Enhancing Community Engagement and Involvement through storytelling

Hearing the voices of those involved in global health research

National Institute for Health and Care Research

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"It is a beautiful thing to work together, to continue to work together, in a trusted, respectful and mutually collaborative way" – community member in TRANSFORM

1. EXECUTIVE SUMMARY

Context

The National Institute for Health and Care Research (NIHR) is committed to Community Engagement and Involvement (CEI) in Global Health Research (GHR), emphasising collaboration with communities affected by research outcomes. This approach aligns with the United Nations Sustainable Development Goals and the 'leave no one behind' agenda. Despite significant progress, NIHR recognises the need to further support researchers in engaging meaningfully with marginalised communities and demonstrating the impact of such engagement.

The concept of storytelling

Storytelling was introduced as a powerful tool to highlight the narratives of CEI in NIHR global health research projects[1]. It aims to showcase how community experiences and insights contribute to research outcomes, inspire mutual collaboration between researchers and communities, and strengthen the evidence base for the impact of CEI on global health research.

Better Decisions Together partnered with NIHR to pilot this storytelling project, engaging three NIHR-funded projects from the Research on Interventions for Global Health Transformation (RIGHT) Programme[2]. Workshops were co-designed with project teams and community members to create a space for storytelling, emphasising the inclusion of marginalised voices. This project demonstrates how the concept of storytelling can be applied in practice to draw out insights and perspectives to evidence the impact the research is having on community members' directly involved and in the local context within which the research is implemented.

"I give my story, to share where I am coming from, so that people can be seen as a whole" – Community Engagement Coordinator - ENHANCE

Stories of Impact

[1] Bauman, J.R. Maximize your research impact with storytelling. *Nat Rev Cancer* 23, 799 (2023). https://doi.org/10.1038/s41568-023-00616-z

[2] https://www.nihr.ac.uk/explore-nihr/funding-programmes/research-and-innovation-for-global-health-transformation.htm

Working meaningfully to include people from the most marginalised communities was a key feature of the stories across all three projects. The community members were able to incorporate aspects of their lives into the work of the projects to create effective communication and ongoing trusted relationships with researchers.

Impact on Community Members

> **"I have become stronger through my involvement in the Academy, I have made friends and feel as if I am part of a family" – Community Member - ENHANCE**

The storytelling workshops revealed significant positive impact on community members as a result of CEI activities, including:

- **Increased confidence and capacity**: involvement in research projects boosted community members' confidence and their ability to engage in various aspects of their lives. For example, a community member affected by stigmatising skin diseases shared a powerful story through images, illustrating her journey from isolation to reintegration within her community.
- **Health-seeking behaviour**: stories highlighted how involvement in research projects changed health-seeking behaviours, such as a community member with lymphatic filariasis who now receives medication and helps others access treatment.
- **Mental health support in slums**: a deeper understanding of mental health issues from their involvement, enabled community members to support their loved ones in seeking appropriate treatment, bridging traditional and medical approaches.

Impact on Research

> **"Stigma is killing the community, it is important to understand and respect the community before you can advocate for them" – Community Member, ENHANCE**

Community engagement and involvement also positively impacted the research process and outcomes:

- **Bridging communication gaps**: co-researchers from the community, particularly those affected by health conditions, played a crucial role in building trust and facilitating open communication between researchers and community members.

- **Traditional and medical integration**: stories demonstrated successful collaborations between traditional healers and medical practitioners, improving community health outcomes and encouraging referrals to health facilities.
- **Raising awareness**: workshops highlighted how CEI raised disease awareness, reduced stigma, and encouraged treatment referrals.
- **Inclusive spaces**: community spaces such as community kitchens provided inclusive environments for discussions, enhancing the effectiveness of involvement.

Impact on Health Policy and Practice

> "…When someone came to my store to buy a psychotropic medicine to help with their mental health, after being involved with TRANSFORM, I was able to help this person choose different medicine from the government suppliers."
> Community Member - TRANSFORM

CEI efforts contributed to influencing health policies and outcomes:

- **Increase in healthcare access and treatment uptake**: a community medicine seller worked with the project team to develop training to ensure all medicine sellers give the right psychotropic medication.
- **Health policy integration**: the Liberian Ministry of Health incorporated research findings into its Neglected Tropical Diseases Master Plan, emphasising community-based approaches to future intervention planning.
- **Empowerment and economic benefits**: CEI empowered individuals and groups to develop collaborative solutions, such as peer support groups producing and selling soap, and generating revenue to cover health costs. This shows how CEI can lead to economic and health benefits.

Key Learnings

The pilot storytelling project provided valuable insights and highlighted several key learnings:

- **Experiential learning**: storytelling offered an in-depth understanding of individual involvement that traditional impact assessment methods might miss, capturing the pathways to impact, by evidencing incremental changes in knowledge, attitudes, and behaviours.

- **Co-developed approach**: a collaborative planning process ensured respectful and relevant storytelling workshop formats, fostering a deeper understanding of the challenges faced by community members.
- **Senior researcher involvement**: engagement of senior research team members in the workshops facilitated a deeper appreciation of community issues, influencing future project planning.

Learning from the RIGHT Projects

- The RIGHT projects exemplified power-sharing and community empowerment, using tools like tablets and visual aids to enhance communication and support.
- CEI extended the reach and impact of health initiatives, encouraging community members to seek treatment and share their experiences.
- Community members' aspirations highlighted the importance of sustainable health and care systems, reinforcing the value of ongoing training and integration of traditional healers.
- CEI significantly contributed to stigma reduction and community reintegration, fostering new relationships and support networks.

> **"I want to stand on my feet and fight for others. I was in the darkness and now I am in the light" – Community Member – REDRESS**

Conclusion

The mutually beneficial aspects of CEI and storytelling contribute significantly to improving health and welfare, enhancing understanding among stakeholders, and achieving the NIHR's vision for inclusive and impactful global health research.

This storytelling pilot project provides a grounded contextual insight into how CEI plays out in the real world providing a richer understanding of CEI approaches. By revealing the far-reaching positive consequences of CEI, the project underscores the importance of documenting and sharing community experiences, and their contribution to maximising impact of NIHR funding.

2. INTRODUCTION

The National Institute for Health and Care Research (NIHR) is proud to acknowledge Community Engagement and Involvement (CEI) as integral to the ability of the Department of Health and Social Care (DHSC) to fund a diverse range and scale of Global Health Research (GHR).

The NIHR's GHR portfolio has continued to evolve and grow at a pace since it was set up in 2016. Over this relatively short period, the NIHR has successfully developed high-quality research management processes that provide the systems and people that enable research to thrive.

CEI has evolved to become an essential element of the portfolio. Engaging people and communities in GHR is increasingly recognised as being central to delivering ethically driven research. It is also considered a core element of the 'leave no one behind' agenda which underpins the United Nations Sustainable Development Goals (SDG)[3].

NIHR GHR portfolio uses UK Aid budget to fund various researcher-led, thematically focused and research capacity strengthening programmes. The focus of this report is the Research on Interventions for Global Health Transformation (RIGHT) programme which funds interdisciplinary applied health research in low- and middle-income countries (LMICs) on areas of unmet need where a strategic and targeted investment can result in a transformative impact.

RIGHT funds research on preventing ill health and optimising disease management in LMICs that are eligible for Official Development Assistance[4]. To date, the RIGHT programme has featured the themed programmes listed below:

- severe stigmatising skin diseases (SSSDs), epilepsy and infection induced cancers (RIGHT 1);
- mental health (RIGHT 2);
- multiple long-term conditions (MLTCs) (RIGHT 3 and 6);
- accidents and unintentional injuries (RIGHT 4);
- health systems strengthening in the context of extreme weather events (RIGHT 5); and
- early detection and management of metabolic risk factors for cardiovascular disease and stroke (RIGHT 7).

[3] https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind

[4] https://www.oecd.org/dac/financing-sustainable-development/development-finance-standards/daclist.htm

Community Engagement and Involvement in Global Health Research

As a core component of GHR, CEI is expected to be strategically integrated across the whole research life cycle. NIHR's vision for CEI is that all GHR is undertaken in collaboration with the communities who are most likely to be affected by the research outcomes, and that those who are marginalised should have a meaningful voice in the full range of the research. It is fundamental that all projects include the voice of people and communities in research prioritisation, planning, implementation and evaluation process. Involving communities in LMICs who are affected by the health challenge being researched improves the reach, quality, and impact of the research.

While the social determinants and other influencing factors of these health issues will vary widely according to cultural and geographic contexts, NIHR expects researchers to acquire a deeper understanding of the intersecting experiences of marginalisation, discrimination and inequalities faced by those most affected, if they are to have a transformative impact on health[5].

Telling the story of CEI in three Research and Innovation for Global Health Transformation (RIGHT) programmes

This pilot storytelling project aims to highlight the benefits and unrealised impact of CEI in GHR, by using capacity strengthening approaches that resonate with current award holders (as tested in a survey conducted to understand CEI learning needs).

This work has included two interconnected strands: peer support and storytelling. Both approaches offer transformative processes in which to connect and communicate between the researchers and the communities they are working with.

