

Visual-Based Research: Photovoice as an Exemplar

A Toolkit for Global Health Research





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We also wish to acknowledge the enduring encouragement and leadership of Professor Harry Campbell, Honorary Professor Ee Ming Khoo, Professor Sir Aziz Sheikh, and Professor Hilary Pinnock. Their vision and commitment have been instrumental in championing Photovoice as a transformative tool for participatory research and community empowerment.

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Professor Harry Campbell MBE
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FOREWORD

The burden of CRD continues to weigh heavily on communities across low- and middle-income countries, where barriers to diagnosis, treatment, and awareness persist. Since its inception in 2017, the NIHR Global Health Research Unit on Respiratory Health (RESPIRE) has worked alongside dedicated partners in Bangladesh, India, Malaysia, and Pakistan to tackle these challenges through robust, contextually relevant research.

In our journey to understand the lived realities behind the statistics, we recognised that numbers alone do not tell the full story. Photovoice, an arts-based participatory approach, has provided a powerful means of bridging this gap. By placing cameras in the hands of people living with CRD, we have gained profound insights into their daily struggles, resilience, and aspirations. These images and narratives have become catalysts for conversation, advocacy, and local action.

This Photovoice Toolkit reflects the collective experience, learning, and commitment of the RESPIRE collaboration in applying Photovoice not merely as a research method but as a means to engage communities, amplify marginalised voices, and inform policies. We hope it inspires researchers, health workers, and community leaders to embrace participatory approaches that place people at the heart of research and solutions.

We commend everyone involved, participants, researchers, and our dedicated partners, for their trust, creativity, and determination. May this toolkit serve both as a practical guide and a reminder that behind every health statistic lies a human story, deserving to be seen and heard.

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About the Toolkit



This toolkit is designed as a visual-based research guide, using photovoice as an exemplar for global health research. By combining images with narratives, photovoice offers a powerful means of inquiry, advocacy, and policy engagement, particularly in low-resource settings and among communities affected by limited literacy and health literacy.

While we build on decades of photovoice scholarship, this resource places patient and public involvement and engagement at its core. Every stage, from planning to deciding how images are shared, was co-designed with community partners. The result is a practical, step-by-step guide to planning, implementing and disseminating photovoice projects in global-health settings. It is written for researchers, community health workers and organisations who want to co-produce knowledge with communities, rather than conduct research about them.

To support learning and reflection, each chapter follows a consistent structure:

- 01 Key Concepts** Introduces foundational ideas and terminology.
- 02 Case Study** Presents real-world examples of how photovoice has been applied in global health contexts.
- 03 Stop and Reflect** Provides prompts and reflective questions to deepen understanding and support local adaptation.
- 04 Activity** Presents real-world examples of how photovoice has been applied in global health contexts.
- 05 Chapter Summary** Highlights key takeaways from the chapter.
- 06 Next Steps** Prepares readers for the next chapter by highlighting key content and suggesting ways to build on their learning.

This structure is designed to make the toolkit adaptable for use in workshops, research teams, or self-guided study. It invites readers to move from theory to practice and from insight to action.

Purpose of the Toolkit



1

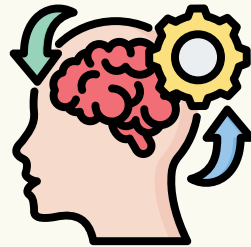
Empower Communities

Provide a platform for individuals to document and voice their lived realities.

2

Enhance Inclusion

Ensure that individuals with low literacy and health literacy are meaningfully engaged in research and decision-making processes.



3

Strengthen Advocacy

Use visual narratives to bridge the gap between lived experiences and policy change.

4

Support Low-Resource Settings

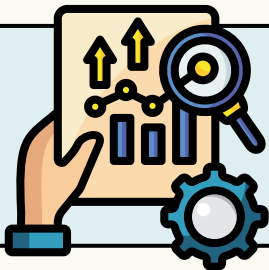
Offer an adaptable, cost-effective method for capturing and sharing community challenges and solutions.



5

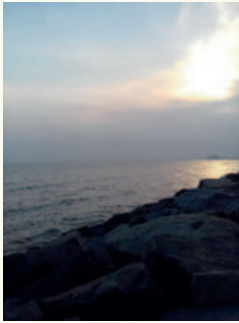
Improve Health Research Methodologies

Promote participatory research approaches in global health research.



Our Vision: Through the Lens of the Community

Why Photovoice?



“My children love the beach. However, I hope I can have the strength of the waves; it has its ups and downs, but never ceases to crash on the seashore. I pray that I’ll never give up, no matter how difficult or how breathless. I will live for my children.”

31-year-old woman with asthma, mother of two.

Alongside this quote, a photo: waves crashing against a rocky shore. Unyielding, determined, like the mother who took it. This is not just an image. It is a message, a metaphor, a life lived.

Photovoice begins here.

Imagine living with breathlessness so severe that even walking from your bed to a chair feels insurmountable. Imagine the fear of holding your grandchild, afraid your illness might harm them. For millions, this is not imagination, it is daily life. Respiratory diseases do not simply affect the lungs, they dictate how people live, work, love, and hope.

Yet numbers alone cannot convey this.

Shifting the Narrative: The Power of Photovoice

Photovoice transforms research into advocacy. By putting cameras in the hands of those living with chronic respiratory illness, it empowers participants to frame their own stories, literally. It shifts the power dynamic from observer to narrator, from data subject to storyteller.

“Even walking on the ground level, I get breathless. I cannot walk up the stairs. Whenever I go out, I carry my inhaler with me.”

72-year-old man with asthma for 35 years



Through the pairing of photographs and personal captions, Photovoice evokes empathy, drives understanding, and fosters policy dialogue in ways clinical data alone cannot.

A Global Commitment to Respiratory Health

Since 2017, the NIHR RESPIRE collaboration, spanning Bangladesh, Bhutan, India, Indonesia, Malaysia, Sri Lanka, and Pakistan, has been working with the University of Edinburgh to transform respiratory health systems in low-resource settings. Much of this work has focused on epidemiological surveys and clinical research, such as the Four Country ChrOnic Respiratory Disease (4CCORD) study, which estimated the prevalence and burden of chronic respiratory diseases (CRDs) in adults in LMICs, based on findings from Bangladesh, India, Malaysia, and Pakistan.

But data alone cannot capture the full story.

Behind the numbers were silent stories of isolation, stigma, breathless nights, and disrupted livelihoods. The question remained: *what does it actually feel like to live with a chronic lung condition in a resource-constrained community?*

To answer that, RESPIRE turned to Photovoice.

Photovoice was not just a research method, it was an invitation. Across Bangladesh, India, Malaysia, and Pakistan, individuals living with CRDs were invited to use photography to capture their world, the things that helped them breathe, the moments that made it harder, and the quiet truths in between.

What emerged were images and testimonies that moved beyond symptoms to reveal the emotional, social, and environmental realities of CRDs. A grandmother too breathless to hold her grandchild. A man who carries his inhaler like a lifeline. A mother who draws strength from the sea to care for her children.

Through Photovoice, participants became storytellers. Their photographs filled the gaps left by conventional research, making visible the often invisible burdens of illness. More than that, they became advocates, co-creators of knowledge, helping shape conversations that inform policy, education, and care.

A Toolkit for Change



Photovoice is where science meets soul. It bridges the gap between cold statistics and the warm, painful, messy truths of human life. This toolkit is built to guide researchers, health workers, and community leaders on how to use Photovoice not only to gather evidence but to spark empathy, dialogue, and ultimately, action.

Because behind every statistic is a story. And behind every story is a voice worth hearing.

“I just watch TV every day. Nothing much I can do. Even walking to this chair from my room is difficult.”

84-year-old man with COPD

A Global Commitment to Respiratory Health

“My husband says that I should not go near the baby, or kiss the baby, because of the breathing difficulty that I have. I may infect the baby. I feel really bad about it.”

42-year-old woman with asthma

Every photo in this toolkit, every quote, every caption comes from the lived experiences of real people who took part in the RESPIRE Photovoice project. These aren't just images. They are insight. They are advocacy. They are catalysts for change.



Let them **SPEAK**. And let us listen, not just as researchers, but as humans.

Who is this Toolkit For?

This toolkit is designed for:



Researchers and Academics

Who are seeking to integrate participatory visual methods into their global health research to enhance community engagement, inclusivity, and impact.



Community Health Workers and Non-Governmental Organisations

Who are seeking to engage communities in meaningful ways to document health challenges and share lived experiences.



Healthcare Professionals and Policymakers

Who aim to understand lived experiences and translate them into actionable, community-informed policies.



Individuals and Communities Affected by Health Conditions

Who are seeking to use photography to express their experiences, raise awareness, and advocate for meaningful change.

By incorporating RESPIRE's experiences into this toolkit, we highlight how photovoice is not merely a research tool but a catalyst for change, ensuring that those affected by respiratory diseases are not simply subjects of research, but active participants in shaping solutions.

Background of Visual-Based Research

Visual-based qualitative research methodologies encompass a range of approaches that utilise visual materials to collect and analyse data. These methods draw on images, drawings, videos, and other artistic media to explore participants' experiences, perceptions, and social realities.

Several visual-based qualitative research methodologies are commonly used, including:

1

Visual Ethnography

Combines traditional ethnographic techniques with visual tools to document and analyse cultural practices through images. Captures everyday life in its natural context, often using photographs or video recordings to offer a richer understanding of social interactions and cultural phenomena [1].

2

Photo-elicitation

Uses photographs as prompts during interviews or discussions, encouraging participants to reflect on images that may evoke memories and insights not easily accessed through words alone. Particularly effective for exploring sensitive topics or difficult-to-articulate experiences [2].

3

Photo-novella

Engages participants in capturing a series of photographs that document key aspects of their lives, complemented by personal narratives or captions to provide deeper context. Empowers individuals to tell their own stories and reveals nuanced insights into complex social and personal issues [3].

4

Auto-photography

Invites participants to take photographs representing their daily lives or specific research themes. Offers a means for participants to visually express their perspectives, providing access to valuable insights into their lived realities [4].

5

Photovoice

Applies a participatory research approach in which individuals use photography to document and reflect on their experiences. Participants may use their own cameras or mobile phones, or be provided with equipment, to capture images that represent meaningful aspects of their lives or communities, fostering empowerment, dialogue, and advocacy [5].

In conclusion, visual-based qualitative methods offer powerful ways to explore human experiences through images. Photovoice, in particular, empowers communities to share their stories and advocate for change.



01

Introduction to Photovoice: Concepts, Preparations, and Design

Overview of Photovoice

Photovoice is a participatory action research method and is fundamentally transformative. The research process enables individuals and communities to document, reflect on, and communicate their lived experiences through photography [5].

The Photovoice method is grounded in three key theories, as described by Wang and Burris [5]. First, it draws on Freire’s theory of critical education, using visual imagery to help people critically examine societal issues and engage in dialogue to identify common themes [6]. Second, Photovoice has historically played a role in challenging gender oppression by emphasising diversity and gender-related issues [7]. Third, it is community-based, empowering ordinary individuals to document and drive change within their communities through the use of a camera [8].

The original Photovoice methodology followed a sequential, group-based process [5]. It began with an initial engagement session, during which the research aims were explained to recruited participants. This helped them understand their assignment and included group training on taking photographs. Within a given timeline, participants were then encouraged to take photographs individually. However, only selected key photographs were chosen by the group to stimulate discussion on personal and community issues of shared importance. This was followed by a group dialogue with policy-makers, using the selected photographs as prompts, and concluded with a workshop evaluating participants’ reflections on the process [5].

Photovoice is a relatively new research method in many RESPIRE settings. To implement Photovoice in the community, we were mindful of local cultural norms [9,10], considered feedback from patient and public involvement (PPI) members*, and adapted the method to suit our available resources and contextual needs [11]. The adapted approach was informed by lessons learned from similar studies conducted in comparable settings [12–15].

**Patient and Public Involvement (PPI) refers to the active involvement of patients, carers, and the public with or by whom health research is carried out, rather than to, about, or for them. PPI helps ensure that research is relevant, acceptable, and responsive to the needs of the people it aims to benefit [16].*

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download
Stakeholder
Engagement in
Global Health
Research:
A Resource Guide



Getting the Team Ready: Study Preparation

Building the Right Team

A successful Photovoice study requires a multidisciplinary team that includes:

- Researchers – who design the study, uphold ethical standards, and lead discussions that shape the research questions and objectives.
- Community facilitators and field workers – who build trust with participants, support them through the process, and connect academic research with lived community insights.
- Data analysts – who interpret both visual and narrative data using qualitative methods to uncover deeper meanings and themes.
- Additional expertise – depending on the study’s focus, this may include specialists in public health, communication, social work, advocacy, or policy to help translate findings into action.

