[I have learnt] We mustn't ostracise albinos, we should protect them. We shouldn't call them bad names'  <i>[Interview with girl following Ukerewe performance – MONO-006]</i> 'Albinism occurs as a result of [melanin] deficiency'</p>

### Indicator 2: Creation of dialogue within artistic outputs that challenges damaging stereotypes and stigma around albinism

Method	Evidence
Assessment of progressive input level from our four audience tiers into the artistic outputs produced at the public engagement event and recorded as physical, audio or visual art forms. This involves assessing the ratio of input between performers and the four audience tiers. (Progressive input may be considered input that both adds meaning to the creative output and invites further input from others)	<p><b>Audience participation revealing community perceptions:</b>  <i>[Drawn scene in Bagamoyo fish market capturing audience reactions to scene]</i> Fish market stallholder in reaction to acted fight: 'The albino wants to rape her'  Captured in audio form (eg. file MONO-006.wav)</p> <p><b>Captured in drawings of community performances</b>  Engagement in dialogue on the concept of chance:  <i>[Recording of community performance on Ukerewe island – MONO-006.wav]</i> MC: 'Did you choose to be the way you are?' Women in response: 'No'</p> <p><b>Engagement in dialogue on the genetic transmission of albinism:</b>  <i>[Recording of community performance on Ukerewe island – MONO-006.wav]</i> MC: 'So the mother gives her child the gene that doesn't produce melanin, and the father gives the child the gene that doesn't produce melanin. What will their child be like?' Audience: 'Albinism'</p>

### Indicator 3: Level of online engagement with disseminated creative outputs

Method	Evidence
Compiling of online dialogue relating to creative outputs	<p>Tier D of our audience remained permanently engaged for the duration of this project through a plethora of regularly distributed online content including articles, images and videos, sharing accounts of project delivery and testimonies from participants and partners</p> <p>Through Standing Voice's digital platforms, the project received a total of 33,445 audience impressions and 780 engagements. ('Impressions' refers to the number of times content was accessed, and 'engagements' to the number of audience interactions such as likes, comments, and shares.) Facebook allowed for 12,616 impressions and 526 engagements; Twitter for 16,682 impressions and 128 engagements. Exposure—another content-sharing platform populated mainly with photo stories—afforded 3,629 impressions, while Standing Voice's direct email marketing secured a further 518 impressions and 126 engagements</p> <p>Online commentary was overwhelmingly positive, with specific descriptors including "Wonderful", "Amazing", and "A great collaboration and initiative"</p> <p>A private project page was created on Facebook to enable team members to disseminate outputs internally and share updates of progress around performance development. This dedicated online space also fostered solidarity across this highly international team, enabling continuous remote engagement between phases of direct implementation in Tanzania</p> <p>This positive online engagement—internally within the project team and externally with a wider global audience—helped to develop the capacity of performance deliverers, thereby consolidating creative outputs. This link between online dialogue and output creation could be strengthened and more closely interrogated with additional funding and scaled delivery</p>





**Sub-outcome 2:** A cross-fertilisation of expertise between scientists and artists, resulting in an ‘engagement of the engagers’: creative artists become more aware of the genetics of albinism, inheritance patterns, the experiences of people with the condition, and the harm caused by discriminatory practices; scientists become more aware of the engagement methods available through collaboration with creative artists

### Indicator 1: Artists’ and scientists’ understanding of albinism and experience of participating in public engagement initiatives

