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Participatory workshop manual to orient photovoice participants for the PROMISE study.

**Prepared By
Wakumanya Sibande**

May 2023

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Acknowledgements

This manual has been adapted from the HIV Self-Testing Africa (STAR) study (2018) participatory workshop manual by Malawi-Liverpool-Wellcome Trust Clinical Research Programme, and the Scotia Participatory Food Costing Project Photovoice guide (2012). Feedback was provided by the PROMISE Malawi team led by Associate Professor Manda-Taylor.

Session 1

Introduction

This session will provide participants with an overview of the workshop. By the end of the session, participants will become familiar with the workshop's ground rules and overall goals.

Outline

- Topic 1A – Introductions
- Topic 1B – Ground rules
- Topic 1C – Overview of the workshop

Topic 1A: Introductions

Objective

- Introduce workshop participants and facilitators to one another.

Time

15 minutes

Materials

None

Procedures

Icebreaker

1. Ask participants to stand in a circle.
2. Participant X should introduce their name, village, and occupation. Participant X should then make the sound of an animal of their choice.
3. Standing next to Participant X, Participant Y should introduce their name, village, occupation, and hobbies. Participant Y should then identify the animal that makes the sound made by Participant X.
4. If Participant Y is *correct*, participant Y should make their animal sound for the next person to identify.
5. If Participant Y is *wrong*, participant X can demand a reward from the group (e.g., clapping, standing with one leg, dancing, etc.).
6. Continue the game until all participants and facilitators have introduced themselves.

Topic 1B: Ground Rules

Objective

- Establish commonly agreed and mutually respectful rules for subsequent sessions.

Time

5 minutes

Materials

Flipcharts, markers

Procedures

Brainstorm ground rules.

1. Explain to participants the need for a set of rules for the workshop.
2. Participants should nominate someone as a scribe.
3. On the flipchart, the participant should write the heading “Ground Rules” and the sub-headings “We Will” and “We Will Not”.
4. The group will then decide what to put in each column. For example:
 - We *will* always be on time.
 - We *will* turn off our phones (or switch to “silent”).
 - We *will* participate to the best of our abilities.
 - We will listen when others are speaking without interrupting.
 - We will not speak badly of one another.
 - We will not be disruptive during activities.

Topic 1C: Overview and expectations of the workshop

Objective

- Provide an overview of the objectives and structure of the workshop.
- Explore personal and community expectations of the photovoice activity.

Time

15 minutes

Materials

Flipcharts, markers, workshop agenda

Procedures

Description of workshop structure and objectives

1. Ask participants: **What is participatory or community-led research?**
 - Explain that: Participatory Action Research (PAR) is an approach to action research emphasising participation and action by members of communities affected by that research.
2. Explain that in the coming weeks, they will be participating in research to understand perceptions and experiences of people living with psychosis and their caregivers' using photos.
3. Describe the activities that will take place as part of the participatory research.

Activity	Community member	Description
Orientation workshop	People with Lived Experience and their care givers	Introduce the photovoice research to the main research participants.
SHOWED workshops/Discussions	People with Lived Experience and their care givers	PWLE and their care givers discuss photos with researchers through individual and group discussions.
Dissemination of key research findings	PWLE, care givers, traditional healers, faith leaders, District mental health teams.	Research participants to present key findings from their research using photos taken.

4. Now describe the objectives of the workshop.
 - Each objective should be written down on a separate sheet of flipchart paper and displayed during the workshop.
 - By the end of the workshop, participants should be able to:
 - Define the context and need for the PROMISE project in their areas.
 - Obtain the necessary knowledge and skills to carry out photovoice research.
 - Commit to a timeline of activities for the photovoice research.
5. Go through the workshop's agenda, including each session's themes and objectives.

Session 2

Psychosis and the PROMISE study in Malawi

This session will provide a brief background and context of psychosis in Malawi and a justification for designing and implementing the PROMISE study. By the end of the session, participants should understand the current challenges facing efforts towards detecting, treating, and caring for psychotic patients. They should also understand what the PROMISE project is, its objectives, outcomes, and approaches.

Outline

- Topic 2A – What is the current context of psychosis in Malawi?
- Topic 2B – Why was the PROMISE study designed, and what does it seek to address?

Topic 2A: What is the context of psychosis in Malawi?

Objective

- Remind participants causes and origins of psychosis.
- Describe the prevalence of psychosis in Malawi.
- Describe the health system's challenges in detecting, treating, and caring for psychotic patients.