This collaborative approach draws on diverse skills and perspectives, ensuring the Photovoice study authentically captures community experiences and supports meaningful impact.

Study Preparation: Key Steps

- A well-prepared Photovoice study lays the foundation for ethical, inclusive, and impactful engagement.
- Understand the community context – Engage local stakeholders early to ensure cultural appropriateness and ethical sensitivity.
- Establish ethical safeguards – Secure informed consent for the use of photographs, particularly when working with vulnerable populations.
- Select appropriate tools – Provide accessible equipment such as cameras or mobile phones, and deliver simple training.
- Develop training materials – Create infographics, audiovisual guides, and hands-on workshops to support both facilitators and participants.
- Plan for data analysis – Define how both visual and narrative data will be interpreted using qualitative methods, ideally with cost-effective analysis tools.
- Create a data management plan – Ensure your plan is realistic and appropriate to your team’s available resources.
- Outline dissemination strategies – Detail how findings will be shared with participants, stakeholders, and decision-makers to support advocacy and policy influence.

Design and Adaptation

Photovoice is not a one-size-fits-all method. The study design should be adapted to the specific needs of the community, the available resources, and the local cultural context.



Below are key strategies for adapting Photovoice in low-resource or diverse settings:

Use alternative technologies

If cameras are unavailable, mobile phones can serve as a practical substitute.

Apply flexible training and data collection methods

Combine in-person and remote formats as needed to accommodate accessibility and logistical constraints.

Address language and literacy barriers

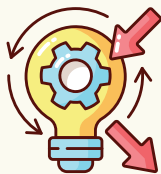
Encourage verbal storytelling or spoken narratives alongside written captions to support participants with low literacy.

Facilitate community-led discussions

Allow participants to identify their own themes and priorities, ensuring that the issues explored are grounded in lived realities.

By thoughtfully adapting Photovoice methodologies, researchers can ensure inclusive participation and maximise relevance and impact, even in challenging environments.

Stop and Reflect



Think about the photograph you recently took.

- Did it capture a moment or emotion that words alone couldn't express
- How might photography, with its ability to capture subtle nuances, reveal public health challenges more vividly than traditional data?

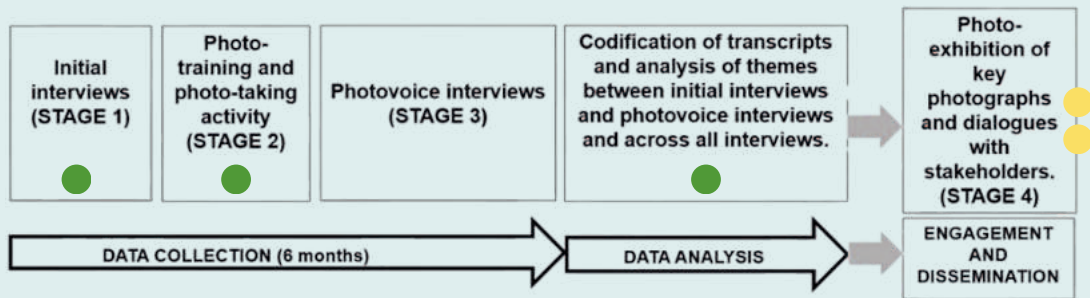


Figure 1.1: Overview of the study steps

(Green circles indicate stakeholder engagement (SE) activities, while yellow circles indicate community engagement and involvement (CEI) activities.)

Case Study 1:

Adapting the Methodology for the RESPIRE Project

We designed a core protocol to fulfil the study objectives, in consultation with six RESPIRE partners across four countries, ensuring that it could be adapted to suit local needs in different settings. This study aims to understand community perceptions of CRDs and engage communities through the Photovoice method.

In the core protocol, Photovoice was adapted into four stages (Figure 1.1). One-on-one or group engagements were used throughout the study, depending on the context of each site. The study began with an in-depth qualitative interview, which served as an entry point to build rapport, gain trust, and introduce the project. During this interview, participants were informed about the full study process, including the Photovoice stage, and invited to take part.

If participants expressed interest in continuing, they received individual training on how to use the camera or smartphone for taking photographs, alongside a discussion on the ethical considerations of visual research. Participants were given up to a month to complete the photo-taking task. In keeping with evolving practice and the increasing accessibility of technology, many sites opted to use smartphone cameras rather than traditional film or digital cameras.

Once the images were captured, follow-up sessions were held to discuss and reflect on the photographs. In Stage 4, community discussions and/or policy dialogues were conducted with participants to share insights and facilitate broader engagement.



By Shahidul Islam, Child Health Research Foundation (CHRF), Bangladesh

Case Study 2:

Building Qualitative Research Skills for Photovoice

The research team at CHRF Bangladesh had extensive experience in quantitative research, particularly in survey-based studies and statistical modelling. However, conducting a Photovoice-based qualitative study required additional competencies in narrative data collection, participatory approaches, and thematic analysis.

To support this, decisions were made to assign researchers with prior experience in conducting interviews and facilitating focus groups to lead the Photovoice study. While some team members were familiar with participant engagement, there were still gaps in areas such as qualitative coding, ethical considerations specific to visual methods, and the adaptability needed for open-ended, narrative-driven research.

To address these needs, a targeted two-month training programme was implemented. It covered the fundamentals of qualitative research, the Photovoice methodology, ethical and community engagement considerations, and practical data analysis techniques. A key component of the training involved a simulated session with real patients. The exercise was designed to feel authentic, research staff were not informed that it was a simulation. These interviews were recorded and reviewed in structured feedback sessions, focusing on interviewing techniques, rapport building, and the ability to elicit meaningful narratives.

Based on performance and responsiveness to feedback, team roles for qualitative data collection were finalised, ensuring that those most suited to the participatory and narrative elements of the study were engaged.

This rigorous approach helped build the team's confidence and competence in applying qualitative research methods. The experience reinforced the importance of hands-on practice, continuous mentoring, and adaptability when integrating participatory methodologies like Photovoice into health research.

Activity 1

Seeing the World Through a Lens – A Photovoice Simulation

Objective: This activity allows participants to experience the essence of Photovoice by capturing images and reflecting on their meanings. It reinforces key concepts of participatory research, visual storytelling, and qualitative analysis.

Instructions:

1

Capture an Image

Take a photograph of something in your surroundings that represents a challenge or strength in your community. This could be symbolic (e.g. an empty clinic chair representing limited access to healthcare) or literal (e.g. a bustling street market reflecting economic resilience).

2

Write a Caption

Write a short caption (1–2 sentences) explaining why you took this photograph.

Consider:

- What does the image represent?
- Why is this issue important?
- What message do you want to convey?

3

Share and Discuss

If working in a group, exchange your photographs and captions with a partner.

Discuss:

- How does their image make you feel?
- Do you interpret the image in the same way?
- What additional context might help others fully understand it?

4

Reflect on Photovoice in Research

Think about how Photovoice could be applied in health research.

- What types of images might patients, carers, or healthcare workers capture?
- How can photographs reveal insights that surveys or interviews might overlook?

Debrief and Discussion Questions

- How did taking a photograph change the way you perceive everyday issues?
- What challenges did you face in expressing an idea through an image?
- How does this exercise reflect the core principles of Photovoice?

Alternative Adaptation for Online or Individual Participants

If completing this activity alone, reflect on photographs you already have on your phone, or search for a public image online that relates to a public health issue.

Follow the same steps: write a caption, reflect on the meaning, and consider how the image could be used within a Photovoice research project.

02

Getting Ready – Preparing Researchers and Materials for data collection



Before conducting a Photovoice study, it is crucial to ensure that researchers are well-trained and that materials are appropriately prepared. A well-prepared research team enables ethical, effective, and meaningful engagement with participants. This chapter explores the essential steps in preparing for data collection, training researchers, and developing key materials to facilitate a successful Photovoice project.

Preparing for Data Collection

Understanding the Research Context

Before starting data collection, it is essential to understand the community in which the research will take place. Consider:

- Community needs and concerns – What health issues or social challenges are most relevant?
- Cultural norms and sensitivities – Are there photography-related taboos or ethical considerations?
- Access to technology – Do participants have mobile phones or cameras? Will they require additional training?

Gaining Entry to the Community



Building trust with the community is essential for fostering meaningful participant engagement. To support this, the research team should begin by partnering with local facilitators and health workers who already have established, trusted relationships within the community. Their involvement helps bridge cultural or communication gaps and lends credibility to the project.

Equally important is the process of obtaining informed consent, which must be handled with clarity and care. Every participant should fully understand what their involvement entails, ensuring that consent is both informed and voluntary. These combined efforts help establish a strong foundation of trust and respect.



Organising introductory meetings with community leaders is also a key step. These sessions provide an opportunity to explain the research purpose, address concerns, and initiate open, transparent communication. Engaging directly with community leaders enables the team to build a collaborative environment from the outset.

Case Study 3:

Field Engagement Experiences in Conducting Photovoice in a Tribal Community, India

Conducting Photovoice in tribal communities requires more than methodological rigour, it demands deep trust, cultural empathy, and responsive, grounded fieldwork. The participatory nature of Photovoice enabled researchers not only to document lived realities but also to engage meaningfully with participants in their own world, on their own terms. This case study illustrates how trust and empathy were cultivated through the method, lessons shaped by MAHAN's decades-long presence in Melghat, a tribal region in Maharashtra, India.

Trust Built Over Decades

MAHAN Trust (Meditation, AIDS, Health, Addiction, Nutrition), founded by Dr Ashish and Dr Kavita Satav, has delivered community-based health services in Melghat for over 20 years. In two of the selected villages, long-standing trust and an existing list of patients with CRD made engagement seamless. In the third, more remote village, no such list was available. Yet, the community welcomed the team, a testament to the enduring relationships MAHAN had nurtured over time (Photo 2.1).



Photo 2.1: Community exhibition



Photo 2.2: Manasi during a fieldwork

Learning Through Observation and Empathy

Empathy deepened not through data, but through experience. Dr Manasi recalled a moment when she saw a young girl carrying a water pot barefoot. Attempting to replicate this act later herself, she grasped the difficulty firsthand (Photo 2.2). In another encounter, an elderly woman offered vegetables to the team. Initially hesitant, Dr Manasi accepted, moved by the generosity. These moments blurred the line between researcher and participant, highlighting the emotional depth Photovoice can surface.

Navigating Gender Sensitivities and Language Barriers

Older and middle-aged women were often reluctant to speak in Hindi, especially in mixed-gender settings. Despite encouraging the use of local dialects, silence persisted. It was only through the support of village health workers, long embedded in the community and trained by MAHAN, that rapport was gradually built. These health workers had normalised women's participation in healthcare discussions, a critical enabler for the project.

Meeting Participants in Their Own World

Engagement meant stepping into the rhythms of everyday life. On one visit, a participant's wife said, *“Ma'am, your life is easy. You come and go by ambulance; we cannot afford to stop.”* Rather than retreating, Dr Manasi stayed, asking about groundnut farming and helping clean the harvest (Photo 2.3). This simple act of solidarity changed the tone: the woman who had initially declined later encouraged her husband to participate.



Photo 2.3: Participant's home

Patience Amid Logistical Barriers

With no mobile network and intense agricultural routines, fieldwork required patience. The team often waited for hours, helping with chores or teaching children. In one instance, a participant initially declined but changed his mind after a compliment on his handmade animal feeding tub; a moment of human connection sparked willingness.



Photo 2.4: Community engagement

Immersive, Culturally Sensitive Engagement

Researchers adapted to local norms, participating in tribal dances, dressing modestly, sitting on the ground, and shedding formal titles. These choices, inspired by MAHAN's community-first ethos, fostered a sense of equality and openness that enabled candid sharing (Photo 2.4).

Responding Respectfully to Disruption

In one case, a man with a history of alcoholism discouraged others from taking part. Drawing from MAHAN's experience in deaddiction, the team avoided confrontation. Instead, they reassured participants that every story was valuable and personal, preserving trust without alienating the individual.

This case study demonstrates that Photovoice is not just a tool for data collection; it is a catalyst for relational and ethical engagement. Its strength lies in its flexibility to meet participants where they are, both physically and emotionally. The success of this study was made possible through MAHAN's longstanding presence, but it was Photovoice that enabled these relationships to be translated into co-created, visual narratives of lived experience.

Training Researchers

A successful Photovoice study depends on researchers who are well-versed in both qualitative methods and participatory approaches.

Key Skills for Researchers

- A solid understanding of the Photovoice methodology is required to effectively facilitate visual-based research.
- The ability to conduct qualitative interviews using open-ended, participant-led conversations.
- A commitment to ethical standards, including ensuring confidentiality, obtaining informed consent, and handling photographs responsibly.
- Strong community engagement skills to build trust and support truly participant-driven research.