Method	Evidence
Filmed and audio-recorded interviews before and after the project actions with audience members to record any change in their understanding and experience, including but not limited to: understanding of the biological aspects of albinism; experience of participating in public engagement initiatives that generate dialogue around albinism by involving the public in the creative process	<p><b>Transformed understandings amongst project team:</b></p> <p><i>[Interview with Daines Mwangamila]</i> ‘Before this workshop I was very afraid of albino people... in this project I learned that albin[ism] comes by chance’</p> <p><i>[Interview with Doris Ahmed]</i> ‘In this workshop I have learnt how albinism occurs – I mean how these people are born’</p> <p><i>[Interview with Peter Ogik]</i> ‘I knew that albinism is an inherited genetic condition. But I didn’t know that it is all about chance’</p> <p><i>[Interview with Sixmond Mdeka]</i> ‘The learnings from the workshop can positively affect my music because I will go very deep [into this issue]. [...] I learnt that albinism is just a condition; it is not a disability. Before, my knowledge of albinism was not deep, but now I know that my genes have caused my albinism, not witchcraft or a curse like many people believe. I learnt what albinism is scientifically and the balls practice play made me understand how a baby with albinism [is] born, but my favourite lesson is knowing that a child with albinism is the result of both parents having albinism genes inherited from their parents and the circle goes on and on and on from generation to generation!’</p> <p><i>[Interview with Theophil Mnyavanu]</i> ‘The project helped me to discover the strength and the power of my art.’</p> <p><i>[Interview with Melkiades Banyanka]</i> ‘I have gained knowledge and understanding about persons with albinism, and new experience in project coordination.’</p> <p><i>[Interview with Christian Maganga]</i> ‘I had a little knowledge about [...] albinism [but] I didn’t know that it happens by chance [...the expert’s] explanation expanded my mind’</p> <p><i>[Interview with John Chiti]</i> ‘I got a deeper understanding of albinism especially on the scientific part. The game of chance has till this day stuck in my mind. I learnt how to explain albinism scientifically. I also learnt how to use art especially drama in engaging the public. As a musician I already knew how to use music in awareness but didn’t know much about how to involve drama. [...] I have learnt about the genes. How a person is born with albinism. And how a black person with normal pigmentation can have a [child] with albinism’</p> <p><i>[Interview with Peter Nabutanyi]</i> ‘Some of my colleagues who participated in the project actually confessed to having wrong perceptions about people with albinism since their childhood and this was a turning point to them.’</p> <p><i>[Interview with Dr. Patricia Lund]</i> ‘A key difference in the creative advocacy project compared with other approaches I have tried in Africa is the physical engagement and involvement with the community audiences in real time. Other approaches, such as radio dramas, posters and information booklets are static; feedback via phone in programmes and discussion groups was usually after the event, not immediate. In this project, the audience had the opportunity to influence and respond to the drama.’</p> <p><i>[Interview with Riziki Julius]</i> ‘People enjoyed our show. People would laugh; sometimes they would be sad. They would shout out as we performed; they would say ‘no’ if something wasn’t right. The nature of the performance meant they were free to engage and be part of it. This is different to just ‘teaching’ people about albinism. Instead, people were creating their own message, and spreading it to others. I think this project should be spread to other villages across the mainland’</p> <p><i>[Interview with Ezekiel Zacharia]</i> ‘I think interactive performance really engages people; it is in my opinion the most powerful way to connect with the audience and activate a change of attitude. It helps to build community understanding of albinism. The messages resonate with the community especially when people with albinism themselves are involved in the performances. After our performances, we left behind a community discussion about albinism; people even asked us to go back and perform again to reach more people. I think this should be extended and happen in all villages across Ukerewe Island’</p> <p><i>[Interview with Abelina Zangule]</i> ‘I learned that community perceptions of albinism can change if adequate education is provided in simple ways like the interactive performances.’</p> <p><i>[Interview with Paschal Merumba]</i> ‘The interactive performances were so much fun. We people with albinism felt it was an excellent way to communicate with our community. The message was clearly delivered and its impact was huge. I would love to be involved again.’</p>

## PRIMARY OUTCOME 2: ACHIEVE A SHIFT IN COMMUNITY ENGAGEMENT TECHNIQUES

**Sub-outcome 1:** Partners increase their awareness of the genetic science of albinism, and—using methods developed through the project—begin to replicate this advocacy in their own initiatives, beyond the immediate parameters of this project’s activities

Indicator 1: Project approach (using dialogue to challenge and change damaging stigma around albinism) is replicated by partners

