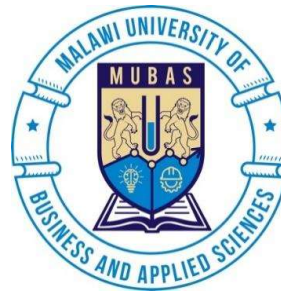


Persons with Albinism: Voices and Experiences (PAVE) Malawi

- ▶ Paul Lynch ¹
- ▶ Christopher Hand ¹
- ▶ Bonface Massah ²
- ▶ Owen Mchekeni ²
- ▶ Tuntufye Juma ²
- ▶ Jenipher Mbukwa Ngwira ³

- ▶ ¹ School of Education, University of Glasgow
- ▶ ² Standing Voice, Malawi
- ▶ ³ Department of Applied Education, MUBAS



1

Background

- ▶ Albinism is widely misunderstood
 - ▶ Those with the condition are at greater risk of physical and social violence that impacts their education and livelihood (UN, 2024)
- ▶ Discussions have focused on the lack of protection of persons with albinism
 - ▶ Their freedom to enjoy the same rights -- without discrimination from others -- in their communities and schools.
- ▶ The Government of Malawi Vision 2063 (2020) explicitly recognises the right of education, facilitating meaningful exploration of the above challenges.
- ▶ Additionally, a recent report by the UN General Assembly Human Rights Council highlights the need to invest into ensuring learners with albinism can operationalise their right to education.

2

3

Current Study & Research Questions

- ▶ Small University of Glasgow grant ([GCID](#); ≈£19k; 6 months) to gather pilot data and work towards developing a larger bid.
- ▶ Using a co-created, multi-method, multi-stakeholder approach to answer key research question(s):
 - 1) What are the challenges and opportunities facing today's children and young persons with albinism, and what might be the implications for psychological wellbeing and education in 2030?
 - 2) What is the level of albinism literacy among parent/caregivers and educators, and their understanding of children / young persons' specific needs?
 - 3) How can positive change be achieved for multiple beneficiaries (i.e., young persons, families, educators, communities, policy makers, etc.)?

3

4

Co-Creation Visit

- ▶ June 23rd till June 28th 2024
- ▶ Planning meetings held at Standing Voice, Malawi offices
 - ▶ Design, Sampling, Materials and Procedures
 - ▶ E.g., Appropriate language for information & consent sheets; large print / 'spaced' materials
 - ▶ Financials, Permissions, and Logistics
- ▶ Four school visits over two days
 - ▶ Lilongwe and Mchinji Districts
 - ▶ Head Teachers, Classroom Teachers, learners
- ▶ Visit to Ministry of Education, Malawi (Inclusive Education Department)



4

Design and Participants

- ▶ Three FGDs with teachers
 - ▶ [15 teachers; 10 female, 5 male]
- ▶ One-to-one interviews with 8 parent-caregivers
 - ▶ [PCRs; 4 female, 4 male]
- ▶ Four FGDs with learners
 - ▶ [26 learners; 11 female, 15 male]
- ▶ Learners also completed individual Learner Worksheets
 - ▶ Today's presentation will focus on the data from the individual Learner Worksheets
- ▶ Data was collected in the week beginning 25th November 2024



5

Learner Biographics

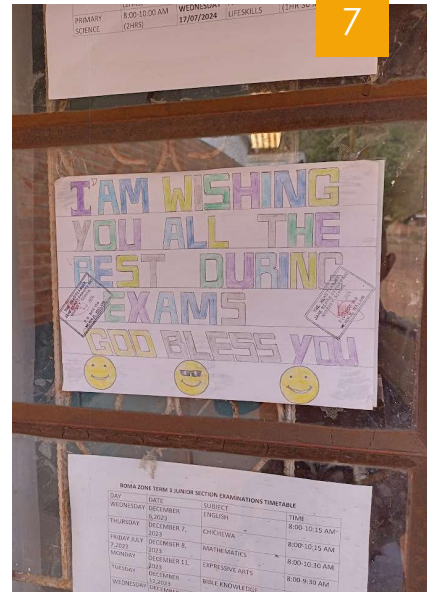
- ▶ 26 Learners
- ▶ 11 Females, 15 Males
- ▶ Mean Age = 13 years, 11 months
- ▶ Youngest Learner = 8 years old
- ▶ Oldest Learner = 19 years old