This pilot aims to achieve the following:

- support researchers and communities involved in research to reflect on their experiences and bring them to life through the power of storytelling;
- tell the story of CEI in the research project;
- inspire and motivate others; and
- provide shared learning

[5] Larson, E., George, A., Morgan, R., & Poteat, T. (2016). 10 Best resources on… intersectionality with an emphasis on low- and middle-income countries. Health Policy and Planning, 31(8), 964-969

"I give my story, to share where I am coming from, so that people can be seen as a whole" – Community Engagement Coordinator - ENHANCE

NIHR engaged Better Decisions Together to work with three GHR projects that are at different stages in the research delivery cycle. Working with each project, initial conversations were held in both small groups and one-to-ones to explore and identify specific areas of focus and to co-design a workshop format that would support a creative space for stories to be told.

Storytelling provides a powerful tool to deepen connection bringing researchers and communities together to communicate their diverse experiences in their own way and language.

The outputs of this work (this report and visual illustrations of the storytelling workshop discussions) are available to share the experience of CEI in three RIGHT projects. This is intended to:

- support greater understanding of the potential of CEI in GHR;
- contribute to a culture of creativity, innovation, and shared learning; and
- add to the existing evidence base.

RIGHT projects

The projects were chosen by considering several factors, including those from:

- across different RIGHT programmes (1, 2 and 3); to ensure they reflect different health themes
- in different geographical locations;
- at various stages in their research cycle; and
- use of a range of different CEI methods.

The three RIGHT projects identified to take part were:

REDRESS (RIGHT 1)

Strengthening people-centred health systems for people affected by SSSDs in Liberia. A research project aimed at strengthening people-centred health systems for people affected by SSSDs. The research aims to reduce illness, stigma, social exclusion, and poverty caused by SSSDs in Liberia.

TRANSFORM (RIGHT 2)

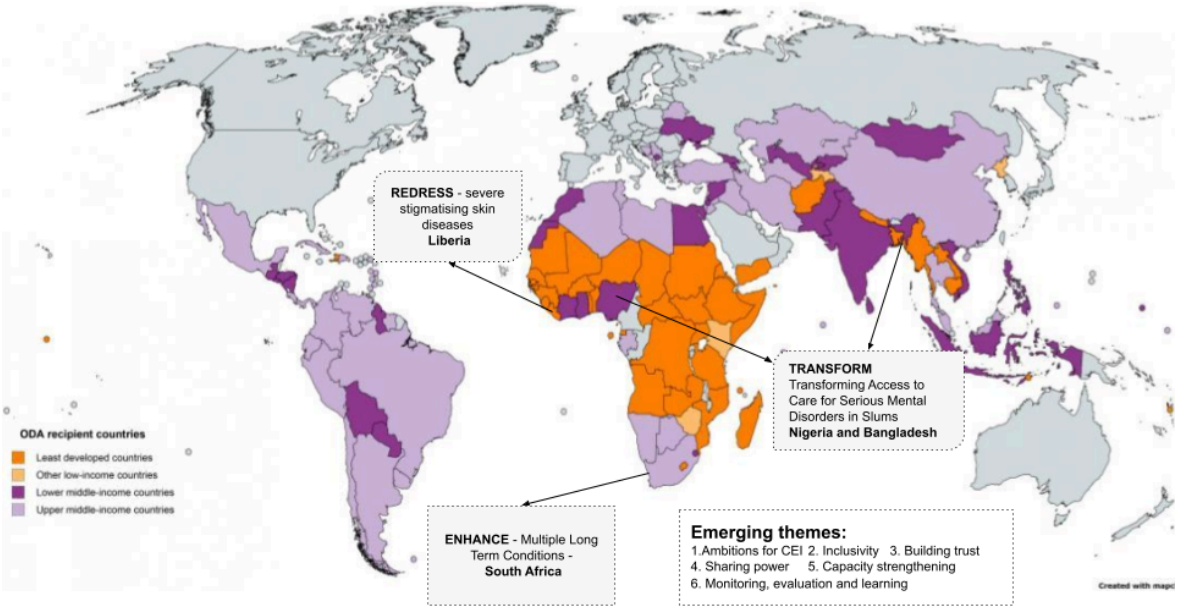
Transforming Access to Care for Serious Mental Disorders in Slums – the TRANSFORM Project is working to research how people who go to faith healers in

Bangladesh and Nigeria to seek help with severe mental disorders, can also get access to medical treatment if needed.

ENHANCE (RIGHT 3)

Development and evaluation of a targeted, integrated, coherent, and people-centred approach to the management of Multiple Long-Term Conditions (MLTC-M) in South African primary healthcare. The research explores how to support persons living with Non-Communicable Diseases to engage proactively in their treatment and care.

Fig 1: Geographical spread of the Storytelling pilot projects



Storytelling aims

Across each of the projects the aim was to demonstrate:

The ambitions of CEI within the project;

- Inclusivity – bringing in and working with marginalised communities;
- Capacity strengthening – support and learning for CEI members;
- Building trust with community members;
- Sharing power; and

- Monitoring, evaluation, and learning.

The storytelling workshops.

Following a co-design meeting and a planning and logistics session with each research project team, storytelling workshops were held with the community members. The workshops were all held via Zoom online platform and lasted three hours each.

Individuals actively involved in aspects of the research were identified by the local research teams and invited to attend the workshop. Community members met together in a room in the local area and were supported by facilitators from the research team and translators on the ground. Each workshop was led by an independent lead facilitator who was supported by a graphic facilitator, both based in the UK. Additional members of the research teams and the NIHR Patient and Public Involvement and Engagement team joined online as observers.

The workshops used a simple storytelling format, based on people, place, plot and purpose to enable community members to share the story of their involvement in research. The sessions explored:

- how, where, and why they became involved;
- what they have been doing in the project;
- reflections on their experience in the project; and
- what difference they hope their involvement will make to the future.

Reading this report

As with any research method, it is important to consider what the engagement approach means for interpreting findings.

A qualitative, story-telling approach was used to allow participants to share their experiences in their own words, and to enable in-depth exploration of views and experiences. As such, this report:

- honours participants' stories by using the language that they used;
- presents participants' stories in detail and in turn, to reflect the nature of the approach; and
- presents limited project team commentary on individual stories (general process learning and reflections are presented in the conclusion).

Language and abbreviations

Abbreviations are used in this report, they are provided here for ease of reference.

Abbreviation	Phrase in full
CAB	Community Advisory Board
CEI	Community engagement and involvement
CHA	Community Health Assistant
CHW	Community Health Worker
DHSC	Department of Health and Social Care
GHR	Global Health Research
LMICs	Low- and middle-income countries
MLTCs	Multiple long-term conditions
MOH	Ministry of Health
NIHR	National Institute for Health and Care Research
NTD	Neglected tropical disease
PSG	Peer support group
RIGHT	Research and Innovation for Global Health Transformation
SSSDs	Severe stigmatising skin diseases

3. THE STORYTELLING WORKSHOPS

3.1 REDRESS

About REDRESS: Reducing the burden of severe stigmatising skin diseases

For many people with severe stigmatising skin diseases (SSSDs), lack of access to health and social services results in significant physical and psycho-social consequences, complex treatment journeys, and catastrophic socio-economic impacts.

REDRESS aims to reduce illness, stigma, social exclusion, and poverty caused by SSSDs in Liberia. Improving fair access to services is an important cornerstone of universal health coverage (the provision of key health services to everyone, regardless of socio-economic status, disability, or gender, for example) and in attaining the Sustainable Development Goals.

Universal health coverage requires action beyond single disease programmes and approaches to ensure that no one is left behind. Integrated health system approaches to managing skin diseases have been proposed as a key solution to these challenges.

Liberia is one of the first countries in the world to develop a national integrated approach to managing SSSDs. This means managing diseases with signs on the skin (e.g. lymphatic filariasis, leprosy, Buruli ulcer, yaws, and onchocerciasis), through a combined approach at the local level. However, there is limited evidence about patient knowledge, priorities and experiences and the equity and effectiveness of the current approach.

REDRESS uses participatory action research, which centres knowledge of persons affected and other key community actors (such as informal providers and community health assistants (CHAs) and promoters) to develop new knowledge with regional and global relevance on affordable, timely, appropriate, and improved treatment strategies that also reduce stigma and addresses other social issues for affected vulnerable populations.

The project has been co-developed between researchers, persons affected by SSSDs and programme implementers at the request of the Liberian Neglected Tropical Diseases (NTD) programme and directly responds to priority health needs, detailed in the country's 'Investment Plan for Building a Resilient Health System'.

Telling the Story of Community Engagement and Involvement in REDRESS

REDRESS defines community engagement and involvement (CEI) as “the meaningful, respectful, and fit-for purpose involvement of a range of community members in one or more aspects of the research project.”

Participation of people affected by SSSDs is at the heart of REDRESS. By taking a person-centred approach that prioritises community engagement they ensure that affected persons and other often unheard voices have opportunity for meaningful and equal participation in all programme activities and meetings. This includes involving them as active participants in making decisions about research study design and the development and implementation of interventions (developed into case management manual and related tools) that seek to strengthen health systems to provide care for people affected by SSSDs.