Method	Evidence
Compile examples of replication over the project lifecycle	<p><b>A strong pattern of increased [informed] advocacy among project team members:</b></p> <p>Through the project, three musicians from across East Africa (Sixmond Mdeka: Tanzania; John Chiti: Zambia; Peter Ogik: Uganda) were connected and trained in advocacy techniques with specific regard for the scientific origins of albinism. They have since collaborated on advocacy-oriented music projects</p> <p>Following this project Elias Sostenes performed songs about the realities of having albinism at WOMAD Festival (as part of the Tanzania Albinism Collective). The songs performed reflect the project’s approach to challenging stereotypes about albinism</p> <p>[Interview with Theophil. Mnyavanu] ‘[this project] increased [my] willingness of being an ambassador who can give education to the societies about albinism’</p> <p>[Interview with Laurette Mhlanga] ‘I enjoyed the outreach program and given the chance, I would love to continue educating the general population about albinism. [...] Working on the albinism AIMS project made me realise I enjoyed public health more than the finance pathway I was targeting. Currently I am registered with the global health department in Stellenbosch and I am pursuing a PhD in Epidemiology.’</p> <p>[Interview with Christian Maganga] ‘I am a filmmaker student I hope one day I will make a film about albinism, but all was from the project, it taught me a lot and it drives me as a filmmaker to keep on making things about albinism and albino challenges as my contribution to my brother and sisters with albinism condition. [...] I can confidently [stand] in front of people to teach and explain about albinism especially by using the game of black and white balls that stand for human genes.’</p> <p>[Interview with John Chiti] ‘The project also helped me to increase my networking as I interacted with new people. [...] I am still friends with the people I met such as [Peter and Sixmond] and we have continued to work together. This is because of the platform the project provided for us. [...] As a director I have been able to teach my team in Zambia about how to use science and art in engaging the public on albinism. We have copied and tried to use the same method and it’s working well. I have taught the rest of my team about the game of chance which they have been able to use in raising awareness.’</p> <p>[Interview with Peter Nabutanyi] ‘That was my first experience and I got to know practically what public engagements are. The project opened my eyes to unexploited approach of passing information through public engagements. From that time, I have participated in two other related engagements, one with Math Camp in Tanzania on how to use Mathematics in solving everyday problems targeting secondary schools as the audience and the second one on sensitizing the society about persons with special needs in Uganda. I learnt how to approach and pass on information in a simple and effective manner. On the other hand, I am now able to get attention and views of individuals from the general public on a specific matter at hand. Professionally, after that project, my interest in working on albinism project with Mark while at AIMS, "Effect of Genetic Drift on Albinism in Sub-Saharan Africa: A Case Study of Tanzania Mainland" increased as I had seen the practical relevance of my research.’</p> <p>[Interview with Dr. Patricia Lund] ‘This joint exploration with such a multi-disciplinary team was an exciting opportunity for me as a bio scientist to share my knowledge of genetics and work alongside those with creative skills to find imaginative ways of getting these messages across. For this project I was delighted to work with a young and enthusiastic team from the vastly different disciplines of creative arts. This generated an energy and exchange of viewpoints that was synergetic and productive, leading to exciting and innovative outputs. [...] Capacity building was a key aspect of this project and an effective model for working in other countries in the region.’</p> <p>[Interview with Charles] ‘[in] the villages where we went, people were asking us to go back as they felt more people must see the performances’</p>







## ASSUMPTIONS

Our project Theory of Change was guided by two assumptions:

- 1) Dance, drama, music and fine arts that involve an audience in a participatory fashion have the ability to generate open dialogue around sensitive issues by involving the public in the creative process itself
- 2) When grounded in scientific facts relating to albinism, this dialogue can be harnessed to challenge and change damaging stereotypes and stigma surrounding the condition

We found both assumptions to be highly applicable based on the level of audience involvement in the public engagement. Early on in implementation we decided to focus the audience participation on the dance, drama and music. The audience still participated in the creation of fine art by simply being the subject of that art. For example, the artist (Theo Reginald) recorded audience reactions and statements in his drawings, which were sketched in situ. We found this to be the best course of action, as this freed up the audience to be fully immersed in the interactive theatre, which was performed without warning in places of local significance, such as village centres or markets.