6

Learner Biographics

- ▶ 20 Primary Learners
 - ▶ 1 Learner @ P2; 3 Learners @ P4;
 - 3 Learners @ P5; 4 Learners @ P6;
 - 3 Learners @ P7; 5 Learners @ P8
- ▶ 4 Secondary Learners
 - ▶ 1 Learners @ S1; 1 Learner @ S2;
 - 2 Learners @ S4
- ▶ 1 Vocational Learner
- ▶ 1 No Data



7

7

Learner Worksheets – Section 1

8

- ▶ 13 questions about various facets of everyday life, particularly schooling and social interaction
 - ▶ travel to school; making friends at school; learning in class; break or lunch break; bullying at school; 'name-calling' – *kupatsidwa dzina*; travelling home from school; bullying / name-calling outside of school; using social media; cyber-bullying; personal safety; personal healthcare

Please tick or circle the emoji or set of emojis that best express how you normally would feel about the following situations. Remember – if you don't want to answer, that's fine. Just leave the rows blank.

1. What do you feel when you travel to school?

Joy	Anticipation	Anger	Don't know
Sadness	Surprise	Fear	No emotion






8

9

Learner Worksheets – Section 2

- ▶ 13 questions; same domains of everyday life, but focussing on valence and strength of feeling

How do you feel about...

travelling to school?				
				
Very Negative	A little Negative	Neither Negative nor Positive	A little Positive	Very Positive

9

10

Learner Worksheets – Section 3

Please rank the following themes in terms of their importance to you right now.

Please mark a 1 beside the most important, a 2 beside the next most important, and so on.

The research assistant can help you.

School	
Friends	
Family	
Work	
Play / Fun & Games	
Money	
Health	
Food and Drink	
Bullying	
Being Online	

Please rank the following things in terms of their likely importance to you when you have finished your current stage of schooling.

For example, if you are currently in Primary School, thinking about what is important after Primary.

If you are in Secondary School, what will be important after you have finished.

Please mark a 1 beside the most important, a 2 beside the next most important, and so on.

The research assistant can help you.

School	
Friends	
Family	
Work	
Play / Fun & Games	
Money	
Health	
Food and Drink	
Bullying	
Being Online	

10



11

Findings – Learners’ Worksheets

11

Learner Worksheets -- Findings

12

		Travel To School	Making Friends	Learning	Breaks	Bullying (School)	Name-calling (School)	Travelling Home	Bullying (Non-School)	Social Media	Cyber bullying	Safety	Health Care
Joy	😊	92%	92%	92%	85%	23%	27%	88%	35%	38%	4%	85%	73%
Anticipation	😬	8%	8%	4%	--	--	12%	--	4%	23%	12%	4%	27%
Anger	😡	--	--	--	4%	27%	23%	4%	23%	4%	19%	--	--
Sadness	😞	--	--	--	8%	27%	23%	--	19%	8%	27%	4%	--
Surprise	😲	--	--	--	4%	4%	--	--	--	--	--	--	--
Fear	😱	--	--	--	--	4%	--	--	4%	--	12%	--	--
No Emotion	✖	--	--	4%	--	--	--	--	--	4%	--	--	--
Don't Know	🙋♂	--	--	--	--	--	--	--	--	19%	12%	4%	--

12

13

Learner Worksheets -- Findings

		Travel To School	Making Friends	Learning	Breaks	Bullying (School)	Name-calling (School)	Travelling Home	Bullying (Non-School)	Social Media	Cyber bullying	Safety	Health Care
Very Negative	☹️	12%	--	--	4%	81%	73%	8%	77%	19%	77%	12%	4%
A Little Neg.	😞	--	--	8%	--	8%	8%	4%	4%	--	--	4%	--
Neutral	😐	4%	--	4%	--	--	--	--	--	8%	4%	--	--
A Little Pos.	🙂	15%	12%	4%	15%	--	--	15%	--	19%	4%	4%	4%
Very Positive	😊	65%	85%	81%	81%	12%	15%	69%	15%	50%	15%	77%	92%
No Response	✖️	4%	4%	4%	--	--	4%	4%	4%	4%	--	4%	--