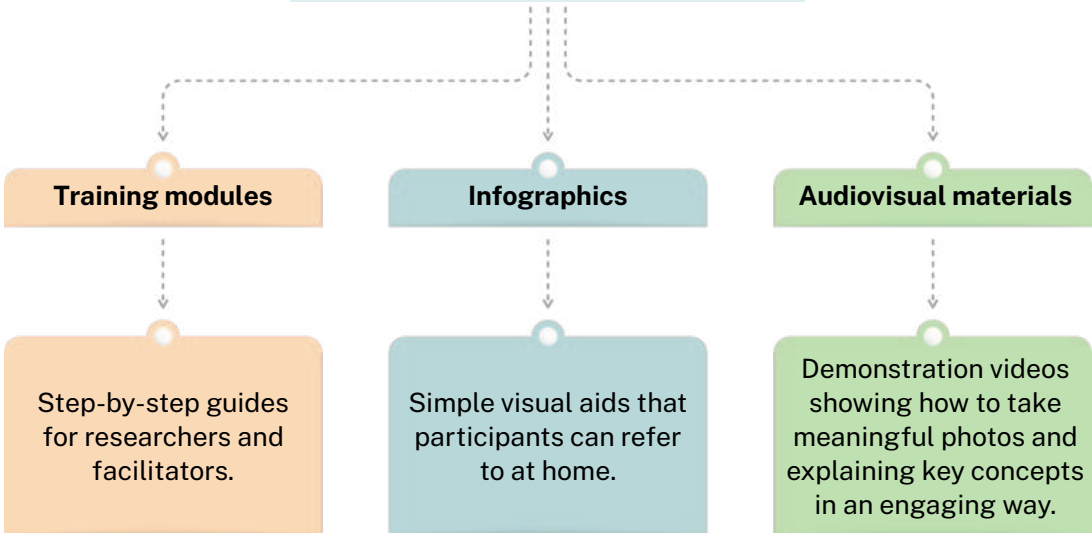


Preparing Materials for Data Collection

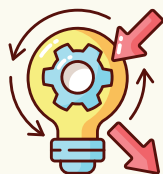


Why Do Materials Matter?
Clear and accessible materials enable participants to understand the Photovoice process and engage meaningfully in data collection.

Three Essential Training Materials



Stop and Reflect



Think about a time you learned a new skill (e.g., baking a cake or driving a car).

- What challenges did you face at first?
- What helped you improve?
- How might these insights apply to training participants to take photographs in the context of research?



By Dipali Digambar Dhamdhere, KEM Hospital Research Centre (KEMHRC), India

Case Study 4:

Enhancing Research through Context-Based Adaptation in Photo-Taking Practices

The Vadu Health and Demographic Surveillance System (HDSS) area, the field site for KEMHRC, benefits from relatively easy access to study participants due to its ongoing surveillance activities. However, a key challenge emerged: most participants, primarily individuals over the age of 40, were not comfortable using smartphones and were unfamiliar with the camera function.

As the research team at KEMHRC initiated the Photovoice study, they observed that participants faced considerable difficulties in understanding the photo-taking process. Many were unsure what to photograph, how many images to take, and what should or should not be included in the frame. This uncertainty led to issues such as blurry, irrelevant, or misaligned images that did not meaningfully contribute to the study objectives. Recognising the need for structured guidance, the team developed a Photo-Taking Guide to support participants in navigating this unfamiliar task.

During the initial phase of data collection, participants encountered both technical and conceptual challenges. Some struggled to hold the smartphone steady, resulting in poor-quality images. Others were unsure which aspects of their daily lives were relevant to the study; some captured random objects unrelated to the research themes, while others took selfies in various settings. Additionally, several participants were hesitant to photograph personal or sensitive situations, highlighting the need for ethical guidance on privacy and consent. Furthermore, instead of curating a few meaningful images, many submitted hundreds of photos, including duplicates and low-quality shots, leading to problems such as reduced phone storage and excessive data usage.

To address these issues, the KEMHRC Photovoice team designed a comprehensive and culturally appropriate Photo-Taking Guide. This guide provided step-by-step instructions using simple language and visual examples to aid understanding. It outlined key themes relevant to the study, giving participants a clear framework for selecting meaningful subjects. A list of Do's and Don'ts was also included, emphasising points such as focusing on a single subject per frame, avoiding cluttered backgrounds, and maintaining privacy by excluding identifiable personal details.

Beyond technical guidance, the team ensured that the guide was closely aligned with the research domains. Drawing on feedback from early participant interviews, they refined the themes to ensure the photographs would capture a broad yet relevant range of lived experiences. This adaptation not only improved the quality of the images but also deepened participant engagement, giving individuals a greater sense of ownership over the research process.

The implementation of the Photo-Taking Guide led to significant improvements. Participants reported feeling more confident and comfortable using mobile cameras, resulting in clearer, well-composed, and thematically relevant images. The structured approach ensured that photographs aligned with the study objectives, making the data more meaningful and suitable for analysis. Beyond research outcomes, many participants expressed a newfound interest in mobile photography, describing it as a valuable new skill. Some shared that they felt empowered to use their phones for personal documentation, an unintended but positive outcome of the study.

The success of this approach highlights the importance of adapting research methods to the technological familiarity and cultural context of participants. KEMHRC's iterative adaptation of the Photovoice methodology illustrates how simple, well-structured tools can transform challenges into opportunities for both researchers and participants. By ensuring participant-friendly resources, ethical safeguards, and practical learning opportunities, the study not only enhanced data quality but also contributed to digital literacy and community engagement.

Activity 2

Role-Playing as a Photovoice Researcher

Objective: This interactive activity helps participants build essential skills for preparing a Photovoice study, including community engagement, informed consent, and ethical practice. It highlights real-world challenges and strengthens problem-solving and communication before fieldwork.

Instructions:

1

Assign Roles

Divide into small groups. Assign each person a role:

- Researcher – Explains the study and engages with the participant.
- Community Member – Acts as a participant (e.g. elder, youth, health worker, farmer).
- Observer – Watches the interaction and gives feedback on communication and rapport.

2

Simulate a Field Visit

The Researcher meets the Community Member and practises:

- Introducing the Photovoice project simply and appropriately.
- Building rapport through respectful conversation.
- Explaining informed consent (purpose, photo use, rights).
- Addressing ethics (privacy, consent, risks).
- Checking technology access (mobile phone/camera use).

3

Reflect and Give Feedback

- Observer: Did the researcher explain clearly, build trust, and address ethical concerns?
- Community Member: Did they feel comfortable and heard?

Rotate roles so everyone experiences each perspective.

Debrief and Discussion Questions

- What strategies worked best for engaging with participants?
- What challenges did you face in explaining informed consent and ethical considerations?
- How can researchers ensure that participants feel comfortable and empowered in the study?
- What improvements can be made before conducting a real Photovoice project?

Alternative Adaptation for Online or Individual Participants

If completing this activity alone, participants can:

- Write a script for how they would introduce Photovoice to a new community.
- Record themselves explaining informed consent and review their clarity and engagement.
- Reflect on potential challenges and how they would handle them.

03

Engaging participants – Photo-training, practical exercises, and adaptations



A Photovoice study is most effective when participants feel confident and empowered to visually share their experiences. This chapter explores how to engage participants through photo-training, practical exercises, and appropriate adaptations, ensuring their photographs align with research objectives while maintaining authenticity and ethical integrity

Preparing Participants for Photo-Taking

Understanding the Research Context

Before participants begin taking photographs, researchers must ensure they understand the study and their role within it. Clarity at this stage helps prevent confusion, ethical missteps, and irrelevant data collection.



Key Steps in Participant Preparation

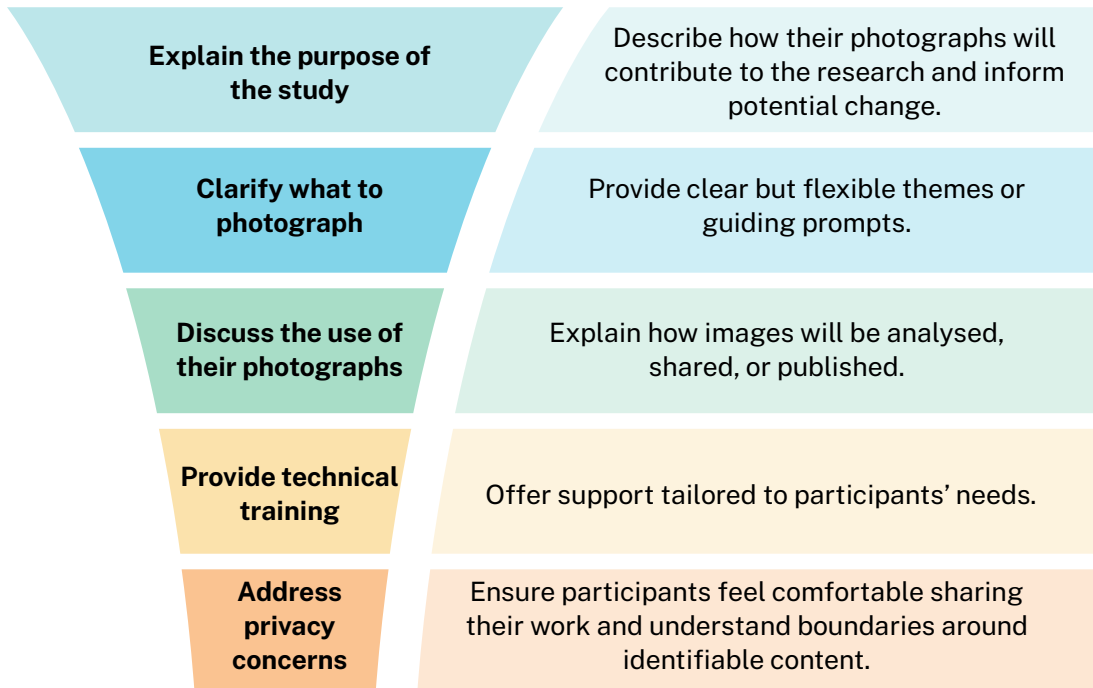
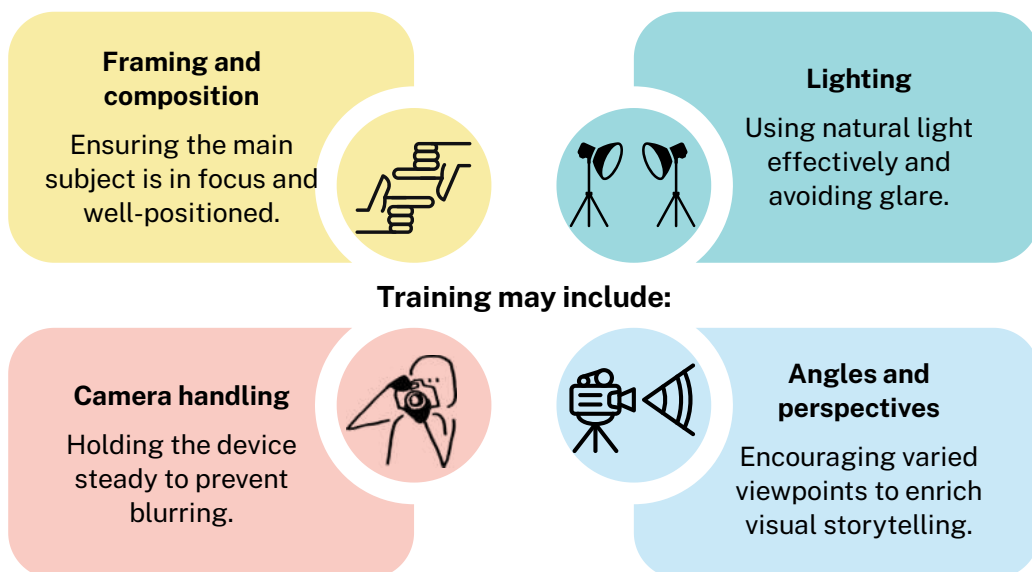


Photo-Training and Photo-Taking

Technical Training

While storytelling is central to Photovoice, basic technical skills help participants take clear and compelling images.



Practice sessions, including test shots and feedback, can build confidence while respecting participant autonomy.

Ethical Training

As Photovoice involves personal and sometimes sensitive storytelling, it is essential to address ethical considerations before data collection.

Consent and Privacy Considerations

- Participants must seek consent before photographing identifiable individuals.
- If children are photographed, consent must be obtained from parents or guardians.
- Blurring faces or cropping images may be necessary to ensure privacy.