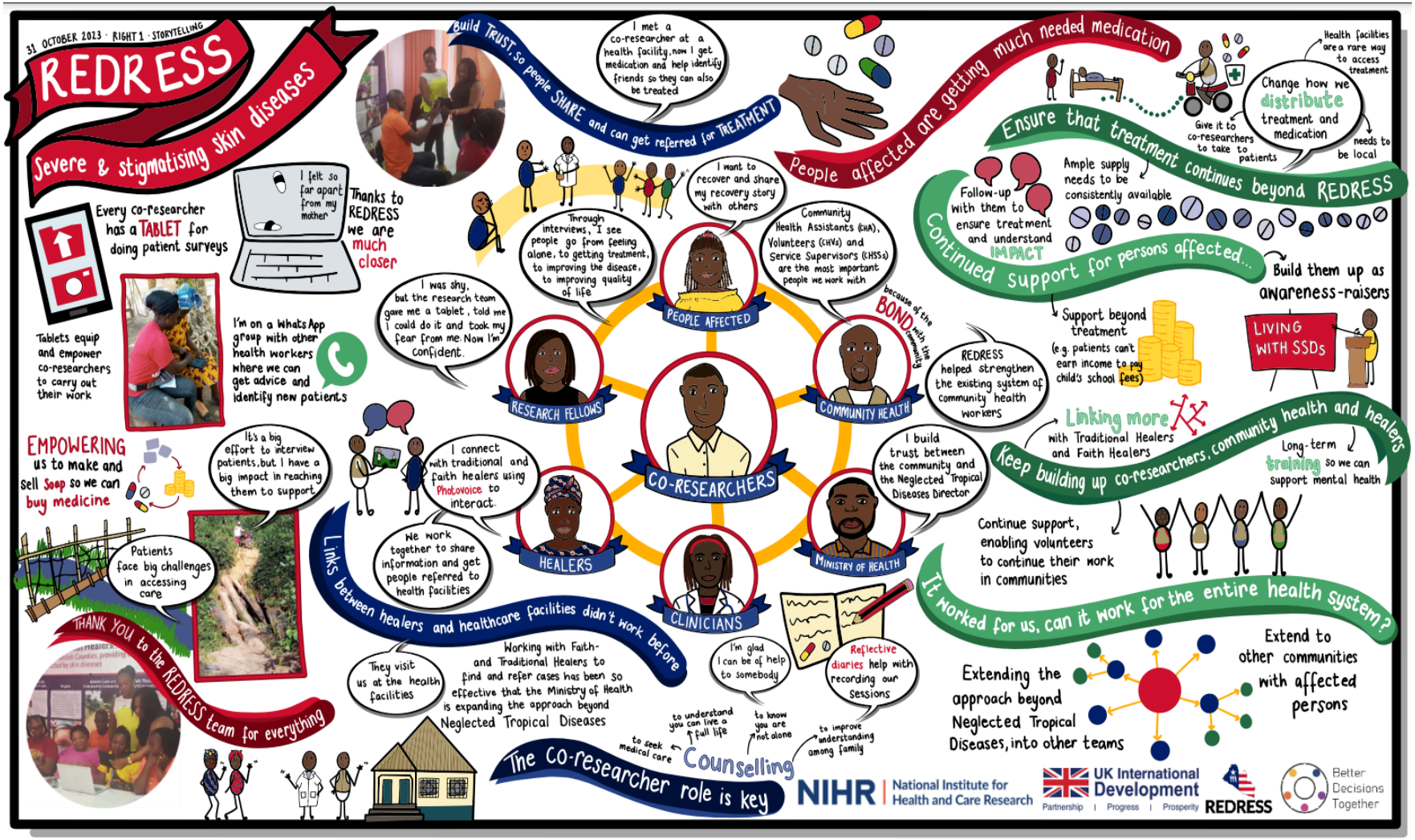
As part of the co-design of the storytelling workshop, several aspects of the REDRESS approach to CEI were identified that were particularly interesting to understand further through the stories of community participants involved. These aspects included:

- Understanding power and how this has been addressed and approached within the CEI approach, using participatory research methods and the role of co-researchers;
- The voice of individuals from the community, their journey and how they have managed to influence policy and practice;
- The Community Advisory Board (CAB), specifically the work bringing together those affected by SSSDs, the role of CHAs, traditional and faith healers, and NTD practitioners; and
- The use of creative engagement methods, including the experiences of those engaged using first person accounts, video stories and photo voice booklets.

The workshop included eight community participants and four local facilitators from Liberia who are all actively involved in a range of different ways across the Counties Lofa, Margibi and Grand Gedeh.

The internet connection to Liberia was particularly unstable on the day, so the workshop took place entirely by smart phone using WhatsApp. Using individual phones for the lead facilitator, the graphic facilitator and one smart phone used amongst the group in Liberia.

Despite the technological and connection difficulties, it did provide an opportunity to hear directly from each of the community participants. It was, however, impossible to record the workshop as planned.


31 OCTOBER 2023 · RIGHT 1 · STORYTELLING
REDRESS
Severe & stigmatising skin diseases
Every co-researcher has a TABLET for doing patient surveys
Tablets equip and empower co-researchers to carry out their work
I felt so far apart from my mother
Thanks to REDRESS we are much closer
I'm on a WhatsApp group with other health workers where we can get advice and identify new patients
EMPOWERING us to make and sell Soap so we can buy medicine
Patients face big challenges in accessing care
It's a big effort to interview patients, but I have a big impact in reaching them to support
THANK YOU to the REDRESS team for everything
Build TRUST, so people SHARE and can get referred for TREATMENT
I met a co-researcher at a health facility, now I get medication and help identify friends so they can also be treated
I was shy, but the research team gave me a tablet, told me I could do it and took my fear from me. Now I'm confident.
Through interviews, I see people go from feeling alone, to getting treatment, to improving the disease, to improving quality of life
I want to recover and share my recovery story with others
Community Health Assistants (CHA), Volunteers (CHVs) and Service Supervisors (CHSSs) are the most important people we work with
because of the BOND with the community
PEOPLE AFFECTED
RESEARCH FELLOWS
CO-RESEARCHERS
COMMUNITY HEALTH
HEALERS
CLINICIANS
MINISTRY OF HEALTH
REDRESS helped strengthen the existing system of community health workers
I build trust between the community and the Neglected Tropical Diseases Director
I connect with traditional and faith healers using Photovoice to interact.
We work together to share information and get people referred to health facilities
Links between healers and healthcare facilities didn't work before
They visit us at the health facilities
Working with Faith- and Traditional Healers to find and refer cases has been so effective that the Ministry of Health is expanding the approach beyond Neglected Tropical Diseases
I'm glad I can be of help to somebody
Reflective diaries help with recording our sessions
to understand you can live a full life
to know you are not alone
to improve understanding among family
to seek medical care
Counselling
The Co-researcher role is key
People affected are getting much needed medication
Ensure that treatment continues beyond REDRESS
Give it to co-researchers to take to patients
Health facilities are a rare way to access treatment
Change how we distribute treatment and medication
needs to be local
Follow-up with them to ensure treatment and understand IMPACT
Ample supply needs to be consistently available
Continued support for persons affected...
Support beyond treatment (e.g. patients can't earn income to pay child's school fees)
Build them up as awareness-raisers
LIVING WITH SSDs
Linking more with Traditional Healers and Faith Healers
Keep building up co-researchers, community health and healers
Long-term training so we can support mental health
Continue support, enabling volunteers to continue their work in communities
It worked for us, can it work for the entire health system?
Extending the approach beyond Neglected Tropical Diseases, into other teams
Extend to other communities with affected persons
NIHR | National Institute for Health and Care Research
UK International Development
Partnership | Progress | Prosperity
REDRESS
Better Decisions Together

Getting to know the community participants involved in REDRESS

The workshop started with getting to know everyone better. Participants took it in turn to introduce themselves and share an object or a photo that was important to them about their involvement with the REDRESS project.

REDRESS participants were:

- Emmanuel (a person affected and co-researcher),
- Hawa (a person affected and Chair of the Peer Support Group – PSG),
- Kebeh (Community Health Service Supervisor and co-researcher,
- Robert (CHA and co-researcher),
- Sylvester (CAB member and co-researcher),
- Hagar (Co-Chair of the CAB, PSG member and co-researcher),
- Dorothy (a clinician and social worker),
- Decontee (a person affected and a photovoice participant).

The group was supported by Hannah Berrian, Wede Tate and Tia Godwin Akpan from the REDRESS team based in Liberia.

Emmanuel was the first to start. He showed the smart tablet that he uses to undertake patient surveys as part of his role as a co-researcher. He described how it is very helpful and means he can collect information easily and share it with the REDRESS research team as part of the on-going research.

Decontee shared two photographs which she had taken as part of her role within the photovoice study which sought to explore her care seeking journey as a person affected, as well as the impact on wellbeing of living with a skin NTD. One of the photos she shared showed ‘beautiful slippers’ set apart from each other. She described how that represents the distance she felt from others as a person affected by SSSDs. The second image was with friends showing them coming together again as understanding and knowledge was gained about SSSDs and the impact this can have on people affected.

Hawa shared the soap made in the PSG that she leads. This soap is used to generate funds to help pay for health costs by group members.

Kebeh shared the smart tablet she uses in her role as a co-researcher, and described how it is used to carry out patient surveys. Kebeh described how the smart tablet means that information is collected easily and doesn’t get lost.

Dorothy is a nurse working at a health facility who has taken part in the REDRESS training, and who has received supportive supervision through REDRESS intervention. She talked about the WhatsApp group where they share photos and discussions with people from the Ministry of Health (MOH) and other health workers to get advice and help to identify possible new patients.

