

# Education experiences of children and young persons with albinism in Malawi

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COMMONWEALTH  
SCHOLARSHIPS

Exploring trusts and tensions of un/belonging in lived experiences of children and young persons with albinism

# Research objectives

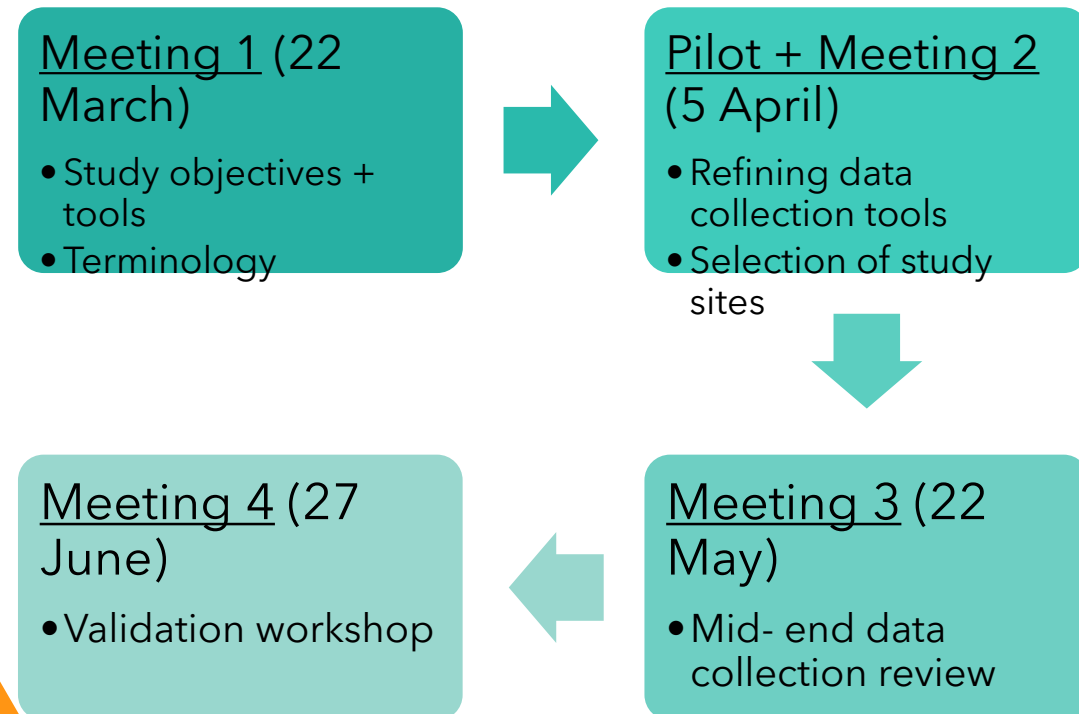


This study aims to:

- (i) explore enablers and barriers to sense of belonging for children and young PWA;
- (ii) amplify and centre voices of young PWA through collaborative knowledge-making using participatory approaches

# Participatory approach: Research Advisory Group

## Research advisory group meetings



## Value of RAG to the study

4 members (3 were PWA with lived experience)

- Terminology: persons with albinism, children with albinism (*ana achi alubino*) not people living with albinism.
- Accessibility of research materials
- Safety / safeguarding issues
- Gate keepers in accessing and recruiting participants
- Refining data collection tools,

Selection of study sites:

Lilongwe – urban + rural

Zomba – urban

Blantyre – rural

Kasungu – rural

### Pilot study

- 4 children with albinism + 4 parents
- Lilongwe rural

# Methodology

Tools	N = 85 (participants)
Participatory workshops <ul style="list-style-type: none"> <li>• FGD</li> <li>• Participatory Drawing</li> <li>• Poetic inquiry</li> </ul>	11 (two were one-on-one) <ul style="list-style-type: none"> <li>• 38</li> <li>• 9 (2 did both drawing &amp; poetry)</li> </ul>
One-on-one interviews <ul style="list-style-type: none"> <li>• Children / young PWA</li> <li>• Social networks of PWA</li> </ul>	<ul style="list-style-type: none"> <li>• 36</li> <li>• 25</li> </ul>
Key informant interviews	12