The result of involving the audience in the dance, drama and music in ways captured in the evaluation table resulted in open dialogue both during (audience statements or call-and-response) and after performances (eg. interviews) on sensitive issues. One of the most powerful examples of this involvement of the audience in the creative process (thereby giving them ownership over the progressive conclusions of the narrative) was in a fish market in Bagamoyo. This was the first team performance and began with a staged fight that attracted hundreds of market-goers. The fight was between a man with albinism and the father of his girlfriend, who disapproved of the man's relationship with his daughter due to his albinism. The immediate reactions were one of assumed wrongdoing by the person with albinism in the scene, with one man shouting, 'The albino wants to rape her!' As the narrative progressed the audience settled, and the MC discussed the genetic inheritance of the condition. At the end of the narrative, the MC allowed the audience to decide the conclusion and asked 'What should the father of the girlfriend do?' to which a man shouted 'Why shouldn't he be with her? What's wrong with that? Let them be together!' Allowing the audience to resolve the conflict in the narrative was repeated in multiple performances in Bagamoyo and Ukerewe to similar effect, demonstrating how the collective reaction of the audiences was transformed through immersion in the creative process.

Furthermore, it appears to be the dialogue around scientific fact that prompted this transformation in attitudes: as there is a clear differentiation between audience responses before the MC explores genetics (i.e. 'The albino wants to rape her!') and following the explanation of genetics ('Let them be together!') In other instances, the project team had elders approach them following the performances asking for further clarifications, and in some instances desperate to discuss the facts in more detail. This demonstrated that it was the scientific facts that really grabbed people's attention. One man who was keen for further conversation with the team expressed that he had 'never before been aware of all this', though he was now a very old man who had spent his whole



life with people with albinism in his community. He expressed shock at his own ignorance. For him and evidently others, immersion in the creative process had captured his attention and engaged his interest, whilst the performance's exploration of solid fact had effected significant shifts in his own understanding, which had previously been bound by stereotypes and stigma.

## KEY FINDINGS

The project evaluation reveals our approach to public engagement was completely new to the majority of participants and audience tiers. Only one team member had previous experience of implementing community engagement performances grounded in scientific fact, and this individual still reported that the project had a profound impact on his understanding of albinism. Team testimonies reveal that both artists and scientists were unaccustomed to public engagement in the manner implemented.

Analysis of team interviews reveals that our artists had limited understanding of the scientific origins of albinism, whether they were students at TaSUBa or musicians with albinism from Zambia, Tanzania and Uganda. It was striking that though our musicians from Zambia and Uganda were both leaders of their albinism associations, they still demonstrated significant gaps in their knowledge of albinism. As individuals with the capacity to conduct far-reaching advocacy and public engagement—through their music and through their association leadership—this was particularly of interest to the project management team. It was also clear that students from AIMS had limited understanding of how to imbue their academic research with practical relevance. Both team interviews and the project outputs (specifically observational sketches of performances; film footage; and narrative and musical compositions) demonstrate knowledge acquisition across the entire team, both on the subject of albinism itself and on strategies for public engagement and sensitisation. This newfound ability was dependent on the cross-fertilisation of expertise between scientists and artists, as evidenced by team testimonies and an analysis of outputs. For example, output analysis reveals that musicians who demonstrated ignorance about genetic inheritance before implementation successfully engaged the public on that topic during community performances. This is also evidenced by the testimonies of community members who were engaged in the performance. Many of these audience members demonstrated knowledge acquisition around the genetic origins of albinism as a result of their exposure to interactive performances, and were remapping their assumptions about people with albinism in light of this.

The project team's interviews with local communities before implementation revealed a causal link between ignorance about the scientific origins of albinism and stigma. Many interviews established that myths and misperceptions around albinism can derive from inadequate exposure to science, such as the belief that inheritance of albinism can be avoided by spitting on oneself. Subscription to beliefs like these marks a total departure from the scientific reality of recessive genetic inheritance, dehumanising persons with albinism.