Robert, a co-researcher and CHA, shared a photo of the road condition and a motorbike to show the challenges patients face to reach care. The picture was of Robert on the way to collect patient data. Robert spoke about how happy he is to be able to help people with these conditions and that the best thing is that now people believe that things can change.

Finding out what the group have been doing as part of REDRESS

Members of the group described some of the people they had met, the places they had been and what they had been doing.

Emmanuel explained how he has been able to build trust between the community, the Officer in Charge (health worker at the health facility), and the Neglected Tropical Diseases director at the MOH. He explained how he has done this in his role as a co-researcher. He told how his role as a person affected who is also a co-researcher has helped people in the community to trust him, to share stories that they don't share with others, because of their shared lived experience with having had a SSSD. This has helped to reduce stigma in the community and to encourage people to take up referral for treatment. Emmanuel described how he attended an international conference, to share his story, where he made connections with other Non-Government Organisations. He also described his role in raising awareness about skin NTDs through being on the radio and at conferences. He told how he has now joined The African Alliance for Leprosy and will be presenting online with participants from other countries in Africa.

Sylvester described the role he plays on the CAB in Grand Gedeh County. How he connects with traditional healers and faith healers. Sylvester explained how he received training and uses Photovoice as a way to interact with Traditional Healers. This has helped grow the relationship. Now he works together with Traditional Healers to make sure information about patients is shared and that people can be referred to the health facility.

Hagar told how she is a community health services supervisor in her community. She works closely with CHAs to supervise them and do awareness and training as part of the roll out of REDRESS intervention. She described how she now knows how to identify affected persons and how to fill in the forms so they can be referred to the health facility for treatment. As Co-Chairperson of the CAB they meet quarterly with persons affected by SSSDs to understand what would be most useful for them. She explained how the PSG was established to empower persons affected. As co-researcher she works with health workers, including Officers in Charge and second screeners, linking with persons affected and Traditional Healers. She told how Traditional Healers now refer people to health facilities.

Hagar spoke of how she used to feel very shy before, but the research team encouraged her and mentored her to not feel afraid.

Hawa explained how she is the Chairperson of the PSG, and how thankful she is for the group. Hawa is affected by lymphatic filariasis, she wants to recover and share her recovery story with others. In the PSG she has met the other persons with Neglected Tropical Diseases, including a woman with lymphatic filariasis in both legs and someone with Buruli Ulcers. Hawa told how this has helped her to put her own condition in perspective.

Decontee is from Grand Gedeh County, she explained how she met Robert who is a co-researcher at the health facility. She is now able to receive medication and helps to identify friends in the community so that they also can be cured.

Robert told how he is a CHA, and research fellow. He explained how he has been trained by the research fellows, Wede and Smith and he uses a data tracker to track the information that is collected by the co-researchers.

Kebeh described how she provides supervision to support CHAs in their work in the community. She was introduced through a co-researcher who recruited her and gave her training on how to use the smart tablet. As a Community Health Service Supervisor, she links between CHAs being a mentor for them on daily activities. She told how she had met lots of people through REDRESS and how important this was to her.

Dorothy shared the work she has done using a reflective diary, and how this was useful in prompting her to think about her work, which encouraged her and increased her interest in this work. She told how she met with Traditional Healers and Faith Healers to promote communication and links between these informal providers and the health facility as part of REDRESS.

Hopes for the future, making a difference

- The group was asked to share what they hoped would be different in the future based on their involvement in the REDRESS project, they hope that:
- REDRESS does follow up surveys with patients, to understand how they have been treated and to see that they are getting better;
- Ways are found to eliminate NTDs;
- Persons affected have long-term training so they can work with the MOH, attend conferences, and be involved in community awareness-raising;
- The CAB continue community awareness-raising, and be recognised by the MOH;

- Links are created between persons affected, the MOH, and county authorities;
- Traditional Healers and Faith Healers are more be linked up, to help people access the treatment they need;
- Health promotion activities within the community are continued;
- Other persons affected with SSSDs are helped;
- Extra help is provided to ensure children can continue with school and tuition, as many PSG members are single parents, and some are also disabled;
- More medication be made available at health facilities;
- Medication and follow-up care continues to be available, so affected persons can continue accessing medication and receiving treatment;
- Motivation sessions are offered for persons affected, Traditional Healers and Faith Healers; and
- Co-researchers continue working in communities and health facilities, serving as representatives in counties.

CEI within REDRESS and influencing policy at The Ministry of Health

The Liberian MOH have been closely involved with REDRESS and took the time to share how the CEI approach is helping them shape their future policies. Findings from REDRESS have been included within the Liberian NTD Masterplan 2023-2027, such as the integration of mental health within care for persons affected by NTDs and the inclusion of traditional and faith healers as part of case detection. Learnings are included as part of the revision of the Community Health Strategy within Liberia.

The MOH representatives spoke about the role of peer advocates and community engagement in identifying and reporting cases related to NTDs in Liberia. They highlighted the success of REDRESS in facilitating patient identification and reducing stigma, and the importance of incorporating traditional and faith healers in the process. They emphasised the need to integrate the community-based approaches into the Ministry's policies and systems. The goal is to strengthen the existing health system and enhance community participation in the fight against NTDs.

3.2 TRANSFORM

About TRANSFORM: Improving access to care and outcomes of Serious Mental Disorders in slums in Bangladesh and Nigeria

People living in slums in low- and middle-income countries (LMICs) are known to experience high rates of serious and enduring mental disorders alongside extremely poor access to mental health care.

People experiencing mental health disorders and their families generally choose traditional and faith-based practices since these are more accessible, considered affordable, and are in tune with their cultural beliefs and traditions. The TRANSFORM project recognises the important role that faith-based and traditional healing can play in delivering care in LMICs, especially for common mental disorders like anxiety and depression, both in Africa and Asia, but those with serious mental disorders benefit from additional biomedical treatment and follow-up.

The TRANSFORM project aims to improve access to care and outcomes for people living with serious mental disorders in slums. Their focus is on developing an innovative collaborative care model involving traditional and faith healers, mental health professionals, primary care practitioners and community health workers (CHWs). The TRANSFORM research programme is being conducted across two slum communities, one each in Korail, Bangladesh and Ibadan, Nigeria.

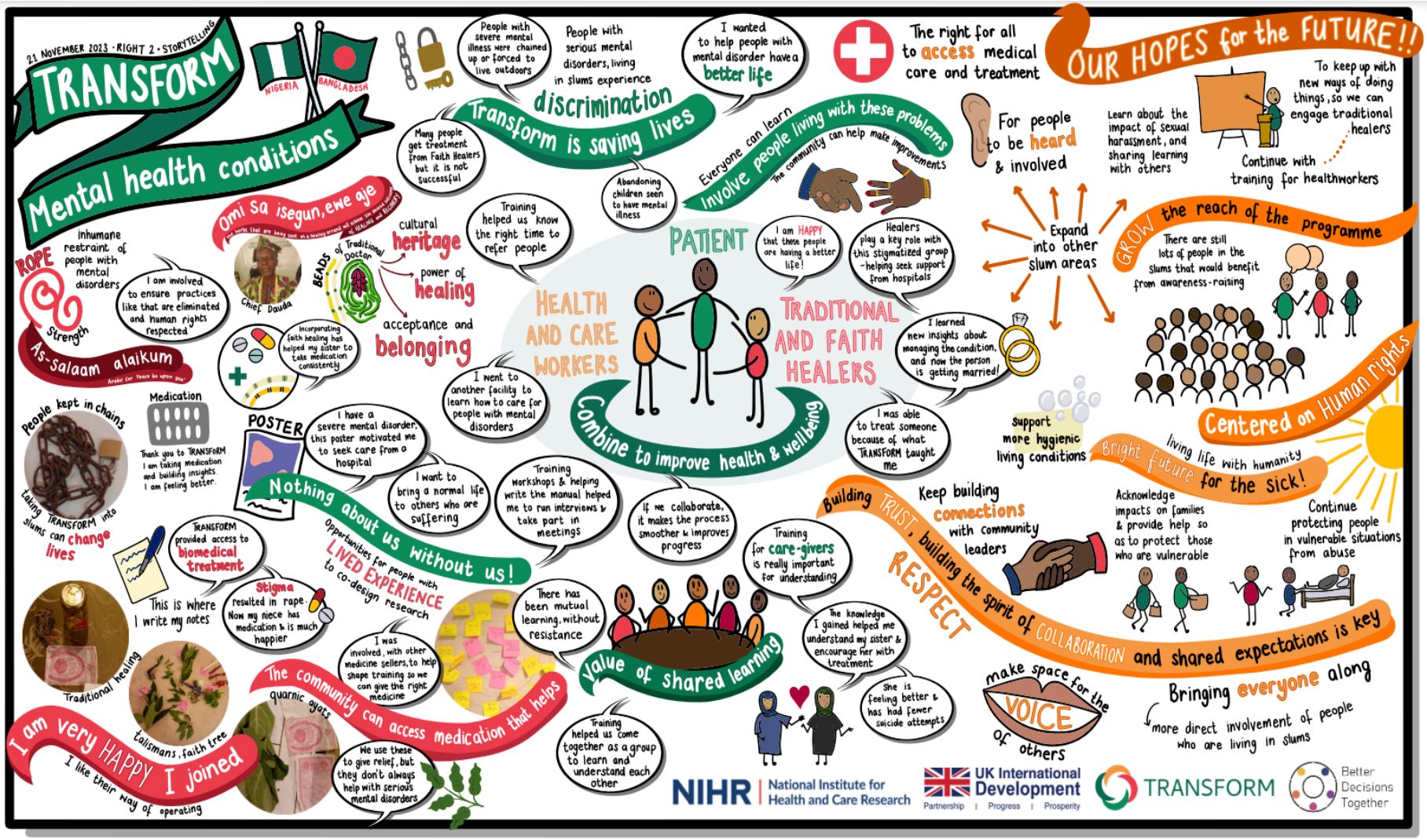
Telling the Story of Community Engagement and Involvement in TRANSFORM

Engaging with community participants is a central pillar of the research approach. TRANSFORM is conducting in-depth studies to understand local communities' awareness and understanding of serious mental disorders and is working closely with traditional and faith healers to understand who seeks care, how care is given and how healers identify and could refer those with treatable serious mental disorder to appropriate medical care.