Culturally Appropriate Photography

- Certain communities may have taboos surrounding photography, such as religious beliefs or gender-related restrictions.
- Researchers should encourage respectful and culturally sensitive approaches when taking photographs, always prioritising local norms and values.

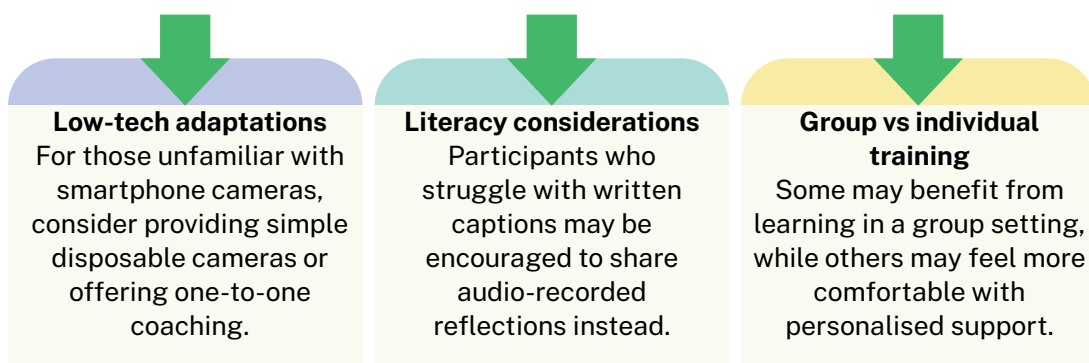
Participant Safety

- Participants should never put themselves at risk to capture an image, for example, taking photos in unsafe environments or while crossing the road.
- They should also be reminded to respect both public and private spaces when taking photographs.

Adapting Training for Different Participants

Not all participants will have the same level of literacy, technological familiarity, or confidence in using cameras. Researchers must acknowledge that participants are not professional photographers and manage expectations accordingly. The goal is for participants to capture images and narratives that are meaningful to them.

Training and support should be adapted to meet participants' individual needs:



Researchers should offer guidance and encouragement, but avoid over-directing. It is essential that participants maintain full ownership of their visual storytelling process.



By Ramsha Tariq Baig, Stakeholder Engagement Champion, Allergy & Asthma Institute Pakistan (AAIP)

Case Study 5:

Enhancing Research through Photo-Training and Photo-Taking: Key Insights and Recommendations

Working on a Photovoice project in the local community near AAIP in Islamabad proved to be a deeply rewarding experience for the researcher. The initiative aimed to use photography as a research tool, enabling participants, particularly women in rural areas, to share their lived experiences with CRDs. This approach offered unique insights into their challenges and daily lives, enriching the research process through authentic, visual narratives.

Key Insights from Photo-Training

The photo-training sessions formed a pivotal component of the project. At the outset, many participants were unsure of what to photograph and expressed concern about the technical quality of their images. Common questions included, *“Do you want a picture of my medicine or my inhaler? Is this good enough?”* The researcher reassured them that the goal was not professional quality but the honest representation of their lived experiences.

One particularly impactful photograph captured a woman with severe asthma cooking over an open fire. She shared, *“This is my life. No matter how bad my coughing gets, I have to prepare meals for my children.”* The rawness of this image powerfully conveyed her dual struggle with ill health and socioeconomic hardship. Such moments illustrated how even simple photographs could carry profound meaning.

To support the training, the researcher developed animated videos that demonstrated ethical practices and common scenarios participants might encounter. These animations depicted everyday challenges faced by people living with CRDs, such as navigating polluted environments or managing daily routines, making the sessions more engaging and relatable.

Addressing Challenges

Despite the project's success, several challenges emerged. Some participants felt self-conscious about revealing their homes or personal conditions. To address this, the researcher emphasised creative freedom, encouraging participants to choose how best to represent their realities. Rather than providing staged examples, participants were guided to focus on what felt meaningful to them.

Ensuring ethical photography was another critical consideration. Participants were trained to avoid capturing identifiable features or including individuals without consent. The animations helped simplify these ethical guidelines, ensuring they were clearly understood and consistently followed.

Recommendations for Future Initiatives

This project underscored the value of visual storytelling in research, particularly in empowering communities to share their perspectives. Based on these experiences, the following recommendations are offered:

Culturally sensitive training

Incorporate relatable visual aids, such as animations or simple scenarios, to engage participants and clarify expectations.

Participant autonomy

Encourage self-expression without imposing rigid instructions or aesthetic standards.

Ongoing support

Affirm participants' efforts throughout the process to build their confidence and ensure meaningful contributions.



Photovoice is more than a method; it is a platform for empowerment. When combined with participatory research, visual tools can capture rich, authentic narratives that offer valuable insights for both communities and stakeholders. This project serves as a powerful reminder of the potential of collaboration and creativity in research.

What Can Go Wrong?

Common Challenges in Photo-Taking



- Blurry or Poor-Quality Images – Participants may find it difficult to hold the camera steady or may take photos in low-light conditions.
- Photos Without Context – Without clear captions or explanations, the meaning of an image can be misunderstood or lost.
- Ethical Missteps – Participants may unintentionally take intrusive or inappropriate photographs, such as capturing identifiable individuals without consent.

Suggested Solutions

- Offer additional practice sessions – Allow time for participants to familiarise themselves with their devices and build confidence.
- Use guiding prompts for caption writing – Help participants reflect on what the image represents and why it matters.
- Review images together – Facilitate a safe and respectful space to discuss photographs, provide feedback, and explore ways to enhance clarity and impact.

Stop and Reflect



Imagine you are a participant in a Photovoice study.

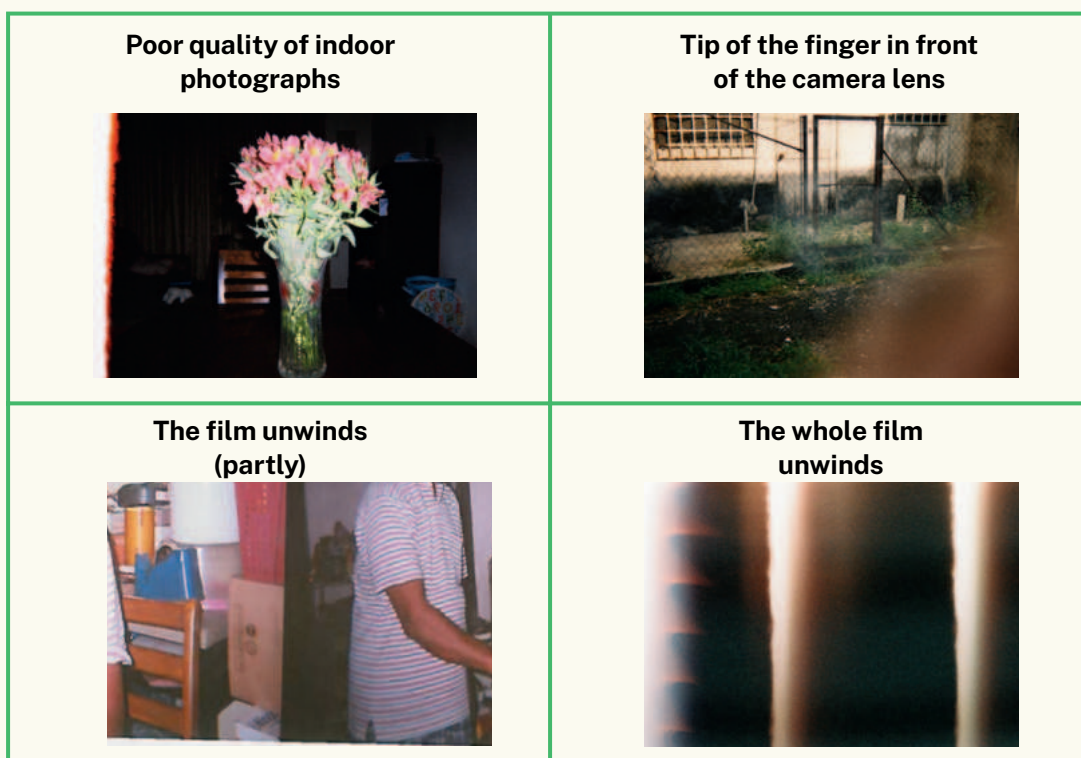
- What challenges might you face when taking meaningful photographs?
- How would you overcome them?
- What kind of training would help you feel more confident?

Case Study 6:

From Film to Smartphone: Evolving Mediums Used to Capture Photographs for Impactful Storytelling

In the earlier RESPIRE Photovoice study, the researcher used disposable cameras, which introduced several limitations in terms of photograph quality (Figure 3.1). However, a notable benefit, highlighted during a photo-interview, was the level of care participants took in deciding what to photograph. Unlike digital or mobile phone cameras, disposable cameras did not allow participants to preview their images, and the limited number of exposures on a film roll encouraged more deliberate and thoughtful image selection.

Figure 3.1: Example of photograph quality using disposable cameras



In our recent projects under RESPIRE, the shift to digital photography reflects both technological advancement and the widespread ownership of smartphones. Most participants are now comfortable using their own devices to document their experiences, which enhances accessibility and allows for more immediate capture of daily life. For participants without a suitable device, we provide a basic camera phone without mobile or internet connectivity. While digital photography offers many benefits, it also presents ethical challenges. Digital images can be easily copied or shared, potentially compromising participant confidentiality and data security.

In our earlier study, the use of disposable cameras was partly motivated by the need to safeguard privacy and retain researcher control over the images. Although participants in our current projects are trained to avoid capturing identifiable images, the risk of inadvertent disclosure remains. Balancing the convenience of digital technology with rigorous ethical safeguards is essential to ensure both meaningful data collection and the protection of participant privacy.

Activity 3

Preparing for Photovoice – Simulated Photo-Training

Objective: Equip researchers and facilitators with practical skills to prepare participants for photo-taking, including technical, ethical, and contextual considerations.

Instructions:

1

Role Assignment

Divide into small groups. Assign the following roles:

- Facilitator/Trainer – Leads the training session
- Participant – Plays the role of a Photovoice participant with a specific background (e.g. older adult, low literacy, unfamiliar with smartphones, or culturally cautious)
- Observer – Notes what worked well and areas for improvement

2

Simulated Photo-Training

Each Facilitator leads a brief 10-minute mock training that covers:

- Explaining the study purpose and the role of participants
- Providing basic camera/phone handling guidance
- Discussing consent, privacy, and cultural sensitivity
- Using prompts to guide photo themes
- Offering adaptations (e.g. using audio captions or one-to-one support)

3

Group Feedback and Reflection

The Observer and Participant share feedback on:

- Was the training clear and inclusive?
- Were ethical issues addressed?
- Were the participants' needs (literacy, comfort, tech skills) considered?
- Did the facilitator allow enough creative ownership?

Debrief and Discussion Questions

- What were the most challenging aspects of delivering photo-training?
- How did the facilitator adapt the training to suit participant needs?
- What support mechanisms could be added to improve participant engagement and safety?
- How can this exercise be applied in real-world settings with limited time or resources?

04

Conducting Interviews and Discussions – Strategies and Practical Insights



While photographs capture experiences visually, interviews provide the context and deeper meaning behind the images. Through discussions, participants can articulate their emotions, challenges, and aspirations, allowing researchers to gain a more nuanced understanding of their realities.

This chapter explores how to conduct interviews and discussions effectively, ensuring that participants feel heard, respected, and empowered to narrate their experiences.

Preparing for the Interview

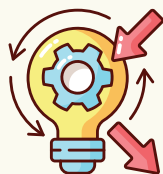
Key Steps in Interview Preparation

Before conducting interviews, researchers should:

- Develop a structured interview guide – Prepare open-ended questions that encourage participants to share in-depth responses.
- Ensure a comfortable, private setting – Choose a location where participants feel safe and free from distractions.
- Obtain informed consent – Explain how interviews will be recorded, stored, and used before starting the session.
- Build rapport with participants – Start with a casual conversation to create a relaxed atmosphere.

A well-prepared interview maximises participation and ensures high-quality data collection.

Stop and Reflect



Think about a conversation where someone shared a deeply personal story with you.

- What made you listen carefully?
- How did you respond?
- What skills are important to ensure an interview is respectful and meaningful?

Using the SHOWED Technique for Photo Discussions

The SHOWED method provides a structured way to analyse images in interviews. This technique helps participants reflect on their photographs while guiding researchers to ask insightful follow-up questions.

SHOWED Framework:

S

What is **Shown** in this photo?

H

What is **Happening** in the image?

O

hOw does this relate to your life?

W

Why are things this way?

E

How can this **Educate** others?

D

What should be **Done** to improve the situation?

Using this approach ensures that participants' photos are meaningfully interpreted while allowing them to control the narrative of their experiences.