Time

20 minutes

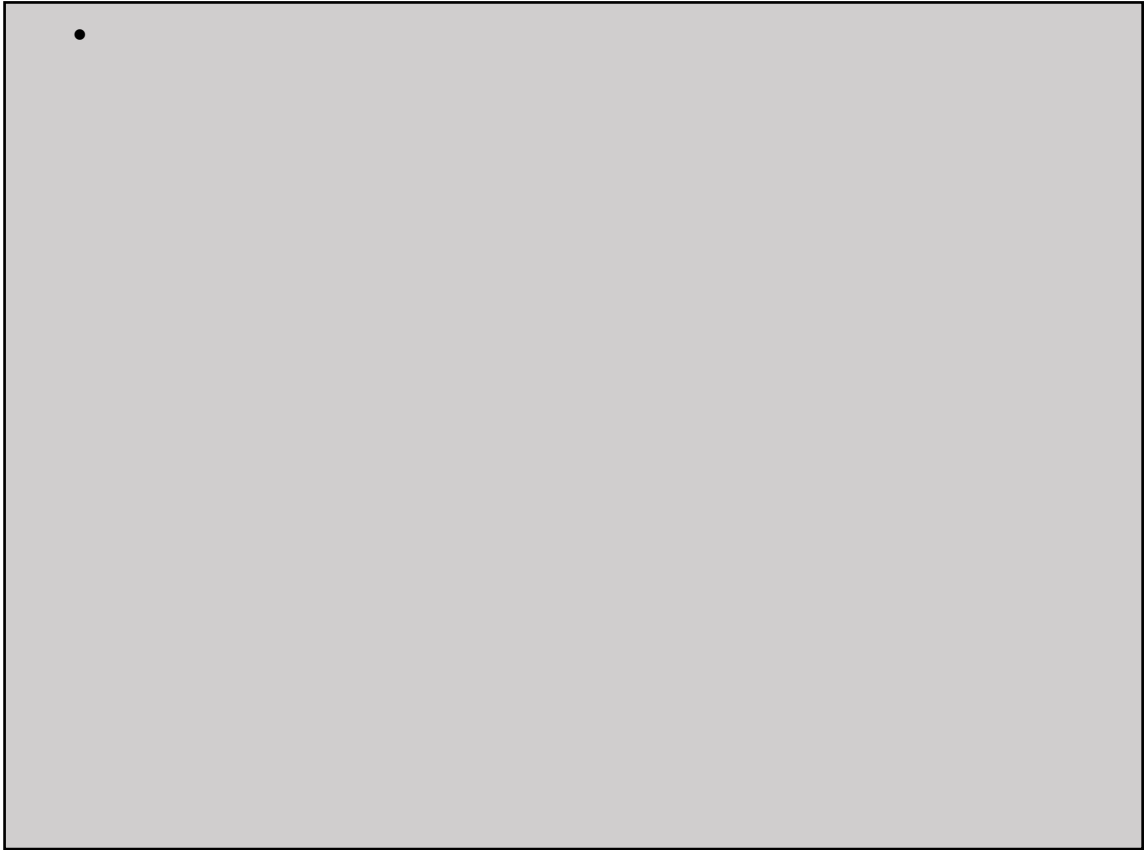
Materials

Ball, Challenge cards

Procedures

Psychosis basics ball toss game

1. Ask participants to stand in a circle.
2. Explain that you will play a game to understand what everyone in the room already knows about psychosis.
3. Toss the ball to a participant. When they catch the ball, the participant should say one thing they know about psychosis. For example:
 - What is psychosis?
 - Describe ways how psychosis is caused.
 - Describe some risk factors of psychosis.
 - Describe ways through which psychosis is treated.
 - Some known challenges faced by communities due to psychosis.
4. Once the participant has stated a piece of information, they should toss the ball to someone else and repeat.
5. Play the game until you reach saturation.
6. During the game, take notes on information shared and highlight any incorrect information.
7. At the end of the game, briefly summarize your notes. Highlight any incorrect information and provide correct information.
8. During the discussion, ensure that the following information on psychosis is communicated:



9. Conclude and ask participants:

- **How has psychosis impacted our lives and the lives of people we know?**
- **How has psychosis impacted our communities?**

Summary

1. Conclude this session by reinforcing and highlighting key challenges that have resulted into the design of PROMISE study.

Topic 2B: What is PROMISE study?

Objective

- Introduce PROMISE and implementing partners.
- Understand the objectives and outcomes of the PROMISE study.
- Understand PROMISE study approaches and methods.