The research is being conducted across five inter-linked work packages. The work packages are centred around CEI approaches that explore:

- community understandings of mental disorders and help seeking;
- training workshops with traditional and faith-based healers and CHWs to identify serious mental disorders;
- building relationships, reviewing training and approaches, and engaging further with traditional and faith-based healers and CHWs;
- determining if there is an increase in people seeking biomedical care who are experiencing serious mental disorders; and

- understanding the costs and benefits associated with the interventions.


21 NOVEMBER 2023 · RIGHT 2 · STORYTELLING
TRANSFORM
Mental health conditions
NIGERIA
BANGLADESH
People with severe mental illness were chained up or forced to live outdoors
People with serious mental disorders, living in slums experience discrimination
I wanted to help people with mental disorder have a better life
Transform is saving lives
Many people get treatment from Faith Healers but it is not successful
Abandoning children seen to have mental illness
The right for all to access medical care and treatment
OUR HOPES for the FUTURE!!
To keep up with new ways of doing things, so we can engage traditional healers
Learn about the impact of sexual harassment, and sharing learning with others
Continue with training for healthworkers
Everyone can learn
Involve people living with these problems
The community can help make improvements
For people to be heard & involved
Omi sa isegun, ewe aje
Chief Dauda
cultural heritage
power of healing
acceptance and belonging
BEADS of Traditional Doctor
ROPE
Strength
inhumane restraint of people with mental disorders
I am involved to ensure practices like that are eliminated and human rights respected
As-salaam alaikum
Arabic for 'Peace be upon you'
Training helped us know the right time to refer people
PATIENT
I am HAPPY that these people are having a better life!
Healers play a key role with this stigmatized group -helping seek support from hospitals
HEALTH AND CARE WORKERS
TRADITIONAL AND FAITH HEALERS
Combine to improve health & wellbeing
Incorporating faith healing has helped my sister to take medication consistently
I went to another facility to learn how to care for people with mental disorders
I learned new insights about managing the condition, and now the person is getting married!
Expand into other slum areas
GROW the reach of the programme
There are still lots of people in the slums that would benefit from awareness-raising
Centered on Human Rights
Support more hygienic living conditions
Living life with humanity
Bright future for the sick!
People kept in chains
Taking TRANSFORM into slums can change lives
Medication
Thank you to TRANSFORM I am taking medication and building insights I am feeling better.
POSTER
I have a severe mental disorder, this poster motivated me to seek care from a hospital
I want to bring a normal life to others who are suffering
Training Workshops & helping write the manual helped me to run interviews & take part in meetings
I was able to treat someone because of what TRANSFORM taught me
If we collaborate, it makes the process smoother & improves progress
Nothing about us without us!
Opportunities for people with LIVED EXPERIENCE to co-design research
Keep building connections with community leaders
Building TRUST, building the spirit of COLLABORATION and shared expectations is key
RESPECT
Acknowledge impacts on families & provide help so as to protect those who are vulnerable
Continue protecting people in vulnerable situations from abuse
TRANSFORM provided access to biomedical treatment
This is where I write my notes
Stigma resulted in rape. Now my niece has medication & is much happier
Training for care-givers is really important for understanding
The knowledge I gained helped me understand my sister & encourage her with treatment
She is feeling better & has had fewer suicide attempts
Traditional healing
Talismans, faith tree
quranic ayats
I was involved, with other medicine sellers, to help shape training so we can give the right medicine
There has been mutual learning, without resistance
Value of shared learning
The community can access medication that helps
We use these to give relief, but they don't always help with serious mental disorders
Training helped us come together as a group to learn and understand each other
I am very HAPPY I joined
I like their way of operating
make space for the VOICE of others
Bringing everyone along
more direct involvement of people who are living in slums
NIHR | National Institute for Health and Care Research
UK International Development
Partnership | Progress | Prosperity
TRANSFORM
Better Decisions Together

As part of the co-design of the storytelling workshop, several aspects of the TRANSFORM approach to CEI were identified that were particularly interesting to understand further through the stories of community participants involved. These aspects included:

- the approach to asset-based working with underprivileged people living with very limited access to resources or services;
- the woman centred research design with slum dwellers; and
- the collaboration with traditional and religious healers.

Getting to know the community participants involved in TRANSFORM

In preparation for the workshop, the NIHR and Better Decisions Together project team met with local teams in Ibadan, Nigeria and Dhaka, Bangladesh. This was to ensure the event would enable each person to be able to share their story. There were a good number of community participants involved in both locations. To ensure everyone could be heard, it was agreed to invite four to five people in each area, and for those taking part to be able to share different stories based on their interests and involvement in serious mental disorders.

The storytelling workshop took place online with a group of five people in Ibadan and a group of four people in Dhaka. The workshop took place on Zoom, which was video recorded, and a consent form was signed by all participants. Those taking part were contacted by the local research teams in advance, to explain what the storytelling workshop was for and who would be there. Each person was invited to bring an object that was important to them about their involvement in TRANSFORM.

The workshop started with getting to know everyone better. Participants took it in turn to introduce themselves and share about their involvement in the project.

Participants in Ibadan were:

- Aturu – a person with lived experience
- Adeleke – CHW
- Chief Abimbola – Traditional Healer
- Bolanle – Caregiver
- Sheik Abdul – Faith Healer

Participants in Dhaka were:

- Tahmina – a caregiver
- Abu – a person with lived experience
- Ruhul – a medicine seller
- Nurul – traditional and faith-based healer

The groups were supported on the day by local facilitators and translators. In each location there were other members of the research team listening in; and Professor Swaran Singh (the chief investigator on TRANSFORM), the team from Warwick University, and the NIHR CEI team joined online.

Professor Singh opened the workshop by confirming the importance of the voice and involvement of community participants within the research, to learn from faith healers and communities to build trust and understanding. He confirmed that what people shared in the workshop would inform the project over the next three years. He extended his gratitude at being able to listen to their stories as part of the workshop.

From Ibadan, Aturu first explained she is a medical scientist, someone with experience of serious mental disorder who lives in the slum area in Ibadan. She is part of the research team at TRANSFORM. Aturu told how she has experience of mental disorders and shared an object, that was to represent a rope. She explained that rope is used to restrain people with serious mental disorders in the slum in Ibadan and that this was inhumane. She shared that she was involved in TRANSFORM to ensure that these practices will be eliminated and so that people can find strength and to have their human rights always respected.

Adeleke told how she is a CHW and became involved in TRANSFORM to help the health facility have the knowledge to get the right care for people with serious mental disorders living in the slum area of Ibadan. She explained how pleased she was to be involved.

Abimbola (Baba) introduced himself and explained he is a Chief, traditional healer, and that he has been involved with TRANSFORM for two years. He showed his beads that he wears around his neck. He explained how they represent cultural heritage and its power of healing as well as its acceptance by biomedical practitioners via the TRANSFORM collaboration. He shared that this gives him a sense of pride and belonging.

Bolanle shared how she has been involved with TRANSFORM for two years. She told how she is a caregiver for her sister, who has experienced serious mental disorders over many years. She explained how her sister didn’t always take the medications she was given, but through TRANSFORM she has been able to receive treatment from a faith-based healer alongside the medication. Bolanle told how this provided on-going validation about combining the two forms of treatment.

Sheik Abdul introduced himself and told that he is the Head of an Association of Faith Healers located in an area in the South-West of Nigeria. He explained that he is very happy that faith and traditional healers are working together as part of

TRANSFORM, so that people can be healed from their mental disorders through this collaboration.

In Dhaka, Dr Tanjir Rashid Soron, the in-country CEI lead, provided translation support for the discussions with other community participants throughout the workshop. He showed a chain with a lock and key. He explained it is very significant for him, as part of his work in Dhaka he met a patient with severe mental disorder in Korail slum who was chained up with a lock and key in a very small room. He explained that by the collaborative works of TRANSFORM into the slum communities the research can change lives.

Tahmina told how she lives in the slum and first got involved in TRANSFORM to ensure it could be a meaningful research project. Tahmina shared a pen and writing pad that was provided by the TRANSFORM research team and explained this is where she writes notes about the lives of people of her community and the project. She explained that there are many activities in the slums but there is nothing for people with serious mental health disorders and that TRANSFORM is the first initiative of its kind.

One participant shared how they are a caregiver for a young adult. They had learned that the person they cared for had been receiving traditional treatments (like holy ropes) but did not have access to medication from the government. In discussion with TRANSFORM, the participant understood that there was access to biomedical medications. The young adult had since been taking this medication for over 8 months. The participant was very thankful that the person is getting better. The participant shared that they were very upset – because of this serious mental disorder, the person they care for was subject to rape multiple times by people within the community. They described how this was because of the stigma attached to having a severe mental disorder. The young adult is now getting the medication and support they need, and is now able to live a much happier life.