Techniques for Effective Interviews

Building trust and encouraging storytelling

- Use active listening – Show that you are engaged by nodding, paraphrasing, and maintaining eye contact.
- Acknowledge opinions – Show that you are actively listening verbally with replies such as *“That’s an interesting thought”*
- Avoid yes/no questions – Encourage elaboration with *“Can you tell me more about that?”*
- Allow silence – Participants may need time to reflect before answering.

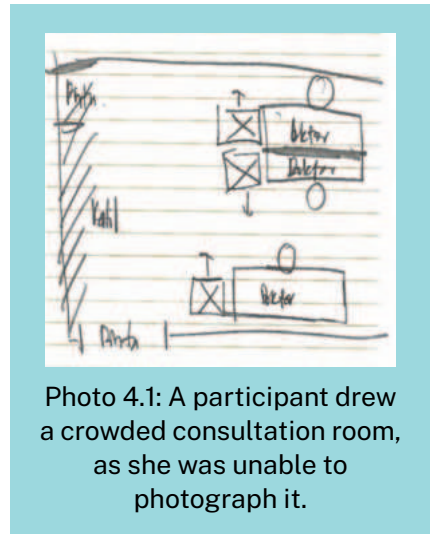
Managing interview dynamics

Some participants may struggle to express themselves verbally. If so:

- Encourage storytelling rather than short responses.
- Allow them to use gestures or draw if they find words difficult or a situation that does not allow them to take photographs (Photo 4.1).
- Be patient; some may take longer to open up.

If participants become emotional, support them by:

- Validating their emotions ("*That sounds very difficult. Thank you for sharing.*").
- Offering a break or stopping the interview if needed.



Handling Language Barriers

- Use native speakers or trained community members as interviewers instead of professional interpreters when possible.
- Relying on non-professional interpreters, such as family members, compromises the authenticity and reliability of the data and may introduce bias [17]. Generally, using family members as interpreters is not recommended.
- If using an interpreter:
 1. Ensure they are trained and familiar with the research topic and ethical considerations.
 2. Encourage direct conversation between the participant and researcher, rather than the interpreter speaking on their behalf which may alter the quality of the data [18].

Stop and Reflect



Imagine you are interviewing someone about a deeply personal experience.

- What challenges might arise?
- How would you make them feel comfortable and safe?
- What questions would help them open up?

Case Study 7:

Visual Insights: Using photographs in qualitative interviews

When we began integrating photographs into qualitative interviews using the Photovoice methodology, it was a new and exciting experience for our team. This approach added a unique and powerful dimension to our work with the community near CMC Vellore.

Initially, we conducted in-depth verbal interviews to explore participants' experiences and perceptions of chronic respiratory diseases. Later, we introduced the idea of using photographs as a way to express and share their stories. At first, we were uncertain whether the approach would work, particularly for participants unfamiliar with smartphones or photography. Many were from older generations, had low literacy levels, and were not as comfortable with technology as we were. Providing training became an important milestone in this journey, it not only equipped participants with the necessary skills but also demonstrated to the research team that Photovoice is feasible even in rural, low-literacy settings. With patience and guidance, participants embraced the method more quickly than expected. Some even involved their grandchildren to help capture photographs. We witnessed their confidence grow as they realised that their stories mattered and that their photographs were powerful tools for expression.



Photo 4.2: Unseen Embrace: A grandmother's silent love

One participant, a grandmother, shared a moment that deeply moved us. Although her love for her grandchild was evident in how she carefully prepared everything needed to bathe the baby, her illness made it impossible for her to lift the child (Photo 4.2). Through her photographs, she documented the preparation process. It was a poignant expression of care and limitation, something words alone could never fully convey.

However, there were challenges as well. One participant, for example, had been abandoned by her husband due to her airway disease and found it difficult to use photographs to express the emotional toll of her experience. While some stories were harder to capture visually, we discovered that photographs often revealed layers of meaning. A seemingly simple image of morning dew (Photo 4.3), for instance, symbolised the struggle of waking up early and facing a day filled with hardship.



Photo 4.3: Morning dew: A silent struggle against the day

Looking back, this method enriched our understanding in ways we had not anticipated. The photographs did more than illustrate physical realities, they conveyed emotional and social dimensions that might otherwise have gone unnoticed. Participants living with respiratory conditions used photography to reflect on their experiences in greater depth, offering a more nuanced perspective than traditional interviews typically allow. The two-week period allocated for photo-taking enabled participants to capture critical moments, subtle details, and complex aspects of their daily lives, ultimately presenting a more complete narrative.

Photographs also conveyed powerful emotional stories. One participant, a young mother struggling to breathe, shared how her husband's drinking had made her life a living nightmare. On one terrifying night, she suffered a severe attack and was unable to catch her breath. Yet, when she needed him the most, he was too intoxicated to help.



Photo 4.4: Photograph speaks: Impact of the disease on the family

As she reflected on the horrific experience, her voice cracked with emotion. *“When he drinks,”* she said, *“he’s not just destroying himself. He’s destroying me, our children, and our future.”* She explained that her illness had worsened the situation for her family, as she now struggled to meet their needs and cover expenses, having lost the ability to work. Her home was in a dilapidated state, with a leaking roof and a disorderly arrangement of belongings within it (Photo 4.4).

Participants felt validated and motivated, knowing that their stories would be shared with a wider audience and could potentially benefit others facing similar challenges. One notable challenge was technical difficulties, for instance, a participant who was using a smartphone for the first time initially took low-quality photographs, requiring some to be re-taken. However, even these imperfect images conveyed powerful narratives. They evoked empathy not only among us as researchers but also among policymakers and community members when the images were later shared.

What can go wrong?

Common challenges in interviews

- Participants provide short responses – If someone only gives one-word answers, try:

1. Asking "Can you describe that more?"
2. Encouraging examples or stories.

- Participants go off-topic – If a participant strays from the research question, gently guide them back with:

"That's interesting! How does that relate to your experience with [research topic]?"

- Emotional responses – If a participant becomes emotional:

1. Pause and ask if they would like to continue.
2. Show empathy and validation ("I appreciate you sharing this with me.").

- Interruptions (e.g., phone calls, background noise) – To minimise disruptions:

1. Conduct interviews in quiet, private spaces.
2. Schedule at a time when participants are least likely to be distracted.

Activity 4

Role-Playing a Photovoice Interview

Objective: This activity helps researchers practice conducting open-ended interviews and handling different participant responses.

Instructions:

1

Work in pairs or small groups.

2

One person plays the researcher, the other the participant.

3

The 'participant' describes a photo they have taken, using the SHOWED method.

4

The 'researcher' practices active listening, asking follow-up questions.

5

Swap roles and discuss:

- What worked well?
- What could be improved?

Debrief and Discussion Questions

- Was it easy or difficult to keep the participant engaged?
- What were the biggest challenges in conducting the interview?
- How did ethical considerations (e.g., privacy, consent) influence your approach?



05

**Data Preparation
– Translating,
transcribing, and
language
considerations**

Once Photovoice data are collected, the next crucial step is to process the information accurately and ethically. Transcribing and translating interviews, captions, and discussions ensures that the insights shared by participants are preserved, analysed, and communicated effectively. This chapter outlines best practices for transcription, translation, and maintaining linguistic and cultural authenticity when handling multilingual data.

Transcribing data

What is Transcription and Why Is It Important?

Transcription is the verbatim documentation of recorded interviews, discussions, or photo explanations. It ensures that participants' exact words are captured for detailed analysis, preserving both meaning and context.

Key Principles for Transcribing Photovoice Data

Verbatim transcription

Every word, pause, and expression should be transcribed accurately to retain context and nuance.

Native speaker review

A native speaker should verify transcripts to ensure local phrasing and expressions are accurately documented.

De-identification

Remove or code identifiable information while retaining the ability to re-link data if necessary. This often involves replacing names with unique codes and storing the key separately. In qualitative research, full anonymisation is challenging, as rich narratives may still include contextual clues that could reveal identities.

Inserting photographs

Insert photographs at the exact point in the transcript where they are mentioned in the audio. This improves clarity and streamlines the analysis process.

Common Challenges in Transcription and How to Address Them

Background noise or poor audio quality

- Use noise reduction tools to enhance clarity.
- Follow up with participants to clarify unclear sections.

Heavy use of slang or informal speech

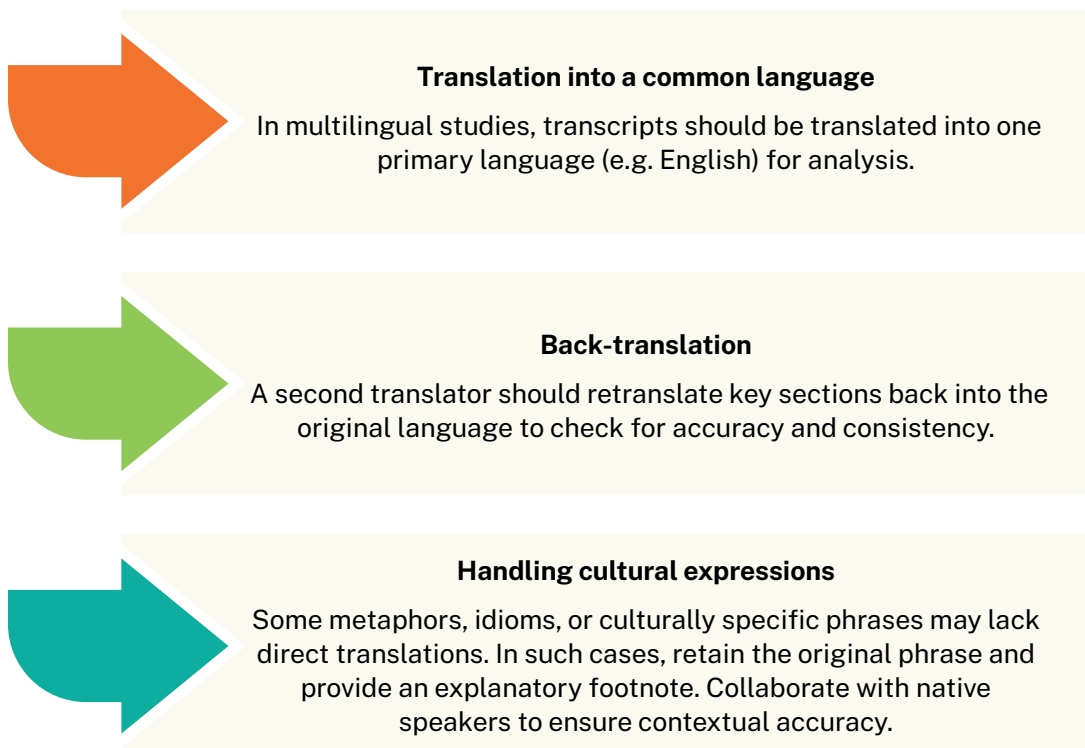
- Preserve original phrasing and add brief explanatory notes in brackets.
- Avoid 'cleaning up' speech too much, to maintain authenticity.

Lengthy interviews making transcription time-consuming

- Use automated transcription tools, followed by manual review for accuracy. Choose paid services that ensure confidentiality and protect data from public exposure.
- Divide transcripts into smaller sections and assign them to different team members to improve efficiency.

Translating Data

Best Practices for Translation in Photovoice Research



Practical Approaches to Managing Multilingual Data



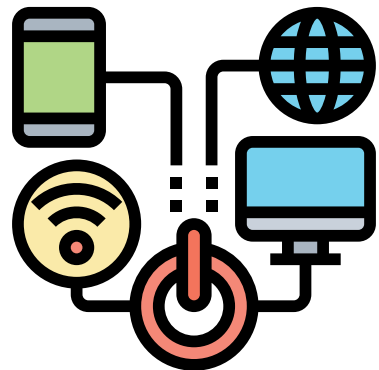
Full vs. selective translation

Not all transcripts require full translation. To optimise resources:

- Translate only key sections (e.g. quotes for analysis or publication).
- Provide summaries for non-essential parts.

Digital tools for translation

- Online tools or AI-based software can support transcription and translation.
- Always verify outputs manually with a fluent speaker.
- Ensure tools used comply with strict data protection protocols to safeguard participant privacy.



Ethical Considerations in Translation

- Maintain participant voices – Avoid simplification or rewording that could distort the original meaning.
- Transparency – Clearly document any substantial edits or contextual clarifications added to translated text.

Common Mistakes in Transcription and Translation — and How to Avoid Them

- Inconsistent terminology

When different translators use varying terms for the same concept, it can lead to confusion.

Solution: Create and use a translation glossary to ensure consistency.

- Over-editing

Excessive rephrasing can alter the participant's intended meaning.

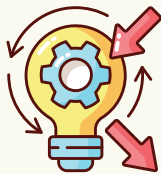
Solution: Maintain transcripts as close to the original wording as possible.