## Participants

48 - Children & young PWA	25 - Social network	12 - KII
<ul style="list-style-type: none"> <li>• 3-9years - children with albinism</li> <li>• 10-19years - adolescents with albinism</li> <li>• 20-23years - young PWA</li> </ul>	<ul style="list-style-type: none"> <li>• Fathers - 2</li> <li>• Mothers - 14</li> <li>• Friends - 16</li> <li>• Grandmothers - 1</li> </ul>	<ul style="list-style-type: none"> <li>• Department of disability &amp; elderly persons               <ul style="list-style-type: none"> <li>• Ministry of Justice</li> </ul> </li> <li>• Malawi police</li> <li>• MaCoHa</li> <li>• APAM</li> <li>• KCH Cancer centre</li> <li>• Community leader</li> <li>• Department of special needs</li> <li>• Teachers</li> </ul>



**Research project:**

Exploring lived experiences & sense of belonging among children & young persons with albinism in Malawi

**Modes of inquiry:**

Participatory Visual Methods



# Findings

**Poetry** and **Drawings** produced by children and young persons with albinism in Malawi

# Themes that emerged from the PVR data

- Skin / colour / colourism
- Resilience
- Belonging
- Un/Safety
- Family relationships
- Barriers to education
- Inclusive teaching
- Skin health
- Visual impairments
- Community policing
- Rural vs urban welfare
- Exclusion from sports
- Derogatory labels



Ine nda jamba nu mbyi Chifumba  
Jamba tete za



Being black in a white vessel  
Whites can't accept me,  
So do the blacks  
Do I exist in a Vacuum?

Being black in a pale light vessel!  
Always undervalued  
where are my privileges?  
Considered in complete being  
is that fair to you?

Being black in a white vessel  
I am also capable,  
given a chance I can take  
the gut to meet level  
I am black in a white vessel



Palibe kusiyana pakazi pamunhu  
wolumala ndi wakugakuga-  
tanse ndife chifaniziro chamungu.

Palibe Kusiyana-  
Tanse ndife amodzi  
Tiyeni zikondene kuzi nafeso-  
Chimwenwe chatku chioneka-

Palibe Kusiyana-  
Abau zikondeni, zilandien-  
musobisale mukazeto.  
nafeso zikhala okondwa  
Palibe kusiyana

palibe kusiyana-  
chanu chikondi ziwonetseteni.  
nafeso chatku chikondi ziwonetseta,  
Titebezereho.

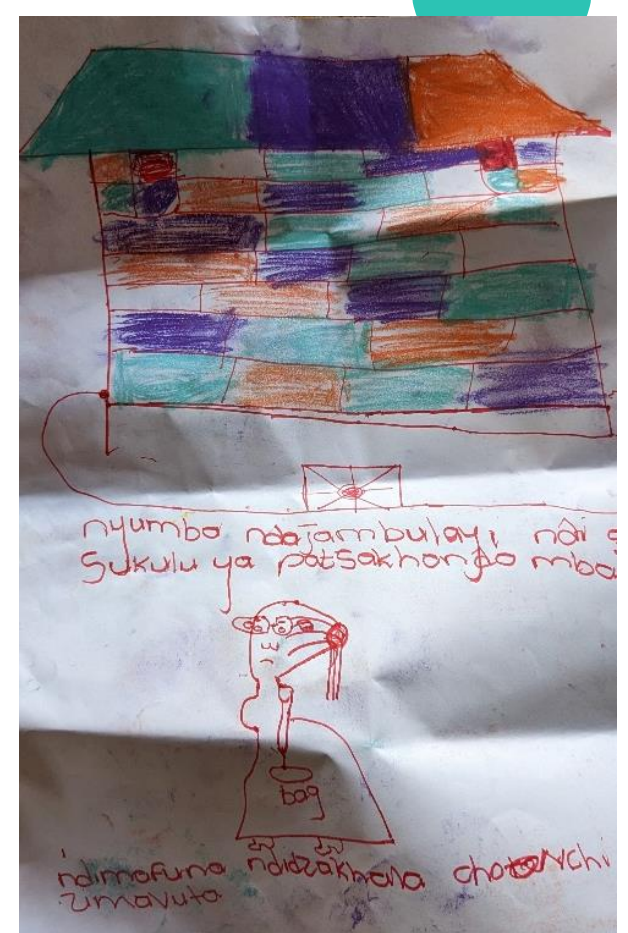
palibe kusiyana.