Time

20 minutes

Materials

Flipcharts, markers

Procedures

1. Describe the institutions and partners behind PROMISE study and their roles and responsibilities in the study.
2. Explain the study design, objectives, duration, and study sites. In your explanation, the following information must be included:

- PROMISE is a longitudinal study that aims to build on existing services to develop sustainable psychosis detection systems and management pathways to promote recovery.
- The study will run for Five years in Chiradzulu, Salima and Ntcheu in the fourth and fifth year.
- The objectives of the study are to understand perspectives of psychosis in Malawi, to develop a psychosis detection system that is acceptable, to establish simple psychosis management system that is acceptable, and to evaluate the effectiveness and cost-effectiveness of the established psychosis detection and management systems.

3. Introduce and briefly explain the main approaches, outcomes, and some activities to be carried out in the study. In your explanation, include the following information:

- Systematic reviews.
- Photovoice research
- HSA surveys.
- In-Depth Interviews with Key Informants such as health care workers, religious leaders, traditional healers.
- Theory of Change Workshops.
- HSA manual development and piloting

4. Summarize by informing participants that they will be involved in some approaches and activities such as photovoice, Focus Group Discussions, In-depth Interviews, and Theory of Change Workshops.

Session 3

Introduction to Photovoice

This session will introduce participants to photovoice as one of the approaches and data collection methods for PROMISE, and how participants will be involved.

Outline

- Topic 3A – What is photovoice?
- Topic 3B – Ethical considerations during photovoice.
- Topic 3C – Basic photography and using smartphones.
- Topic 3D – Guiding questions.
- Topic 3E – Photovoice tools, materials, and forms.

Topic 3A: What is photovoice?

Objective

- Discuss various research approaches, including photovoice.
- Define photovoice as a data collection method.
- Discuss some advantages of using photovoice in the community.
- Understand the power of photographs.

Time

30 minutes

Materials

Flip chart papers, markers, sample photograph

Procedures

Discussion on different research approaches, including photovoice.

1. Discuss with participants and ask: **Who has ever been involved in a research study? What examples of research activities do they know?**
2. Write their responses down.
3. During the discussion, ensure that you discuss all possible research methods and then introduce them to another way of collecting data; photovoice. In your introduction, include the following information:

- Photovoice is a part of participatory action research that engages people who do not usually have a say in the decisions that affect their daily lives as a way for them to deepen their understanding of an issue. The goal of photovoice is to support the self-empowerment of participants by providing them with the opportunity to express their experiences and speak through photographs.

Discussion on benefits of using photovoice.

4. Now ask participants to discuss in groups what they think are the benefits of photovoice as a research approach.
5. Let them share what they discuss and add the following to their list if they have not been mentioned.

Benefits of photovoice

1. Empowering.
2. Allows community members to show how they view their community.
3. Allows people to speak differently about themselves, others, and the community.
4. Power-sharing research.
5. Involves community.
6. Creates a sense of belonging.

The power of photographs

6. Ask one participant to describe a memorable photo of their community. In their description, ask them; **What was happening in the photo? How is that photo related to their lives? How can that photo be used to educate others? What can be done about what is in the photo?**
7. Display your sample photograph to your participants and ask them: **What do they see? What is happening in the photo? How may that photo relate to their lives? How can that photo be used to educate others?**
8. Write down their responses on flip-chart paper.
9. Then explain to them how powerful photos can be when unearthing experiences, and perceptions because a picture is worth a thousand words.
10. Explain why photos will be important for them to express their views, experiences, and that of others, connect with other people in their communities, understand and connect with issues, and advocate for change.

Brainstorm of expectations

1. Divide the participants into two groups and give each group a sheet of flipchart paper.
2. Ask each group to discuss and write down their expectations of the photovoice exercise using the following sub-headings:
 - “Hopes”: **What do you and your community hope to get from the photovoice participatory action research under PROMISE study?**
 - “Fears”: **What do you think will not happen, or fear may happen?**
 - “Contributions”: **What special experience, perspective or skill do each of you contribute?**
3. Ask a representative from each group to present their sheet to the wider group.
 - Probe any expectations which may not be met and why.
4. Display the sheet for the rest of the workshop.

Topic 3B: Ethical considerations during photovoice

Objective

- Introduce core principles of ethical research.
- Identify subjects of photovoice research.
- Discuss possible ethical considerations during photovoice research.
- Discuss measures of ensuring ethical photovoice research.
- Discuss possible ways of addressing reported cases of unethical practice.

Time

45 minutes

Materials

Flipcharts, markers, and stick-on notes.