Project evaluation revealed that interactive community performances grounded in scientific fact can successfully generate open dialogue around albinism, and that such dialogue can debunk myths and install alternative concepts that situate albinism in a scientific light. The audio recordings and

observational sketches of those performances evidence this process. The spontaneous implementation of performances in public spaces meant our audiences were accessed at random: this enabled us to reach a broader cross-section of society and avoid ‘preaching to the converted’, engaging individuals with no designated interest in—or connection to—this cause. In most cases, the narrative performed was pliable and open-ended so that audiences could determine its conclusion. The audience’s favourability toward the protagonist with albinism—and endorsement of a positive or negative denouement—similarly became a proxy for shifts in public perception. In one scenario, the audience called out derogatory remarks initially, before turning to support the protagonist in the closing stages. This dynamic is revealed both in audio recordings and drawn representations of the performance, and was repeated throughout the implementation process. Crucially, the audience was invited to determine the narrative conclusion only following engagement on genetic inheritance. Audience and team interviews reveal that the concept of ‘chance’ inheritance was key to reshaping perspectives on albinism. In particular, the knowledge that one can ‘carry’ albinism genetically without having the condition oneself was a powerful catalyst for audiences’ reconsideration of what albinism is.

In summary, our project evaluation reveals the team successfully engaged civil society in dialogue grounded in scientific fact, and subsequently successfully challenged and changed damaging stereotypes and stigma surrounding albinism. The change in damaging stereotypes is clearly evidenced in post-performance interviews with audience members, and in the evolution of audience responses during performance delivery.





The project evaluation also reveals a marked development in team members' professional activities immediately following implementation. This development is evidenced in team interviews and through an analysis of team members' professional activities following the project. Results include new regional collaborations between creative artists, such as an advocacy song recorded by three team members immediately following implementation in Bagamoyo. The artists involved represented Tanzania, Uganda and Zambia and have since been invited to perform at the inaugural Albinism Festival in Conakry, Guinea in April 2018. Reflecting on his intentions for the joint song, 'What Do You Say Now?', John Chiti provided the following insight: "We didn't want to do the usual complaining in the song, rather we wanted to be positive and bring out albinism in a positive way. The main concept of the song is that we the singers have made it in life as stars, celebrities and heroes. We are successful people regardless of our condition. We are even inspiring other people in our society. So now we go back to those who used to laugh at us, those who discriminated [against] us because of [our] albinism. They thought we [couldn't] do anything because of having albinism. Now we ask them: what do you say, now that I am a star? What do you say now? You were wrong about me."

We have also observed renewed enthusiasm for robust and socially relevant research to expose and publicly clarify the genetic science of albinism in communities divided by stigma. This is demonstrated by one participant's study into the effect of genetic drift on albinism in Tanzania, and his new appreciation for the "practical relevance of [his] research", which he directly attributes to the impact of this project. We conclude this evidenced development in participants' professional activities constitutes a further channel of constructive engagement with wider society around the genetic science of albinism.

Whilst the project evaluation evidences successful achievement of project outcomes, our dissemination process identified emergent challenges that will be particularly pertinent in the scale-up of this pilot. During a meeting held with the Tanzanian Prime Minister's Office, the Deputy Minister responsible for disability committed to supporting scale-up of this project by engaging television broadcasters for nationwide advocacy broadcasts. Adapting our outputs for television would manifest new challenges relating to the immediacy of engagement and promotion of participatory dialogue with audiences. Negotiating this difficulty requires discussion with the project team prior to future scale-up.

The intended scale-up of this project will also seek to mitigate any limitations identified thus far. An identified limitation of the pilot pertained to the channelling of responses from our global audience into creative outputs on the ground in Tanzania. During community performances, the team was able to receive and react to audience engagement on the spot. This process of involving the audience in the creative process itself ensured the performance was a joint exploration of albinism through science. Securing that joint exploration is more complex when engaging a global audience. The project's online reach is very positive, but future scale-up of the project would seek to incorporate online responses more tangibly into the development, delivery and dissemination of outputs.







## AUDIENCE ENGAGEMENT AND DISSEMINATION

- A. Students and teachers (of mathematics and science); healthcare professionals: individuals with a foundation of scientific or medical knowledge, who may not be well informed about albinism

The project team reached Tier A through a robust engagement of the AIMS student body, which comprised one of the main public engagement events conducted by the project team in Bagamoyo. The feedback from AIMS students demonstrates that the project had a positive impact on the professional outlook of these scientists. During scale-up we seek to develop further avenues to strengthen our engagement of the medical community.