- Skipping participant review

Misinterpretations may go unnoticed if participants do not review their transcripts.

Solution: Offer participants the opportunity to review and clarify their statements before finalising the translation.

Stop and Reflect



Think about a time you translated a word or phrase from one language to another.

- Did the meaning stay the same?
- Were there cultural expressions that were difficult to translate?
- How can researchers ensure meaning is preserved when working with multilingual data?

Case Study 8:

Translating multi-lingual data: Decisions and experiences in handling transcripts

In qualitative research, I transcribed all recorded interviews verbatim in their original language, ensuring accuracy, quality, and anonymisation. To enrich contextual understanding, I included notes on background noise, interruptions, emotional expressions (e.g. sighs, crying), and speaker emphasis (e.g. stressed words or hesitations). These details enhanced data interpretation and provided a more comprehensive understanding of participant narratives.

I am proficient in Malay (the national language of Malaysia) and English. Therefore, I analysed photographs and transcripts in their original languages. Depending on the research needs, quotes from English transcripts were often used directly for publications and public exhibitions. However, since English is not the native language for most Malaysians, it is often spoken in a colloquial manner that may not be easily understood by a global audience. As a result, English quotes were sometimes rephrased for clarity in academic outputs.

Occasionally, I translated English quotes into Malay for public exhibitions to ensure accessibility for audiences with limited English proficiency. Conversely, Malay quotes were translated into English for publication purposes. To maintain consistency and accuracy, I employed a structured translation approach, focusing only on quotes and captions selected for dissemination. All translations followed a back-to-back translation process to ensure both linguistic and conceptual accuracy. Professional linguists conducted back-translations, and I reviewed the outputs for semantic and contextual fidelity.

Given Malaysia's multilingual context, some interviews were conducted in Mandarin or Tamil. In these cases, native-speaking members of the research team translated the transcripts into English. The decision to translate full transcripts into a common language, English, depended on the research centre's requirements and available resources. Since I am only proficient in Malay and English, I analysed photographs alongside the translated English transcripts. Full translation was sometimes necessary in global health research to enable effective collaboration among international research teams.

In Malaysia's linguistically diverse environment, participants frequently code-switched, alternating between two or more languages during interviews. Researchers must determine whether all such segments require translation for analysis or publication. I also encountered metaphors, idioms, and culturally specific expressions that lacked direct English equivalents. In these instances, I retained the original phrase and provided explanatory footnotes to preserve contextual and cultural meaning.

Activity 5

Transcription and Translation Challenge

Objective: Develop skills in listening, verbatim transcription, and accurate translation.

Instructions:

- 1 Play a short audio clip of a recorded interview.
- 2 Transcribe the first three minutes verbatim.
- 3 If working with multiple languages, translate your transcript into English.
- 4 Compare your work with another participant. Discuss: Which words or phrases were difficult to translate, and why?

Debrief and Discussion Questions

- What was challenging about transcribing the exact words?
- Did any expressions lose meaning in translation?
- How can translation choices influence the interpretation of research findings?

Alternative Adaptation for Online or Individual Participants

If completing this activity alone, participants can:

- Write a script for how they would introduce Photovoice to a new community.
- Record themselves explaining informed consent and review their clarity and engagement.
- Reflect on potential challenges and how they would handle them.

06

Analysing Photovoice data – Approaches and practical examples



The analysis of Photovoice data involves interpreting both visual and narrative information shared by participants. As a qualitative approach, Photovoice analysis focuses on identifying themes, patterns, and insights grounded in lived experiences.

This chapter outlines the various approaches to analysing Photovoice data, including the steps involved in thematic coding. It also discusses how researchers can interpret images alongside participant narratives to draw meaningful and contextually rich conclusions.

Making sense of qualitative data in Photovoice research

Photovoice research offers a unique window into participants' lived experiences by combining two powerful forms of qualitative data: photographs and narratives. While the images capture moments of personal significance, the accompanying explanations, captions, and discussions give voice to the thoughts, emotions, and meanings behind those moments. Together, they create a rich tapestry of insights that go beyond what words alone can convey.

Analysing this data is a thoughtful and layered process. It begins with organising and coding the material, but the real value lies in identifying themes and patterns that reveal deeper understandings of participants' perspectives. Each photograph and narrative carries a story, and through careful interpretation, researchers can uncover why participants chose certain subjects, what those choices represent, and how they connect to broader social and health issues.

The aim of this analysis is not only to document experiences but to interpret them in ways that align with the research objectives and generate real-world impact. By identifying themes with broader relevance, findings can be applied beyond the immediate study context, offering insights for health systems, policy, and practice in similar settings. Highlighting the most pressing concerns and perspectives allows researchers to bring forward the key messages shared by participants. Interpreting the meanings behind images fosters a deeper appreciation of their significance, while grounding the findings in the study's goals helps ensure focus and relevance.

Crucially, the way these insights are communicated matters. Findings should be presented in a compelling and accessible format, whether through reports, exhibitions, or policy briefs, so they can inform and inspire meaningful change. After all, Photovoice research is not only about collecting data; it is about amplifying voices, promoting empathy, and fostering a deeper understanding of the human experience.

Types of qualitative data analysis used in Photovoice

Several qualitative analysis methods can be used to analyse Photovoice data, including:

Approach	Strategy	Outcome	Presentation of Findings
Thematic analysis [19, 20] (Most common approach)	Identifies themes or patterns of meaning within the data. Reduces large amounts of information into key ideas. Explores both explicit and implicit meanings in photos and narratives.	Organises key findings into themes relevant to the research objective. Provides a structured framework for understanding participant experiences.	A summary of the most significant themes, supported by participant quotes and images.
Grounded theory approach [21]	Generates a theory based on emerging data, rather than applying pre-existing frameworks. Uses open and axial coding to group findings into broader concepts. Useful for exploring new or understudied social issues.	Develops a new theory or conceptual model based on qualitative data. Identifies key relationships between themes.	A structured description of the theory, including categories and key themes supported by participant narratives.
Narrative analysis [22, 23]	Examines how participants construct and share their stories. Focuses on how experiences are structured through personal accounts. Prioritises individual voices and storytelling over broader themes.	Produces rich, descriptive accounts of participants' lived experiences. Highlights how individuals frame their own narratives.	Findings are presented as coherent personal stories or case studies, preserving the original flow of participants' narratives.
Discourse analysis [24]	Investigates language and social interactions within participant discussions. Considers how participants describe their experiences and why they use certain words. Useful for research that examines power, social norms, and identity.	Identifies multiple interpretations of language and the way meaning is constructed socially. Highlights hidden assumptions or power structures within conversations.	Findings are presented as descriptive accounts of meaning within text, including language patterns and participant interactions.
Phenomenological analysis [25]	Aims to understand the lived experiences of participants. Focuses on the meaning of experiences rather than broad patterns. Helps researchers see the world through participants' eyes.	Provides deep insights into individual emotional and psychological aspects of a phenomenon.	Findings are presented as a narrative synthesis of participant experiences, often using direct quotes to illustrate emotional depth and perspectives.

Case Study 9:

Conducting a thematic analysis

Thematic analysis is one of the most widely used approaches in Photovoice research. In this study, we followed the steps outlined by Braun and Clarke [19, 20].

Step 1: Data familiarisation



Researchers begin by immersing themselves in the data, reviewing photographs, transcripts, and field notes in detail. This initial phase involves identifying early thoughts, emotional cues, and emerging patterns.

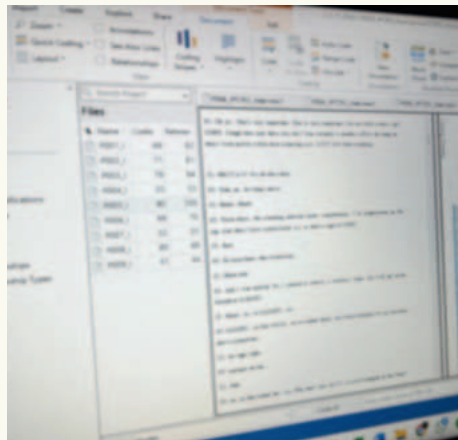
Three levels of reading are typically employed:

- **Literal reading** – What is in the data?
Focuses on the content and structure of what is presented.
- **Interpretive reading** – What does it mean?
Involves drawing inferences and understanding the underlying messages.
- **Reflexive reading** – How does the researcher's perspective shape the interpretation?
Encourages awareness of personal biases, positionality, and influence on data analysis.


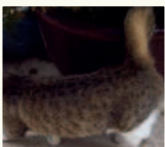

Step 2: Generating Codes

At this stage, researchers begin identifying patterns and organising the data in a systematic way.

- Recognise patterns in the visual and narrative data.
- Label key words, phrases, or concepts within transcripts and field notes.
- Ensure that codes are internally consistent (grouping similar ideas together) and externally divergent (clearly distinguishing between different themes).



Example of coding in Photovoice interviews:

	Transcript	Code
	<i>"I cannot take this (coconut milk). So, I will start to cough if I add it in my food."</i>	Coconut milk triggers asthma
	<i>"My youngest daughter loves cats, but I can't let her have one because I'll start sneezing and then coughing."</i>	Cats trigger asthma
	<i>"When I cycle, I will have asthma symptoms. So, I usually do not exercise. I know it's important but I will be breathless."</i>	Cycling triggers asthma

Step 3: Identifying themes

In this stage, researchers move from coding individual data segments to identifying broader, meaningful patterns across the dataset.

- Merge related codes into overarching themes that capture shared experiences or key issues.
- Examine connections across different participants' narratives and photographs.
- Develop rich descriptions of how various factors, such as social support, healthcare access, and environmental conditions, interact and shape lived experiences.

Example of themes emerging from Photovoice data:

Data from interviews	Code	Category	Initial Theme
<i>"I cannot take this (coconut milk). So, I will start to cough if I add it in my food."</i>	Coconut milk triggers asthma	Food triggers asthma	Asthma triggers
<i>"My youngest daughter loves cats, but I can't let her have one because I'll start sneezing and then coughing."</i>	Cat triggers asthma	Pet triggers asthma	Asthma triggers
<i>"When I cycle, I will have asthma symptoms. So, I usually do not exercise. I know it's important but I will be breathless."</i>	Cycling triggers asthma	Exercise triggers asthma	Asthma triggers

Step 4: Reviewing and Refining Themes

- Check whether each theme accurately reflects the underlying data.
- Identify and consolidate overlapping or redundant themes.
- Ensure that themes remain grounded in and faithful to participants' lived experiences.

Step 5: Defining and Naming Themes

- Clearly define each theme and explain its relevance to the research objectives.
- Connect themes to relevant theoretical frameworks and existing literature to support interpretation.

Example of finalised themes:

Theme	Illustrative Codes
Barriers to Asthma Management	Lack of awareness; difficulty avoiding asthma triggers
Coping Strategies	Inhaler use; adapting daily activities
Emotional Impact	Frustration; anxiety about breathlessness

Stop and Reflect



Think about a time when you looked at a powerful photo or image.

- What message did it convey?
- Did your interpretation change after reading a caption or story behind it?
- How does this apply to Photovoice analysis, where images and words work together?



by Biswajit Paul, Christian Medical College, Vellore, India

Case Study 10: Practical tips for data analysis

Analysing the data collected from the Photovoice study was both challenging and rewarding. From the outset, we chose to approach the process with an open mind, using inductive coding to allow themes to emerge naturally from the data. This decision enabled us to uncover insights we had not initially anticipated.

Collaboration was central to ensuring a rigorous and nuanced analysis. After coding the interviews individually, we came together as a team to discuss, refine, and validate our findings. This iterative process proved essential, what one person might have overlooked, another picked up. Each team member brought a unique perspective, particularly as we had all been involved in the interviews and were deeply familiar with the participants' contexts.

While qualitative analysis software was useful in organising and managing the data, we recognised the importance of balancing digital tools with manual review to preserve the richness and emotional depth of the narratives. The photographs introduced another layer of complexity, but also added significant depth. We found ourselves engaging not only with emerging themes but also with the emotions, symbolism, and context captured in each image.

A key takeaway from this process was the importance of ongoing dialogue. Every team discussion sparked new ideas and helped us develop a deeper appreciation of the participants' stories and how these narratives linked to broader thematic concerns. For those undertaking similar projects, we recommend keeping the process collaborative and letting the data guide the analysis, rather than imposing predetermined frameworks.

Activity 6

Analysing a Photovoice Dataset

Objective: Practise coding, identifying themes, and interpreting data from a Photovoice study.