# Low vision & visual impairments

*"The weakness with schools in the village is that firstly, there are so many pupils. Having a lot of pupils made it hard for me to raise my challenges to the teacher about not seeing what's written on the chalkboard clearly."* **Girl, 14, Blantyre rural**

Inclusive practices mentioned were:

- teachers enlarging their handwriting on the chalkboard,
- giving learners with albinism the option of learning braille,
- printing exam papers in large font and,
- having desks of CYPWA positioned in the very front of the class nearest to the chalkboard



*"...here at school, I had a teacher who honestly treated me well. When I couldn't see on the chalk board the teacher would give me a personal textbook and the teacher would even allow me to take textbooks home, and I'd return the book the next day. This teacher honestly really helped me"* - **Girl, 16 years, Lilongwe urban**

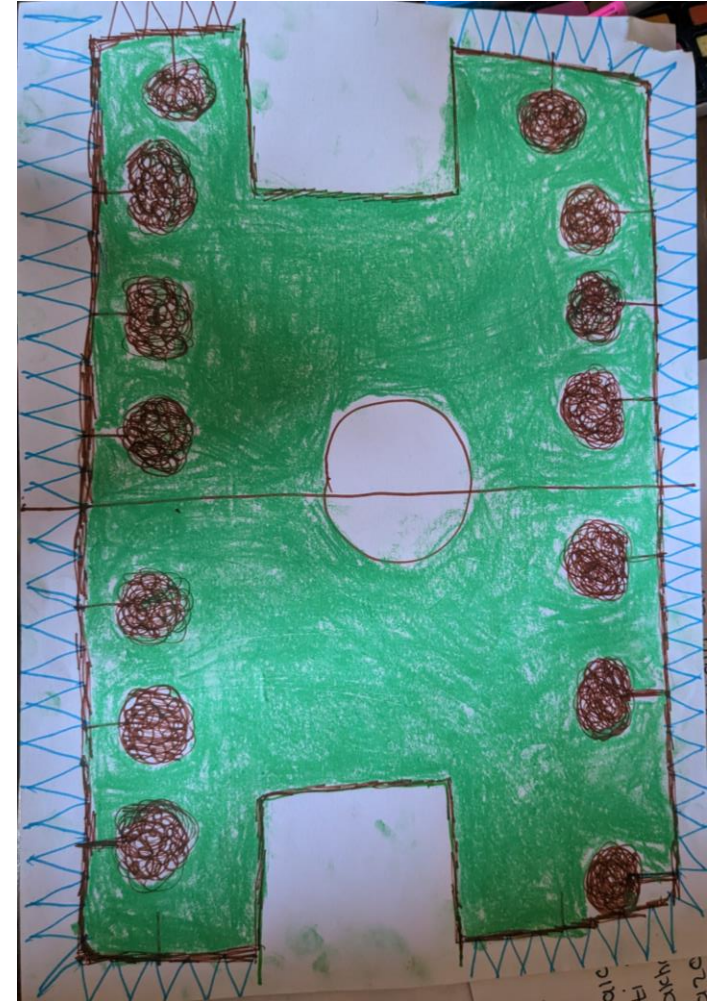
*"I picked this spot myself. I was given a special desk where I sit"* - **Boy, 12, Blantyre rural**



# Skin health: outdoor activities & sports participation



*"I've drawn a ground because when people come, they can play there. I've also drawn a fence around it there so that they can find shade [from the sun]" - **Girl, 14 years, Kasungu rural***



# Responses against labelling & stigma

I too can

Have my voice amplified on the radio

## I too can

10, boy with albinism

Teach and be happy.