- B. Students and teachers (of other disciplines); journalists and media personnel; politicians and policymakers; lawyers; social welfare workers; religious leaders: formally educated professionals with no specific biological or scientific training

The project team reached Tier B through community performances in local districts and schools. On Ukerewe Island, two community performances focused solely on community primary schools, inviting strong engagement from students.

In addition, we saw a strong engagement from young media and journalism professionals at TaSUBa, which was a positive direct result of working so closely with TaSUBa. In addition, we were pleased to have positive engagement with the Prime Minister's Office, which pledged support of future project scale-up and recommended converting performance outputs into televised engagement tools.

In anticipation of future scale-up, we are considering plans to strengthen our engagement of religious leaders.

- C. Villagers; farmers; small business owners: members of the public with limited formal education

Tier C was engaged extremely effectively through interactive public performances, many of which were performed completely spontaneously in open-air village spaces. Across the 15 public engagement events, an estimated primary audience of 3,250 people was reached. Ordinary villagers were some of the most vocal contributors to performance development and delivery. In Phase III of implementation, villagers on Ukerewe Island were also trained as performance deliverers, intensifying their engagement with the science of albinism and empowering them to act as ambassadors speaking out against ignorance and division in their communities.

- D. Global audience

Tier D of our audience was continuously engaged with a range of online content including articles, images and videos. These provided updates on project progress and circulated direct testimonies from participants.

Through Standing Voice's digital platforms, the project received a total of 33,445 audience impressions and 780 engagements. ('Impressions' refers to the number of times content was accessed, and 'engagements' to the number of audience interactions such as likes, comments, and shares.) Facebook allowed for 12,616 impressions and 526 engagements; Twitter for 16,682 impressions and 128 engagements. Exposure—another content-sharing platform populated mainly with photo stories—afforded 3,629 impressions, while Standing Voice's direct email marketing secured a further 518 impressions and 126 engagements. Online commentary was overwhelmingly positive, with specific descriptors including “Wonderful”, “Amazing”, and “A great collaboration and initiative”.

In addition to the remote dissemination achieved digitally, Standing Voice was delighted to share the progress of this project directly with a wider global audience through a series of international appointments throughout 2016 and 2017. In June 2016, Project Manager Jon Beale shared project conceptualisation and delivery plans with the entire delegation at 'Action on Albinism in Africa': a UN-led forum, co-delivered by Standing Voice, that facilitated the exchange of best practices and recommendations between expert representatives from 29 African countries and an array of disciplinary fields. In March 2017, the project's local coordinator Alex Magaga visited Naivasha, Kenya, to attend a three-day International Engagement Workshop coordinated by the Wellcome Trust, sharing implementation updates in a presentation that was recorded and later uploaded to online collaborative open-access community engagement platform Mesh. This was followed in June 2017 by a project showcase at the Wellcome headquarters in London, delivered by Jon Beale and Sam Clarke of Standing Voice. Jon reflected on the journey of the project from inception to implementation, while Sam came fresh from the field with the latest updates on performance development and delivery in Tanzania. The team enjoyed further opportunities to platform the project in June 2017, at the London Symposium on Albinism in Africa at the University of Westminster, and again in September, when Sam Clarke presented reports of the project in its closing stages at the United Nations in Geneva, during an Experts' Workshop on Witchcraft and Human Rights (which was live-streamed and later housed online via United Nations Web TV). The impressions and engagements cumulatively secured through this schedule of international appointments are difficult to quantify precisely, but will no doubt number in the tens of thousands at minimum. More significantly, disseminating project findings across this diversity of fora yielded exciting opportunities for partner feedback, enabling the production of a rich and thorough evidence base from which to launch future replication and scale-up of this pilot.





## LOOKING FORWARD

We have identified two areas for development to be prioritised in future scale-up of this pilot.