Instructions:

- 1 Select a photograph from a Photovoice dataset.
- 2 Read the accompanying participant transcript or caption, and identify key codes.
- 3 Group similar codes to develop preliminary themes.
- 4 Discuss in pairs or small groups:
 - What themes emerged?
 - How does this data contribute to answering the research question?
 - How could this analysis inform advocacy or policy recommendations?

Chapter Summary

- Photovoice analysis involves interpreting both images and narratives.
- Thematic analysis is the most common method, helping to organise data into meaningful patterns.
- Coding and theming allow researchers to identify key issues raised by participants.
- Using an iterative approach ensures accuracy and participant validation.

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07

**From Findings to
Impact – Report
Writing and
Dissemination
Strategies**

Once Photovoice data have been analysed, the next step is to communicate the findings effectively to a range of stakeholders, including community members, researchers, policymakers, and funders. The true impact of a Photovoice study depends not only on what is discovered but also on how those discoveries are shared and acted upon.

This chapter outlines best practices for writing reports, presenting findings, and disseminating results, even when working with limited resources.

Writing an Effective Photovoice Report

Key Components of a Photovoice Report

Executive Summary	A brief overview of the study, key findings, and recommendations.
Introduction	Background information, research objectives, and guiding questions.
Methods	Description of participant recruitment, data collection processes, and analysis techniques.
Findings	Thematic presentation of results supported by participant narratives and selected photographs.
Discussion	Interpretation of findings, implications for practice or policy, and connections to existing literature.
Recommendations	Practical and actionable suggestions for policymakers, organisations, or community stakeholders.
Conclusion	Summary of the study's contributions and suggested next steps.
Appendices	Supporting materials such as full transcripts, ethical protocols, consent forms, or participant reflections.

Enhancing Reports with Visuals

Incorporating photographs with participant-generated captions strengthens the storytelling aspect of Photovoice. It also makes the findings more engaging, emotionally resonant, and accessible to non-academic audiences.

Practical Tips for Writing Photovoice Reports

Use Simple, Clear Language

Avoid academic jargon to ensure your report is accessible to all audiences, including community members and non-specialist stakeholders.

Let Participants' Voices Shine

Incorporate direct quotes and photographs to centre participant experiences and maintain authenticity.

Be Ethical

Only include photographs and narratives with informed consent. Protect participant anonymity where necessary, especially when dealing with sensitive topics.

Structure the Report Logically

Follow a clear and consistent structure so readers can easily follow your key messages and arguments.

Balance Data with Storytelling

Integrate thematic analysis with participant narratives to create a report that is both rigorous and compelling.

Adapt for Different Audiences

Tailor your outputs, some stakeholders may prefer comprehensive reports, while others may engage more with summary briefs, photo essays, or infographics.

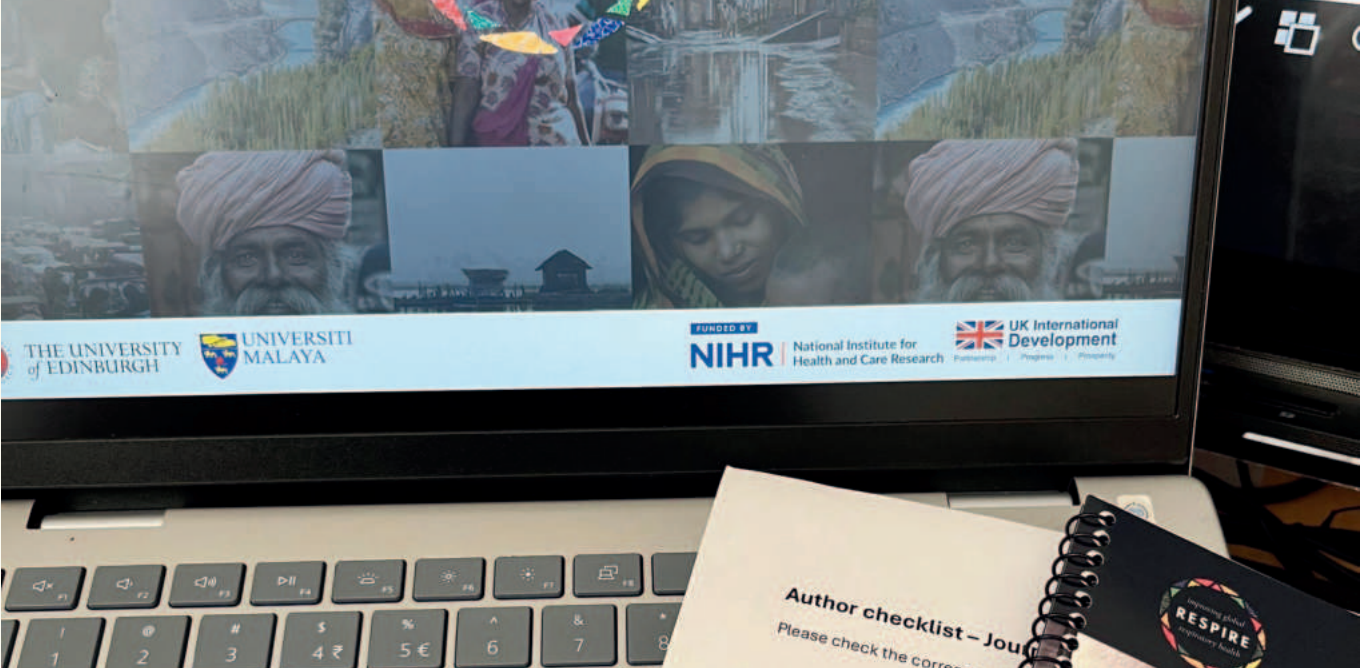
Example of Effective Writing

Instead of this:

"Findings indicate that there are significant barriers to healthcare access."

Try this:

"A mother in our study described how she walked three hours to reach the nearest clinic, only to find it closed. This highlights the urgent need for more accessible healthcare services."



by Ai Theng Cheong, Shariff Ghazali Sazlina, Universiti Putra Malaysia

Case Study 11:

From our experience - sharing from the expert

Drawing from our experience in publishing qualitative research, the first crucial step is identifying a relevant journal. Manuscript preparation must be aligned with the journal's scope, style, and word count limits, as outlined in its Instructions for Authors. It is important to recognise that requirements differ between health science journals and journals focused exclusively on qualitative research.

In most health science journals, the manuscript typically follows the IMRaD structure: Introduction, Methods, Results, and Discussion. Regardless of the format, the manuscript should be focused and clearly reflect the research question(s) guiding the qualitative inquiry.

Introduction

The introduction must go beyond establishing the rationale for the research. It should also:

- Clearly state the research questions, purpose, and specific objectives.
- Demonstrate how these questions address gaps in the current literature.
- Where relevant, include the theoretical framework used and the researchers' philosophical stance to ensure conceptual consistency.

Methodology

The methodology should logically follow from the research questions and introduction. To ensure transparency, we often refer to the Consolidated Criteria for Reporting Qualitative Research (COREQ), a helpful tool for maintaining rigour and clarity in reporting.

The methods section should detail:

- The qualitative design and data collection approaches (e.g. in-depth interviews, focus group discussions, observation, or photo elicitation methods such as Photovoice).
- Strategies used to ensure trustworthiness and rigour, guided by Lincoln and Guba's (1985) four evaluative criteria:
 - Credibility
 - Transferability
 - Dependability
 - Confirmability

Reflexivity should also be addressed, as it is an essential element in qualitative research. The researcher is not a neutral observer but an active part of the process, and reflexivity enables acknowledgement of their role in shaping data collection, interpretation, and findings.

Results

The results section typically begins with a description of the study context and participant characteristics to help readers interpret the findings. However, caution is required, despite anonymisation, participants may still be recognisable due to purposive sampling and detailed descriptions (e.g. age, role, ethnicity, or location).

Findings are commonly presented through themes, models, or frameworks, supported by selected participant quotes and (in the case of Photovoice) photographs. In Photovoice, images are not merely illustrations but integral to the narrative, offering a visual representation of lived experiences. Each image is accompanied by the participant's narrative to preserve their voice and agency. Ethical considerations, especially around privacy, consent, and cultural sensitivity, must be prioritised when selecting and interpreting images.

Discussion

The discussion provides a deeper analysis of the findings, examining how they:

- Reinforce, extend, or challenge existing knowledge
- Address the original research questions
- Contribute to theory, policy, or practice

The goal is not only to interpret the data but to translate insights into meaningful recommendations for both academic and non-academic audiences.

Dissemination Strategies: Sharing Findings with Impact

Identifying Your Audience

Effective dissemination depends on tailoring the format to suit different stakeholders. Doing so ensures that findings are understood, shared, and acted upon.

Audience	Preferred Format	Example
Community Members	Visual storytelling, photo exhibits, videos, social media	Local exhibition showcasing participant photos with captions
Policymakers	Policy briefs, executive summaries, stakeholder meetings	One-page policy brief with key recommendations
Academics and Researchers	Research articles, conference presentations, reports	Journal publication or conference poster presentation
NGOs and Health Organisations	Infographics, case studies, online campaigns	Infographic highlighting key health challenges in the community

Low Budget, High Impact Dissemination

Even with limited resources, findings can be shared effectively using creative and cost-efficient methods:

1. Community-Based Dissemination

- **Photo Exhibitions:** Display participant images at local community centres, shopping malls (Photo 7.1), schools, or libraries. Use reusable prints or opt for low-cost digital exhibitions via projectors or screens.
- **Community Dialogues:** Facilitate small-group discussions where participants present their photographs and share stories.
- **Printed Summaries:** Provide simple, one-page reports in local languages.



7.1 Community photo-exhibition at a mall in Klang, Malaysia



2. Digital and Social Media

- **Social Media Campaigns:** Share compelling images, quotes, and findings on platforms like Facebook, Instagram, or Twitter/X.
- **Short Videos:** Use free tools to produce 2–3 minute visual summaries.
- **Infographics:** Create engaging visuals using tools like Canva to communicate key messages clearly.

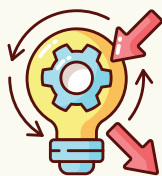
3. Policy Engagement

- **Brief Policy Reports:** Create concise, two-page summaries focused on actionable recommendations.
- **Stakeholder Meetings:** Present findings to local government, healthcare leaders, and NGOs (Photo 7.2).
- **Leverage Partnerships:** Collaborate with existing organisations or networks to amplify reach and credibility.



7.2: Policy Makers of Tamil Nadu attended the State-level Dissemination Workshop at Chennai

Stop and Reflect



Think about a time when you read a research report or article that left a strong impression.

- What made it engaging or memorable?
- Was it the storytelling, visuals, or clarity of message or all of them?
- How can you apply these elements to a Photovoice report?

Case Study 12:

Communicating findings in policy events

Sharing our findings with policymakers was a vital part of this project, and we learned a great deal about how to make research meaningful for those in positions of power. From the outset, we made it a priority to engage policymakers at various levels, local, district, and state. This early engagement ensured they were aware of the project and made them more receptive to our findings later on.

One of the most impactful ways we communicated our findings was through photo exhibitions. The photographs told stories that resonated deeply with the audience. I still remember one policymaker, whose mother had suffered from a respiratory disease, sharing how the images brought back memories of his father stepping in to cook for the family. These moments of connection helped bridge the gap between abstract policies and lived experiences.

We also organised smaller community meetings (Photo 7.3), where we shared these stories and visuals with local leaders and stakeholders. Their feedback was invaluable. For example, they recommended hosting more localised events in the villages where participants lived, an approach that helped us reach people more effectively.



Photo 7.3: A community photo exhibition and video screening on Photovoice

Naturally, there were challenges. For instance, some senior policymakers, such as the State Health Secretary, were unable to attend, despite our efforts to schedule meetings in advance. However, we leveraged our networks and engaged with other influential figures who could support and advocate for change (Photos 7.4, 7.5 and 7.6).

What stood out to us was how much the participants themselves valued being part of these events. They felt heard and seen, and took pride in sharing their stories. This sense of collective empowerment extended beyond the research, it fostered community connection and gave participants a sense of validation.

For anyone undertaking similar projects, we would recommend engaging policymakers from the outset, leveraging visual storytelling, and tailoring dissemination methods to suit different audiences. Photographs have a unique ability to make the intangible tangible, and when paired with participants' voices, they can spark meaningful conversations and influence change.



Photo 7.4: Capturing attention: Photographs conveying messages



Photo 7.5: A Participant explaining the photograph to the policy makers



Photo 7.6: Photo exhibition dissemination workshop: Capturing stakeholders participation

Activity 7

Designing a Dissemination Plan

Objective: Support researchers in thinking strategically about how to share their findings effectively with different audiences.