Abu shared a poster of the TRANSFORM project. Abu has been living in the slum since 1976. He explained how he is a person with lived experience of severe mental disorder and the poster motivated him to seek care from a hospital. He told how three months after starting the treatment he began to feel better. He is very grateful to the TRANSFORM project. He had been suffering for more than three years. He wants to bring a normal life to others who are suffering. He told how he never gives up hope for himself and for others. Abu has been involved in the TRANSFORM project from the beginning and has been involved in indepth interviews and focus groups to help co-design the research.

Ruhul told how he is a medicine seller in the slum area, and how there are many shops for people to purchase medicines without prescriptions. He explained how

he has been involved in the TRANSFORM project since the beginning and has taken part in a few different activities, including workshops where he was involved in co-designing the research along with other medicine sellers. Ruhul showed the flipchart paper and sticky notes with all the ideas they came up with. They developed key points to help with training to make sure medicine sellers and community health workers get a clear understanding of serious mental disorders and provide the best help possible from their end. He explained how when someone came to his store to buy a psychotropic medicine to help with their mental health, after being involved with TRANSFORM, he was able to help this person in a better way to seek biomedical care. He saw that this is a great help to the community to access medication that can help. He spoke about how there are lots of opportunities in the future and how grateful he is that TRANSFORM is doing this research.

Nurul introduced himself and his role as a traditional and faith healer. He shared medicinal leaves from a faith tree, images of religious deities, and a talisman used to get rid of black magic. He explained that these are all used in helping to give relief to people experiencing mental disorders. He told how these practices don't always help with serious mental disorders. He came to know about TRANSFORM through female community workers, and since then there has been mutual learning without resistance, learning from each other. Nurul explained about the benefits of the training provided by TRANSFORM so that he can work with people through their faith in traditional healers to also access medication. He shared how happy he is to be a part of the research project.

Finding out what the group have been doing:

The groups in Ibadan and Dhaka described some of the people they had met, the places they had been and what they had been doing.

In Ibadan, Aturu explained about the manual she had been involved in writing, and the training workshops she had been doing. This helped her to be able to conduct interviews with people and take part in meetings with stakeholders. Aturu mentioned how the best thing about being involved is how people with lived experience are seen as important, and that there is 'nothing about us, without us'. She told how she believed, 'dreams can come true!'.

Adeleke told how she had found the training enlightening. She explained about the importance of telling their stories to refresh memories, and that TRANSFORM has helped enlighten her. She told how she went to another health facility to learn about how to take care of people with mental disorders. Adeleke said, the training has really helped health workers to know the right time to refer people and to

make sure people get the help they need. She explained how the training provided by TRANSFORM has helped to come together as a group to learn. It has helped to open her eyes to understand better the role of traditional and faith-based healers and CHWs together. Adeleke would like to see more training in the future to keep up to date with new medicines and ways of doing things, so she can give the traditional healers the ‘heads up’ about new ideas and to make sure they continue to work together. Adeleke was very thankful for the work of TRANSFORM.

Chief Abimbola (Baba) made a traditional greeting, ‘Omi sa isegun, ewe aje’. He explained this is a greeting as well as a prayer by traditional healers which literally translates into: ‘the herbs that are being sent on a healing errand will achieve the desired outcomes of healing and recovery’. Because of the things that TRANSFORM has been able to teach him, Baba shared how a lady came to him with a mental illness caused by the death of her husband, and he was able to treat her. He was able to encourage the family and to help support her to come out of the illness. He told how there are several other faith healers that come to TRANSFORM meetings and they are learning together to achieve the goal.

Bola shared that as a caregiver TRANSFORM has helped her to understand her sister better. She told about when her sister went to the faith healer, she was fasting for seven days and how this made her lose her stature. Bola told about the knowledge she has gained and how it has helped to support her sister. She explained how she was able to encourage her sister to take new medicine regularly. Now, she is feeling better, has more insights about her condition and has had less suicide attempts. Bola told how since she joined TRANSFORM she has been enlightened and she understands better that traditional and new medicine can be combined. She told how she hopes this will continue to achieve well-being for people suffering from mental disorders.

Sheik Abdul talked about someone he healed. He told how he was treating this person at his healing centre, when the TRANSFORM team came to do some interviews during the treatment. He told about how he learned new insights into how to manage the condition of the person. He explained that right now this person’s condition has changed. He shared that since working with the TRANSFORM team, he is happy that they come to his healing centre and that they have a trustworthy relationship. He also told that he is happy to report that the person he was treating recently reported that they are getting married!

In Dhaka, Tahmina explained how she has been involved in TRANSFORM from the beginning, as she wanted to help people with mental disorders have a better life. She described how people with serious mental disorders in slums live in chains and experience discrimination, and how people from the community who

live with these problems can link with TRANSFORM so everyone can learn. She told how in this way community members can help make improvements. Tahmina spoke about the importance of training for caregivers. She described how those living in slums have limited understanding of mental disorders and are easily ignored, living with no hope. She explained how the traditional and faith-based healers play an important role with this stigmatised community by helping people to see that they can also seek help from hospitals. This means people are getting better.

Ruhul explained how since the last meeting with TRANSFORM there had been important learning that people can be treated for serious mental disorders with medicine – that they can go on to enjoy a normal life. He said that he is happy that people can get the help they need. He spoke of how medicine sellers come together to help come up with the right way of doing things – bringing together family with medicine sellers and CHWs as equal and important parts of the team.

Hopes for the future, making a difference.

The groups in both Ibadan and Dhaka shared their hopes for the future.

In Ibadan, these were:

- Giving voice to others, through trust, collaboration, and shared expectation, carrying everyone along;
- For people to be heard and involved;
- The right for all to have access to medical care;
- A continued focus on human rights;
- Access to employment for community participants;
- On-going training and knowledge to help health workers to support people with serious mental disorders;
- Increased community awareness of severe mental disorders;
- That those living in the slums can get access to the care that they need through building ongoing connections with community leaders;
- That there is a bright future for the sick, living a life with humanity;
- For the TRANSFORM programme to continue; and
- Learn, as healers, to know how to use gods' help to take care of people so that people with severe mental disorders don't get abandoned.

In Dhaka, the groups hoped that in the future:

- The impact of sexual harassment for people living with serious mental disorder will be understood, and this knowledge shared with others;

- Training will be delivered so there can be more direct involvement of people living in slums in this work, so more people can benefit;
- The TRANSFORM programme will grow to other slum areas and be provided over the longer-term;
- The wider impact of serious mental disorder on the family will be acknowledged, with help provided to protect those who are vulnerable;
- It will be ensured that people with lived experience of serious mental disorder are protected from abuse; and
- Working together will continue, in a trusted, respectful, and mutually collaborative way, as it is a beautiful thing to work together.

Professor Singh offered some final words of reflection and thanks to conclude the workshop. He shared that he believed that behind every agony is an untold story.

> “These stories are gifts that we are grateful to have received. Prof Singh

He explained how the TRANSFORM team is learning from the people, from the community who are involved, and will continue to do so – that there will be a legacy of community contribution and he will ensure it is a lasting one.

3.3 ENHANCE

About ENHANCE: Exploring how to strengthen care and support for persons living with Multiple Long-Term Conditions

Multiple Long-Term Conditions (MLTCs) is the experience of living with more than one long-term condition, such as, HIV, diabetes, and depression. South Africa faces particularly serious challenges in terms of its growing NCD burden in addition to the HIV epidemic and has one of the highest multimorbidity prevalence levels across LMICs. As part of the evidence led approach of this study, an epidemiological analysis of the public and private sector data, concluded that South Africa has high levels of HIV, hypertension, diabetes, and arthritis, and this is reflected in estimates of the most frequent disease combinations: hypertension and arthritis, hypertension and diabetes, and hypertension and HIV.

In South Africa health workers use PACK (Practical Approach to Care Kit) or APC (Adult Primary Care) – a compilation of clinical policies and guidelines – to help them decide how to manage their patients. PACK standardises an approach to long-term care, but when there is more than one condition, the number of different components to check is overwhelming, making decisions difficult about what to prioritise and leaving little space for patients to share their health concerns. ENHANCE aims to co-develop and evaluate a health systems intervention to strengthen the care that persons with MLTCs receive.

Through working closely with those affected by MLTCs, policymakers, health service managers, and health workers, a complex health systems strengthening intervention has been developed. To ensure adequate ongoing engagement of people living with MLTCs in the research design and its outputs, a whole work package has been dedicated to deepening understanding of patient and community preferences and priorities for MLTCs. This approach hopes to support individuals to become champions who can contribute to civil society organisations beyond the project.

Telling the Story of Community Engagement and Involvement in ENHANCE

At the outset, the research team were keen to avoid establishing another civil society organisation for MLTCs. They set out to use the approach of an Advocacy Academy, aimed at bringing together members of major civil society groups representing interests from all three condition clusters and those concerned with Universal Health Coverage more generally. The initial idea was to provide a support network with peers experiencing similar MLTCs, informal skills development in advocacy, and a platform for voicing recommendations for

improved service delivery. The Advocacy Academy initially set out to include activities such as workshops (to bring people together to empower participants to become advocates for change in the way their health and care needs are met) and a ‘living diary’ (so that between workshops participants could capture their thoughts, perceptions, and experiences of living with MLTCs).