Songs blasting

I too can

Drive a fancy car.

To my office of work

Since I don't care

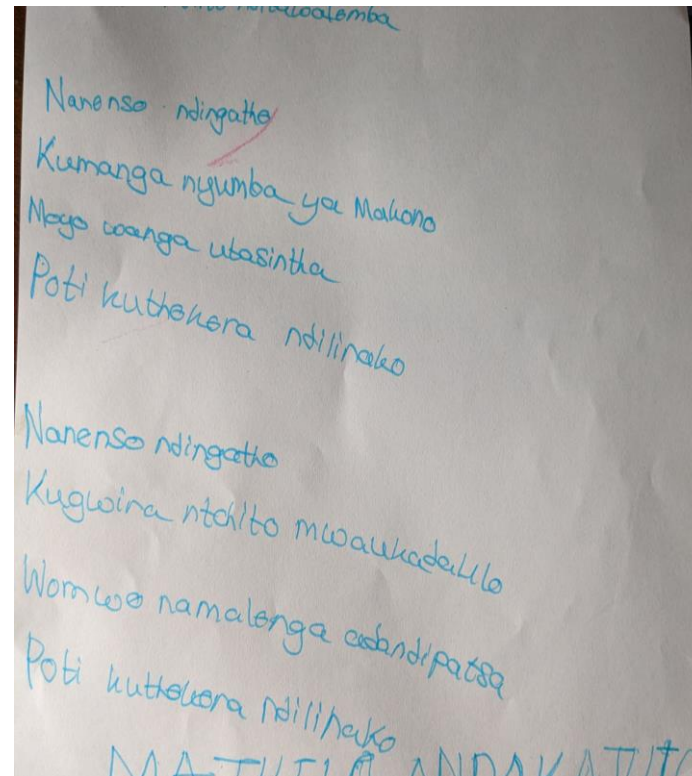
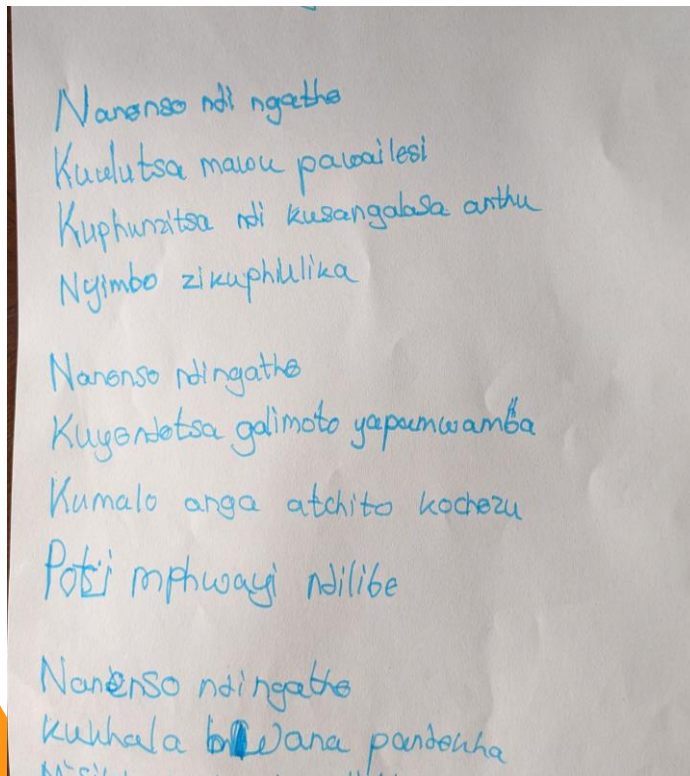
Become an independent boss!

With a store full of goods

I too can, build a modern house.

My life transformed.

I have the capability, I too can.





A movie recommendation for you

# Thank you!



## Flickr gallery:



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