We found it difficult to tangibly embed the responses of our global audience into the creative process unfolding on the ground in Tanzania. The ability to react to a physically present audience's remarks makes community performances a very powerful method for establishing dialogue. It is this dialogue that offers the space for a joint exploration of albinism and its scientific origins. As there is a dialogue present, the conclusions drawn are partly owned by the audience and therefore more likely to be remembered and considered. However, a global audience presents a new challenge, as this audience responded to the project in hindsight; therefore the moment for dialogue during the creative process had passed. Physically present audiences had the chance to define the narrative conclusion giving them ownership over the artistic output created in that moment of interaction. Again, this ownership was central to the concept of engagement rather than simply feeding information to the audience. The online audience had no such power to define creative outputs during implementation. This was a limitation we seek to work on moving forward, and we are considering potential strategies to overcome this challenge. This may include the creation of an artistic output over a longer period offering the global audience opportunities to actively participate in its execution. This takes the concept developed at the local level to an international scale.

Additionally, we would like to develop our process for selecting implementation locations. The choice was made to implement in Ukerewe and Bagamoyo based on area-specific facts that were already known and understood, such as the high number of attacks against people with albinism in Mwanza Region. However, we would like to develop this process of geographical selection to involve more consultation with partner organisations, including albinism associations, prior to implementation. This flexibility would also allow us to react to evolving contexts, such that we could implement the public engagement in areas where an attack was very recently reported, or a similar incident of relevance had occurred.



This project has unfolded at a critical time in East Africa. A decade after news of the egregious human rights violations facing Africans with albinism first surfaced in the international press, reports of violence and abusive social exclusion continue. The increased visibility of albinism within global discourse around human rights has not always been reflected with parallel empowerment of people with albinism and their families at the grassroots level. This is a deeply marginalised and misunderstood population, whose genetic condition continues to trigger ridicule, suspicion and violence in many communities across Tanzania and beyond.

Tackling this problem at its difficult structural root, this project has devised a formula to strike at the core of communities with memorable and impacting advocacy. Uniting and building universal capacity for a diverse network of stakeholders, the project has empowered communities to claim ownership and accountability over the plight of persons with albinism, and posit their solutions to manifold challenges encountered by this group. Poised on the cusp of art and science, this project has provided an enabling interface for people with albinism to speak back to their societies and forge alternative pathways of understanding. Positively received by its participants and audiences, this pilot has been an urgent and timely intervention whose impact has rippled across East Africa. Developing these efforts on a wider geographical scale will provide further capacity development for implementing partners, and invaluable reinforcement in the fight to empower persons with albinism in Africa.





## A WORD OF THANKS

Standing Voice would like to extend sincere thanks to the project partners who all excelled in achieving implementation to a high standard. The core partners of this project were:

- Coventry University [Lead Partner]
- The Creative Arts Institute of Bagamoyo (TaSUBa) Tanzania
- The African Institute for Mathematical Sciences (AIMS) Tanzania

In addition, the project benefitted hugely from collaboration with the following civil society organisations:

- The Source of the Nile Union of Persons with Albinism (SNUPA)
- The Albino Foundation of Zambia (AAF)
- The Ukerewe Albinism Society (UAS)

The project team would also like to express gratitude to the Government of Tanzania for its receptivity to this project and endorsement of its future replication.

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**‘Our performances really touched people. You could see an instant reaction from the audience. Our approach instigated a change of perceptions.’**

Charles Karillo

**‘This co-creation that transcends the world of science and the arts brought together complementary skill sets and generated a good deal of positive energy, resulting in vibrant community engagement events.’**

Patricia Lund

**‘It’s not easy to marry scientists, artists and musicians to explain the genetics of albinism. But this project made it possible.’**

Peter Ogik

**‘I saw audiences dancing, clapping and sympathising with us during our performances. This was a sign that the message we took to the public was well received.’**

John Chiti

**‘[Collaborating with] different professionals—scientists, mathematicians, perform[ers], visual and creative artists—[was totally new for me, and different to previous...] activities I have been involved in’**

Sixmond Mdeka

**‘The feedback from the communities we engaged was positive both in Bagamoyo and Ukerewe...They appeared to understand our message easily. I think the combination of science and art that we employed was essential in making our points understood easily.’**

Melkiades Banyanka

**‘The chance to have been part of [this] team was enlightening. Most of the stories we hear [about albinism] seem to be fables, but [working] hand-in-hand with the affected subpopulation made me realise the depth of the problem and the need for interventions. [...] I have learnt that we are all equals.’**

Laurette Mhlanga