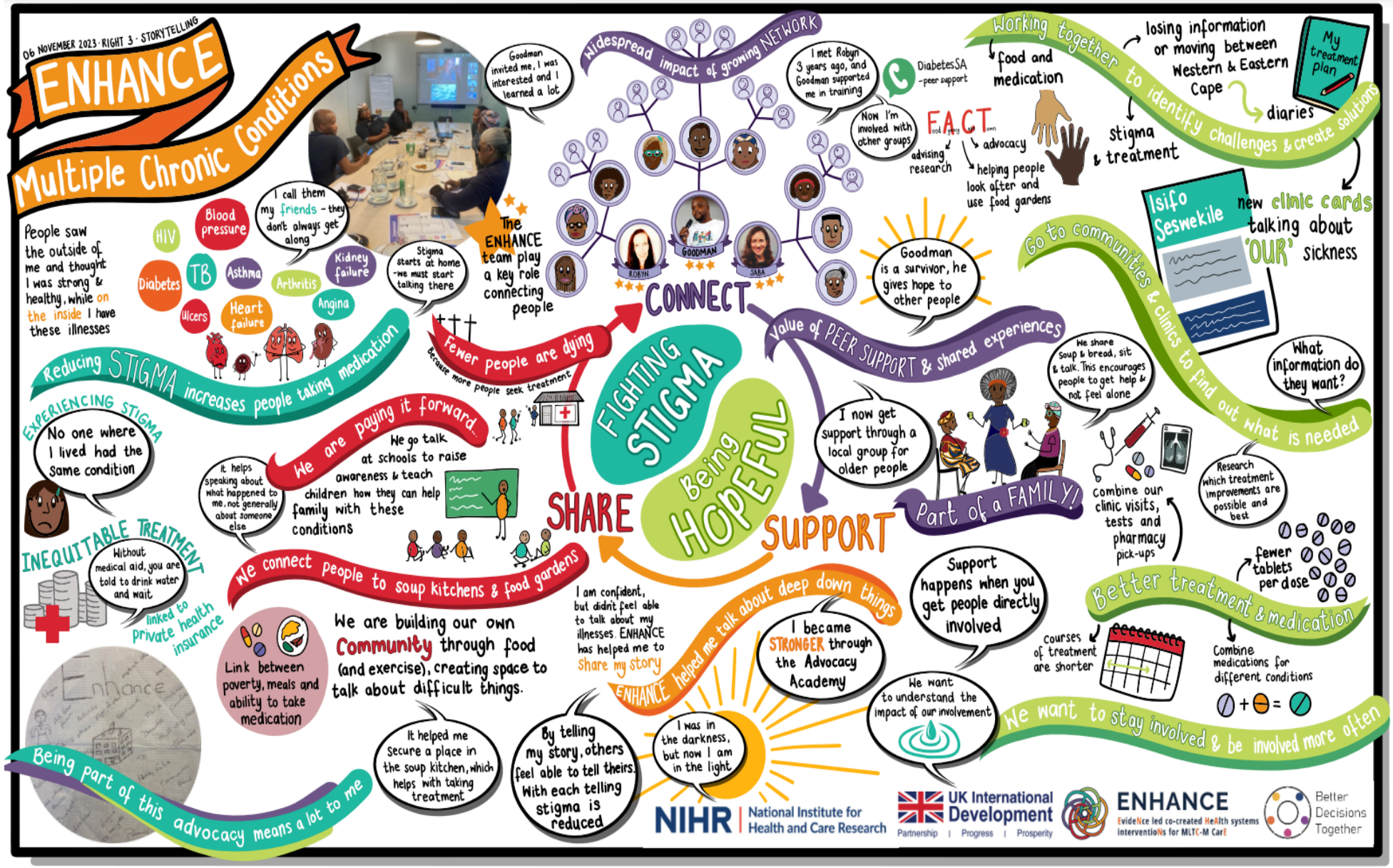
The Advocacy Academy intended to recruit people from existing civil society organisations, however this proved difficult as people with more than one chronic condition were poorly represented in active roles within such organisations. Instead, the approach was to leverage membership and reach of these organisations to recruit people living with MLTCs to build advocacy capacity and allow their voices to contribute to strengthening MLTC care. This approach has led to a greater level of inclusion of marginalised voices in understanding the needs of people living with MLTCs. Condition-specific advocacy organisations are involved in stakeholder workshops that take place through the life of the project. Some of the Advocacy Academy members have been referred to these organisations, an example of this is Diabetes South Africa, for which two of the members have enrolled in a diabetic advocacy course.

From the outset of the project, the need to adopt a ‘learning by doing” approach has been important. Part of this is evident in the development of the content to meet the needs and priorities of those involved in the Advocacy Academy. For example, during the first workshop, although it was assumed that the group may be able to meet virtually for some of the meetings, further engagement with the group highlighted that this was not a feasible option for several reasons. Some participants did not have smartphones or access to affordable data. In addition, the group had already evolved into a form of community support, compromised by virtual modes of engagement. The need for individual sessions with participants in the group also emerged in the first workshop as some individuals shared stories of traumatic experiences and disclosed their HIV diagnosis for the first time to the group. It was clear that there was a need to better understand each member of the group to tailor advocacy development with consideration of each person’s context, knowledge of their own conditions and treatment, and passion.

Members of the Advocacy Academy have been involved in the co-creation of the intervention as well as the advocacy training, based on their experience and priorities for MLTC care. It has become clear that there is interest in more active involvement in advocating for the project and ENHANCE intervention. As all the members were users of the public sector clinics in which the trial would take place, they would be given an opportunity to be involved in various activities to advocate within their facilities or stakeholder meetings.

As part of the co-design of the storytelling workshop, several aspects of the ENHANCE approach to CEI were identified that were particularly interesting to understand further through the stories of community participants involved.

- The journey of CEI and how they have adapted based on a strengths-based approach to working with capacity within communities and the role of your community co-applicant.
- The Advocacy Academy Model, including design of the academy and the development of training.
- Addressing power differentials through building trust with individuals (for example doing home visits) and different civil society organisations, including challenges.
- Telling a story in context and using memoirs.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ENHANCE
Multiple Chronic Conditions
People saw the outside of me and thought I was strong & healthy, while on the inside I have these illnesses
HIV
Blood pressure
Diabetes
TB
Asthma
Arthritis
Kidney failure
Ulcers
Heart failure
Angina
I call them my friends - they don't always get along
Stigma starts at home - we must start talking there
Goodman invited me, I was interested and I learned a lot
The ENHANCE team play a key role connecting people
Widespread impact of growing NETWORK
ROBYN
GOODMAN
SABA
I met Robyn 3 years ago, and Goodman supported me in training
Now I'm involved with other groups
DiabetesSA - peer support
FACT
advising research
advocacy
helping people look after and use food gardens
Working together to identify challenges & create solutions
food and medication
losing information or moving between Western & Eastern Cape
stigma & treatment
My treatment plan
diaries
Isifo Seswekile
new clinic cards talking about 'OUR' sickness
Goodman is a survivor, he gives hope to other people
CONNECT
Go to communities & clinics to find out what is needed
What information do they want?
Value of PEER SUPPORT & shared experiences
We share Soup & bread, sit & talk. This encourages people to get help & not feel alone
I now get support through a local group for older people
Part of a FAMILY!
Reducing STIGMA increases people taking medication
Fewer people are dying
because more people seek treatment
FIGHTING STIGMA
Being HOPEFUL
SUPPORT
SHARE
EXPERIENCING STIGMA
No one where I lived had the same condition
INEQUITABLE TREATMENT
Without medical aid, you are told to drink water and wait
linked to private health insurance
We are paying it forward.
We go talk at schools to raise awareness & teach children how they can help family with these conditions
it helps speaking about what happened to me, not generally about someone else
We connect people to soup kitchens & food gardens
Link between poverty, meals and ability to take medication
We are building our own Community through food (and exercise), creating space to talk about difficult things.
I am confident, but didn't feel able to talk about my illnesses. ENHANCE has helped me to Share my story
ENHANCE helped me talk about deep down things
I became STRONGER through the Advocacy Academy
Support happens when you get people directly involved
We want to understand the impact of our involvement
Combine our clinic visits, tests and pharmacy pick-ups
Research which treatment improvements are possible and best
Better treatment & medication
fewer tablets per dose
Courses of treatment are shorter
Combine medications for different conditions
We want to stay involved & be involved more often
It helped me Secure a place in the soup kitchen, which helps with taking treatment
By telling my story, others feel able to tell theirs. With each telling stigma is reduced
I was in the darkness, but now I am in the light
Being part of this advocacy means a lot to me
NIHR | National Institute for Health and Care Research
UK International Development
Partnership | Progress | Prosperity
ENHANCE
EvideNce led co-created HeAlth systems interventioNs for MLTC-M CarE
Better Decisions Together

Getting to know the community participants involved in ENHANCE

In advance of the workshop, the project team met with the local research team to ensure the session would meet the needs of the community participants who would be coming along. To provide further support and help individuals feel confident taking part, Goodman Makanda (the Community Engagement Co-ordinator) contacted and met each participant at home. He explained the storytelling workshop to Advocacy Academy members – why it was happening and how individuals might share their stories.