13

14

Learner Worksheets -- Findings

Themes -- Now				Themes -- Future			
	Mode	Mean	St. Dev.		Mode	Mean	St. Dev.
School	1	1.5	1.2	School	1	2.0	2.3
Friends	2	3.7	2.4	Work	1	2.7	2.0
Family	3	2.8	1.2	Health	1	3.3	2.4
Work	4	4.8	2.2	Friends	2	3.7	2.5
Play / Fun	5	5.3	2.2	Family	3	3.5	1.6
Money	6	5.2	2.3	Money	6	4.2	2.2
Health	7	3.9	2.7	Play / Fun	7	5.4	2.2
Food & Drink	8	6.0	2.8	Food & Drink	8	5.1	3.1
Being Online	10	8.2	2.5	Bullying	9	7.3	3.7
Bullying	10	9.1	1.8	Being Online	10	8.4	2.9

14

15

Preliminary Discussion

- ▶ Reasons to be cheerful 😊
 - ▶ Learners describe many of their day-to-day experiences as Joyful
 - ▶ Including travelling to and from school, making friends, and learning in class
 - ▶ Safety, Personal Healthcare
 - ▶ These dimensions are typically associated with "Very Positive" feelings
- ▶ Ambiguity or Challenges 😞
 - ▶ Bullying inside and away from school, including cyberbullying, and social media
 - ▶ "Very Negative"
 - ▶ Anticipation and less-certainty around engagement with Social Media

15

16

Preliminary Discussion

- ▶ More 'agreement' / consistency in rankings of domains' importance now vs. future
 - ▶ Indicated by smaller standard deviations in rankings across domains.
- ▶ Subtle shifts in Current Priorities vs. Anticipated Future Priorities
- ▶ School / Education is seen as both a priority now, but also in future
- ▶ As expected, the perceived importance of Work increases in the future
- ▶ Health / healthcare makes a substantial 'climb' from present to future
- ▶ Being Online and Bullying are not seen as 'priorities' or particularly important to our learners with albinism either presently nor in their near futures.

16

17

Next steps

- ▶ Transcription and translation of FGD and Interview recordings
- ▶ Qualitative data analysis across data sets and participant groups
- ▶ Synthesis of findings across datasets
- ▶ Write up of end-of-grant report
- ▶ Dissemination
 - ▶ Publications
 - ▶ Conference Proceedings
- ▶ Reflective Review of Current Research
- ▶ Secure next-step funding
 - ▶ Upscale to Pan-Malawian sampling
 - ▶ Pan-Regional upscaling
 - ▶ E.g., Tanzania, Zambia, Zimbabwe

17

18

Thank you very much!

Zikomo Kwambiri!

Naonga chomene!

We would like to invite questions and receive your feedback

18

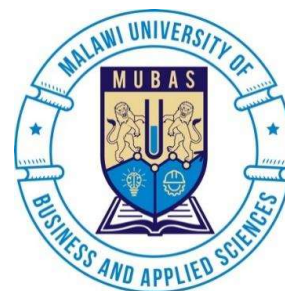
Acknowledgements

- ▶ The funding for this research was provided by the Glasgow Centre for International Development Small Grants Project.
- ▶ Ethical Approval via University of Glasgow College of Social Sciences
- ▶ We would like to acknowledge the support from:
 - ▶ The wider team at Standing Voice
 - ▶ Professional services colleagues in the School of Education at University of Glasgow
 - ▶ The Ministry of Education, Malawi (Inclusive Education Department).

19

Team Contact Details

- ▶ Dr Paul Lynch
- ▶ Paul.Lynch@glasgow.ac.uk
- ▶ Dr Christopher Hand
- ▶ Christopher.Hand@glasgow.ac.uk



20