Procedures

Principles of ethical research with human subjects

1. Describe the three ethical principles.

- Respect for persons
- Concern for welfare
- Justice

Research subjects

2. Discuss possible participants and subjects in the photovoice research.
3. Let them write down their suggestions and summarize the discussion with the following:

- Participants: those taking the photographs. In this case, PWLE and care givers.
- Anyone whose private property or image may appear in the photograph taken by the participant (In this case, the 'subject' of the photograph)

4. Explain that as facilitators and researchers, you are aware of and understand the ethics involved for the photographs' participants and potential subjects.
5. Discuss with workshop participants some of the potential areas of ethical consideration in photovoice research.

6. Write down their suggestions. In summary, present the following information if not included.

- Important areas of ethical consideration during photovoice include:
 - a) **Privacy:** Photovoice participants must respect the privacy of those in the community. This includes both an individual's space, such as the inside or outside of a home or workspace, and the individual's privacy while in public space.
 - b) **Being placed in false light by images:** It is important that the subject's thoughts or feelings are not misrepresented by the photographers' narrative. The photographer must be sensitive of this during their photovoice experience.
 - c) **Protection against use of a person's likeness for commercial benefit:** It is unethical to use the photos taken by photovoice participants on promotional brochures or websites without the participant's and subject's permission.

7. Conclude by explaining that these are the most common and important ethical considerations in photovoice. As photovoice participants, they must remember them and be on the look as they take photographs of their subjects.

Ensuring ethical practice during photovoice

8. Ask participants what can be done during photovoice to ensure ethical practice. Write down their responses on a flip chart paper and summarize the discussion with the following information:

- To ensure ethical practice, photovoice participants must be fully informed about the photovoice project and must freely give their consent to be part of the project.
- Participants must understand that the photographs they take are theirs and can decide how their photographs can be used afterwards.
- Participants have the right to remove any of the photos they contribute at any point during the project.
- Photovoice participants should get written permission before taking a photograph of: **an individual (where the person is the focus of the photo). This includes family members and applies to places we often think as "public", such as stores, but are private. NB:** A participant is not required to get permission when taking a picture of a group of people where individual faces are not recognizable or if the participant is taking a photo of something and a person just happens to walk into the shot.

9. Explain to participants about obtaining informed consent from research subjects. Explain that informed consent must also be obtained from them as participants in the research. In your explanation, include the following:

- For subjects, obtaining informed consent means fully informing research subjects about the project prior to taking photographs of them.
- Full information includes who is conducting the research, how any information will be used, any potential risks, discomforts, and benefits, how and when they can withdraw their pictures, and contact information in case of any ethics violations.
- For participants, full information includes the same as those of the subject. As participants, they must also be aware that they can withdraw from the project at any point in time. Withdrawing from photovoice project means that photographs and their associated captions are removed from the project as well as any of their contributions to the group discussion.

10. Explain to participants these other ethical considerations:

- **Personal safety:** As participants enter the community to take photographs, they must be aware that their personal safety is more important than anything else. Participants must always use their best judgement and never put themselves in risky situations. For instance, don't stand in the middle of the road for that perfect shot, and be cautious about where you travel in the community, particularly by yourself, in the pursuit of a photo.
- **Confidentiality:** Photovoice participants must be aware that all conversations and discussions that are a part of the photovoice study must be kept confidential. Participants must always remember the confidentiality agreement.
- **Anonymity:** Participants must be informed that they are responsible for sharing their photos and their experience with all other participants during the sharing and discussion session. Participants will be given the option to be anonymous or anonymize some of the subjects during display. Project facilitators are responsible for protecting the identity of participants.

Addressing unethical practices

11. Explain to workshop participants the two possible ways to handle unethical practices during photovoice.
- a) Seek clarification from other participants or gatekeepers briefed before the photovoice project's inception.
 - b) Report the case to the local Principal Investigator or Ethics Committee chairperson using the contact information on the information sheet and consent form for further investigations.

Topic 3C – Basic photography and using smartphones.

Objective

- Understand basic photography concepts and what makes a better or more powerful photograph.
- Understand how to use smartphones.

Time

40 minutes

Materials

Flipchart papers, markers, smartphones

Procedures

Basic concepts of photography

1. Ask the participants if there is anyone that has experience with photography. If there is any, let them share what they know about photography and discuss it with the wider group. In the discussion, add the following information:

- Place the sun at your back when taking photographs.
- Use the flash outdoors even on a sunny day.
- Hold your camera steady. Hold the camera with both hands. This helps to avoid camera shake or vibration that leads to blurry pictures.
- Focus carefully on your subject.
- Pay attention to how you arrange the people, objects, and environment in your photograph; don't always think you must put the thing in the middle of the frame.
- Consider your distance from the subject.
- Clean your lenses.
- Shoot a burst of photos.