The workshop started with getting to know everyone better. Participants took it in turn to introduce themselves and shared something of how they felt about being involved in the Advocacy Academy. Each member of the group was a person with lived experience of MLTCs.

Participants were:

- Sharon
- Noxolo
- Nomzamo
- Pamela
- Nomvuyo

The group was supported in the room by Goodman and Robyn from the ENHANCE research team in South Africa. Saba from the ENHANCE research team and colleagues from NIHR joined online to listen.

Goodman explained he is the Community Engagement Coordinator with the ENHANCE project and a person who lives with MLTCs. He shared that through his personal experience he has had his eyes opened to the physical and mental impact of having multiple conditions. He advocates for health issues in the community to help more people engage with their treatment.

Noxolo shared how she had first been diagnosed with a long-term condition in 1992. Since then, she has developed three other long-term conditions and now she must take so much medication. She shared how she has become stronger through her involvement in the Academy, she has made friends and feels as if she is part of a family. Noxolo explained how she meets people from the community, they share soup and bread, and sit and talk. This helps encourage people to get support with their conditions, and not to feel alone.

Nomzamo told how she first found out she had a long-term condition in 2010 and has since been diagnosed with four other conditions. She explained how she met Goodman, and he helped her to become strong through sharing her story. She

explained how sharing her story helped others to see that there are ways to feel healthy. By educating people about their health issues, she is able to stop people from dying. Nomzamo explained that the local soup kitchen is an important place for people to meet and get help and support.

Nomvuyo explained she was from the Eastern Cape of South Africa and as a survivor of a long-term condition had experienced stigma within her township. This led to depression and made life very difficult.

She shared how she had to sit down and talk to herself about finding ways to live with it. She was introduced to Goodman, who got her involved in the project. She described how she felt very shy and lacking in personal confidence, and that being involved has broadened her mind and confidence a lot. She told of how she speaks to other patients at one of the clinics, about her experiences and what it means to be living with MLTCs. She explained how she does this now because it comes from her heart, and she wants to stand on her feet and fight for others.

Sharon described how she has six conditions that she likes to think of as her ‘best friends’, and how her ‘best friends’ don’t always get along. She explained how there is a discrepancy in the health system, ‘If you have medical aid, then you can get rushed to hospital, but if you don’t have medical aid, you will be advised to drink some water and wait’. Community kitchens were really important places to raise awareness, to help others know how to manage their conditions. Sharon explained how her confidence has grown, how she is able to be herself and has made friends. Going to the group has given her a chance to be together, make jokes and be part of a family.

Pamela explained how she is living with two long-term conditions, and how she was not confident to easily share about her illnesses with other people. But now she is able to talk more openly.

Finding out what the group have been doing as part of the ENHANCE Advocacy Academy

The group described some of the people they had met, the places they had been and what they had been doing.

Sharon told how she met Robyn from the research team 3 years ago as part of the PPDA in development of the grant application. Since she became involved in the Advocacy Academy, she has been linked to the Diabetes SA Alliance and completed advocacy training; and the Food Agency Research Cape Town research group. She has become very interested in the importance of access to food in poverty-stricken areas. She explained how she became actively involved in

‘backyard gardens’ where people grow different vegetables, and with schools to help children learn about the importance of food (they also get to take home fresh vegetables on a Friday). Sharon also told how Goodman supported her to take part in a course, where she gained a certificate.

Noxolo explained how she met Robyn and then Goodman from ENHANCE, and how she has been meeting with some of the elderly people in her township. At a meeting, Noxolo sat down with four ladies and spoke about her experiences of living with MLTCs and her ideas. She told about the extreme poverty in the community and the importance of access to healthy food. She explained how poverty affects all people – men, women, older and younger. She described how she went door to door to get people involved. Every Tuesday everyone gets involved in a community kitchen, where they prepare and cook veggies, eat soup and bread. Everyone gets involved (peeling and preparing), and after making the food they sit and eat and talk. This is a time to express their feelings, to find out and learn more about each other. Noxolo told how together they decided to visit the schools, to help educate the children about diseases.

Nomvuyo told how she first met Saba and Robyn from ENHANCE when she was talking about her journey at her clinic with her community. She explained that people don’t have much awareness of some conditions and that people are scared. She explained that because Goodman is a survivor of his conditions that he gives hope to other people – that there is life beyond illness. Now people are interested to hear about experiences that people have had, with others managing and surviving with other conditions too, so that awareness is raised.

Nomzamo explained how she met Goodman, Robyn, and Saba. She told how proud she is of herself for having the confidence to go to the clinic. She explained how she is now involved with the bible society and soup kitchen. She spoke about how important it is for people to have food over the weekend as they can’t take their medication on an empty stomach; and how fewer people are dying because they are taking their medication. She described how stigma is killing the community and that it is important to understand and respect the community before you can advocate for them.

Pamela described how it is that she has no judgement of anyone else. She explained why it is important for people to have access to healthy food, as it is not good to take medication on an empty stomach. By providing good food at the soup kitchen, people can take their medication properly and this extends their life.

Goodman explored how he is inspired by the people and community around him. He explained how he takes time to understand people and get them directly involved, and how this education and support helps people stay involved. He

described how he tells people his story, to share where he is coming from. He also spoke about seeing people as a whole – how their physical conditions affect their mental health – and how this helps to understand where they are coming from. He explained how telling his story of living with MLTCs helps others feel able to share theirs; that each time someone tells their story, more people are made aware, and stigma is reduced.

Hopes for the future, making a difference

- The group shared their hopes for the future, they hope that:
- they can sit down with their families [to discuss their MLTCs], as they feel stigma is best dealt with in the family first;
- children can know that they have a specific condition and understand how to keep themselves and others safe, improving life and outcomes for everyone;
- treatment for conditions will be available more quickly, be easier to take and be available to everyone;
- medication that addresses multiple conditions could be provided, with pharmaceutical companies looking to make this possible;
- data is collected to understand what people want from their treatment;
- clinics will be able to see you for all your conditions at the same time; and
- people understand how their involvement in this research is making a difference.

4. CONCLUSION

As a pilot, this storytelling project proved an invaluable opportunity to hear directly from community members as an experiential learning opportunity to understand individual stories of involvement within three NIHR funded RIGHT projects.

This participative and immersive experience has been beneficial in learning about the ambitions for CEI within each project and the motivations behind individuals involvement and their hopes for the future.

It is clear from the stories shared that there is significant benefit from CEI in global health research. Through inclusive community led approaches, the experience of community members in the research extends well beyond day-to-day involvement in the projects. This is realised through strengthening the capacity and energy for learning. Moreover, through the essence of sharing power with the people, is the enablement of developing trust, a bond, and an ongoing shared hope for change and improvement.

Learning from the storytelling pilot

There were challenges with participants, observers, and facilitators joining from across the globe. This requires careful consideration in design (catering to translation and multilingual delivery), on-site audio-visual setup, contingency planning for poor internet connections, and number of participants in each session. However, those challenges are worth overcoming, due to the value of amplifying community members' voices and wider acknowledgement by international organisations involved in research funding and delivery.

Storytelling was well suited to this process for several reasons. It emulated people’s experiences of storytelling in their own communities; it enabled an organic, participant-led approach; it enabled the capture of impact stories which might have been missed in traditional approaches due to the truly immersive experience of directly hearing and illustrating from the community members; and it supported trust and power sharing by providing participants a platform to share what they felt was important, in their own voice, and honouring those voices and stories through this report.

Other aspects of power-sharing which proved invaluable to the success of the process included working with local research teams in workshop design and facilitation; allowing organic sharing by the community members without a rigid adherence to workshop agendas or intended process plans; and having senior members of the research teams observing events with the view to take learning on board to shape future project work.

Learning from the RIGHT projects

These RIGHT projects highlighted several valuable approaches to power-sharing and empowering local communities and persons affected. For example, providing tablets enabled community members to support research or treatment access and signalled their role to local communities; visual tools equipped people to better communicate, supporting relationship-building; skills development resulted in new income-sources; acknowledging traditional healers and faith healers as part of the health and care system; and CEI and development supported persons affected to build their own profiles, becoming speakers at events or members of other groups.

CEI and storytelling has resulted in wider reach and impacts in communities – co-researchers sharing their own stories, encouraging community members to seek treatment, and they in turn then want to share their stories with other persons affected to encourage them to seek treatment. Co-researchers played a key role in connecting persons affected into treatment and research processes.

Community members' hopes around the future of medication and care provision told a story of the importance of the RIGHT projects in supporting health and care access that was previously limited or impacted by a lack of sustainable systems that support treatment (such as regular access to food). Additionally, many community members' hopes for the future reinforced the discovered impacts, for example hopes for continued training, or links between traditional healers and biomedical healthcare provision show that these are valuable to the communities.

CEI has had a significant impact on awareness-raising and stigma reduction, helping affected persons to reconnect with their communities, as well as create new communities and relationships through peer support.

Thank you to all involved

The NIHR and Better Decisions Team would like to extend our gratitude to all the community participants and the research teams who helped plan, prepare, and facilitate in the rooms at each workshop.

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We would like to thank the Liberian Ministry of Health for giving their time to speak.

It was an honour and privilege to hear from everyone involved and to understand just a little about the stories behind the involvement of community participants in each of these RIGHT projects.

Our gratitude and thanks also go to all those who took part, who shared their stories, so openly and generously with us.