2. Conclude by emphasizing that participants must remember these basic concepts to produce high-quality, meaningful photographs.

Using smartphones

3. Introduce smartphones to participants and let them familiarize themselves with them. This process must include the following:

- Switching on and off the phone.
- Charging the phone.
- Navigating through the phone's menu.
- Opening and closing the camera, using flash, switching to night mode, rotating the camera, and deleting photos.
- Opening and closing the gallery.

4. Conclude by discussing tips on how to take care of smartphones to avoid damage.

Topic 3D – Guiding questions for photographs

Objective

- Guide participants on the photos they should take in their communities that will depict experiences and perspectives.

Time

20 minutes

Materials

Flipchart papers, markers

Procedures

1. Explain to participants that they are supposed to use smartphone cameras to take pictures that depict how they see psychosis, what they think it is, their experiences with the condition, and solutions to the challenges.
2. Please discuss with the participants some of the themes they can use to reflect how they experience living with psychosis and caring for someone living with psychosis. In your discussion, the following themes must be discussed.

- How psychosis is conceived as an experience.
- Challenges they face living with psychosis and caring for someone with psychosis.
- What are some of the idioms of distress they use to articulate psychosis as an experience?
- What role do healthcare providers, healthcare leaders, and traditional and religious leaders play and can play in the treatment and management of people living with psychosis?
- How do experiences and how do they conceive psychosis influence care-seeking practices?

Topic 3E – Photovoice tools, materials, and forms

Objective

- Introduce tools, materials, and forms to participants during the photovoice process.
- Understand photovoice forms.

Time

30 minutes

Materials

Flipchart paper, markers, consent forms and other forms, smartphones

Procedures

1. Present smartphones and chargers to participants as their main photovoice research tool.
2. Introduce and explain consent and other forms that participants will use throughout the process. When explaining, include the following information.

- First, explain about the study information to research subjects and obtain verbal consent before handing in a written consent for them to sign.
- Subjects that are able to write will sign by themselves, while those that are not able to write will identify an impartial witness to sign on their behalf.
- Make sure that subjects sign two forms. One copy will be left with them and the other copy will be kept by the participant for the study's record.
- Ensure that consent forms and all other forms are safely kept in pocket files that will be provided.
- It is the participant's responsibility to ensure that consent forms and other forms are correctly signed.

- **List of all forms**
 - Participant information sheet
 - Photovoice Private Property Photography Release form (Appendix 8).
 - Photovoice Photography release form.
 - Photovoice participants informed consent form.

Session 4

Next Steps

The session will introduce the next steps of photovoice research.

Outline

- Topic 4A – Photovoice research timeline and next steps.

Topic 4A – Photovoice research timeline & Activities

Objective

- Present and explain the implementation timeline.
- Introduce key photovoice activity dates.
- Understand the next steps of the photovoice activity.

Time

20 minutes

Materials

Flipchart paper, markers, photovoice timeline

Procedures

1. Present the following timeline to participants and let them mark important dates on their calendars.

- **29th May 2023 – Photovoice orientation workshop**
- **7th June 2023 – First photos feedback session**
- **19th June 2023 – Second workshop session 1 individual discussions**
- **20th June 2023 – Second workshop session 2 group discussions**
- **7th July 2023 – Third workshop/Dissemination**

2. Explain to participants that during the second workshop, photovoice participants will meet facilitators individually and select their best photos that they will later describe or provide a narrative using the SHOWED technique.
3. Let them also know that after individual discussions, they will go through the photos as a group of patients and caregivers.
4. Lastly, inform them that the final stage of the photovoice process will be a dissemination workshop/exhibition where they will present and discuss the main themes from their photos with other relevant stakeholders on psychosis.

Session 5

Role Play

This session will introduce participants to a practical photograph-taking activity and interpretation of photos.

Outline

- Topic 5A – Participants taking sample photographs.

Topic 5A - Participants taking photographs.

Objective

- Participants must be able to take good-quality photographs and produce a narrative out of the photos taken.

Time

20 Minutes

Materials

Smartphones, consent forms, SHOWED technique guide.

Procedures

1. Let the participants move around the venue and take pictures of their choice using the guiding questions.
2. Move around and ask them about the photos they have taken using the SHOWED technique guiding questions.
3. Provide feedback from your observations on the quality of the photos taken and the meaning of the photos taken.

Session 6

Questions & Answers

Time

15 Minutes

PROMISE Study Partners



References

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