Instructions:

- 1 Identify a target audience (e.g. community members, policymakers, funders)
- 2 Choose a dissemination format (e.g. policy brief, social media campaign, photo exhibition)
- 3 List low-cost strategies to maximise impact (e.g. community dialogues, infographics using free tools, leveraging existing networks)
- 4 Present your dissemination plan to the group and receive feedback

Debrief and Discussion Questions

- What challenges might arise in reaching your chosen audience?
- How can you adapt your findings to suit different stakeholders?
- What resources, financial, human, or technical, are needed for successful dissemination?

Chapter Summary

- Effective writing makes findings clear and impactful.
- Tailoring reports to different audiences ensures broader engagement.
- Low-cost dissemination strategies can be just as effective as high-budget ones.
- A well-planned dissemination strategy maximises the research's influence.

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08

Ensuring Data Protection – Ethical Considerations for Qualitative Data and Photographs

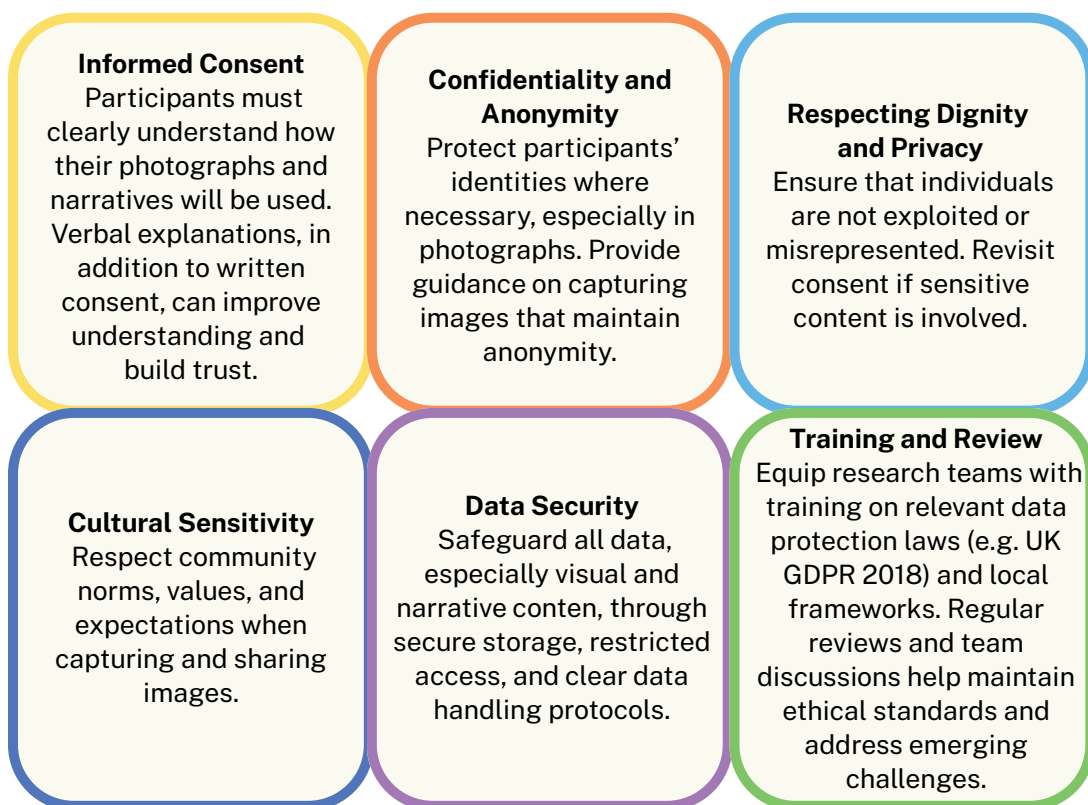


Ethics play a central role in Photovoice research, which often involves more complex considerations than many conventional participatory methods. This complexity stems from the diversity of participants in terms of literacy, age, socio-economic background, and familiarity with technology, as highlighted in several case studies. These factors demand a responsive and sensitive approach throughout the study.

Multiple visits, pilot testing, and ongoing engagement with participants and caregivers often led to adjustments in our approach. This iterative process reinforced the importance of protecting privacy and upholding participant rights. A rigorous approach to informed consent, data protection, and confidentiality is essential.

This chapter highlights key ethical principles and good practices for safeguarding participant data and navigating the unique ethical challenges posed by visual storytelling and qualitative research.

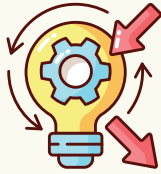
Key Ethical Principles



Practical Insight

Before starting fieldwork, develop a Data Management Plan (DMP) tailored to the community's context. Revise this plan based on participant feedback to reduce the risk of re-identification and ensure ethical integrity.

Stop and Reflect



Imagine someone took a photo of you without your permission and shared it publicly.

- How would you feel?
- What steps should researchers take to ensure ethical photography?
- How does Photovoice differ from other qualitative methods in terms of ethical concerns?

Informed Consent for Photographs and Interviews

Best Practices for Obtaining Consent

- Provide written consent forms that clearly explain:
 - The purpose of the study
 - How photographs and narratives will be used
 - The right to withdraw at any time
- Allow participants at least 24 hours to consider their participation before giving consent.
- Consent should be specific, indicating whether photographs may be used for:
 - Research purposes only
 - Public dissemination (e.g. social media, exhibitions, policy briefs)
 - Group discussions and presentations
- If identifiable individuals appear in photos, separate consent must be obtained.

Example Scenario

A participant wishes to photograph a neighbour's home to highlight poor living conditions:

Step 1: Ask the homeowner for permission.

Step 2: Explain how the photo may be used.

Step 3: Obtain written consent if agreed.

Protecting Confidentiality and Anonymity

Photovoice images may reveal identifiable individuals, locations, or sensitive contexts.

To protect privacy:

- Blur or crop photos where anonymity is required
- Use pseudonyms in captions and transcripts
- Store consent forms separately from participant data
- Keep consent forms in locked storage immediately after collection

Example of Ethical Photo Use:

- ✗ Close-up of a participant's face in a vulnerable moment
- ✓ Wide-angle shot showing context while maintaining anonymity

Safe Handling and Storage of Data

To ensure data security:

- Store digital files on password-protected servers
- Keep printed consent forms in locked cabinets
- Limit access to identifiable data to authorised research team members

If images are to be shared publicly or on social media, obtain additional explicit consent

Ethical Use of Research Equipment

When providing cameras or smartphones to participants:

- Brief them on safe use and data protection
- Clarify ownership of the photographs (participant vs. researcher)
- Be mindful of community norms regarding photography

Example of Ethical Equipment Use:

A participant uses a borrowed camera to document healthcare challenges:

Step 1: Explain their responsibility for equipment care

Step 2: Ensure safe return of the device after the study

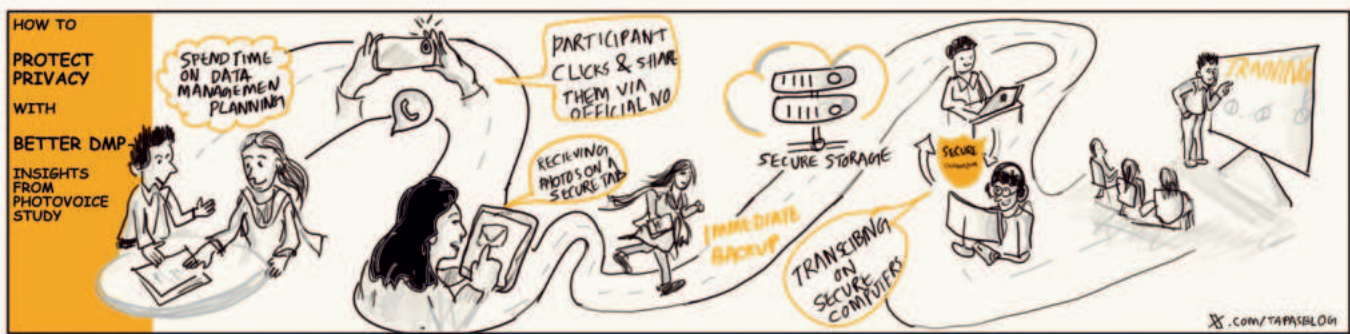
Step 3: Discuss and agree on data ownership, participants should have a say in how their images are used

Stop and Reflect



Imagine you are conducting a Photovoice study in a community:

- How would you ensure participants understand data protection risks?
- How can you balance ethical concerns with the need to advocate for change?
- How should researchers handle ethical dilemmas around identifiable images?



by Dipali Dhamdhare and Tapas Kumar Mohanty, VRHP, KEMHRC, Pune

Case Study 13:

Keeping Privacy with Better Data Management Planning

This case study outlines effective data management practices and challenges encountered during a Photovoice study in KEMHRC, Pune, India. During early interviews, audio recordings were temporarily stored on voice recorders instead of being immediately backed up to secure, encrypted systems. This posed a risk of data loss and highlighted the need to adhere strictly to the DMP. Such breaches, even if minor, must be reported to the trial sponsor per ethical standards.

Corrective Measures Implemented

Immediate Data Backup

- Audio files were transferred to an official laptop and backed up to the secure institutional server.
- Files were then deleted from the recorder.

Data Encryption

- Encrypted containers were created using VeraCrypt, protected with 20-character passwords.
- Passwords were shared securely via a password-protected 7-Zip file, with the password sent separately through WhatsApp (end-to-end encryption and auto-delete enabled).
- Copies were securely stored with the PI, Co-Is, and Data Manager.

Transcription Security

- Transcription was done on password-protected desktops.
- Encrypted containers were used for all file transfers (via hard drives/flash drives).
- Only necessary files were shared, and all completed transcriptions were deleted before new ones were issued.

Collaborative Transcription and Quality Checks

- MS SharePoint was used for real-time collaboration on transcripts using restricted access files.
- This ensured simultaneous analysis and quality control without compromising data security.

Photograph Collection and Storage

Designated Equipment

- A dedicated tablet with an official WhatsApp number was provided for receiving images.
- The device had no third-party cloud backups and was connected only to the official Wi-Fi network.

Daily Download and Secure Storage

- Photos were downloaded daily, renamed using participant IDs (per DMP), and stored in encrypted containers.

Weekly Backup

- Encrypted files were backed up weekly to:
 - VRHP's secure server
 - Mirror server at KEMHRC, Pune
 - AWS secure cloud server

Device Security

- Tablets, audio recorders, and portable media were stored in a locked cabinet with access limited to the Project Coordinator and PI/Co-Is.

Development of Standard Operating Procedures (SOPs)

A detailed SOP was developed to align with:

- The UK GDPR (2018)
- India's Digital Personal Data Protection Act (DPDP Act, 2023)

The SOP outlined:

- Backup and encryption protocols
- Password management procedures
- Data access controls

Capacity Building and Team Learning

Training

- Training for Field Research Assistants (FRAs) and transcribers was conducted in Marathi, based on real field experiences.
- Emphasis was placed on practical steps, GDPR compliance, and local data protection laws.

Ongoing Awareness

- Weekly team meetings foster cross-learning and problem-solving.
- Discussions included emerging challenges from tools like AI, with guidance on responsible use to avoid unintentional data breaches.

Activity 8

Ethical Dilemmas in Photovoice

Objective: Develop practical strategies to navigate ethical challenges commonly encountered in Photovoice research.

Instructions:

1

Read the Scenario

A participant takes a powerful but sensitive photograph of a child living in poor conditions. The participant wishes to use the image to raise awareness, but the child's parent has not been informed.

2

Group Discussion

Discuss the following:

- What ethical risks are involved in using this image?
- How should the researcher respond to the participant's request?
- What steps should be taken to ensure the responsible and ethical use of the photo?

Debrief and Discussion Questions

- How can the process of informed consent be reinforced in visual research?
- Are there situations where certain images should be excluded from research outputs, even with participant consent?
- What ethical considerations and guidelines should govern the use of such images on social media or public platforms?

FINAL REFLECTIONS AND FUTURE DIRECTIONS

Reflection

Photovoice is more than just a research method; it is a powerful tool for storytelling, advocacy, and social change. By placing cameras in the hands of participants, it shifts the traditional research dynamic, allowing communities to document their lived experiences and influence policies that affect them.

As we conclude this toolkit, it is important to reflect on the lessons learned, the challenges ahead, and the future possibilities for Photovoice research.

Key Lessons from Photovoice Research

Empowering Communities Through Participatory Research

Photovoice goes beyond data collection, it actively involves participants as co-researchers, ensuring their voices are heard and valued. This approach:

- Elevates lived experiences as meaningful research evidence
- Challenges traditional research hierarchies by centring participant perspectives
- Creates a platform for advocacy, amplifying voices that are often marginalised

Ethical Considerations Must Be Ongoing

Ethics in Photovoice is not a one-time checklist but a continuous process. Researchers must:

- Ensure informed consent, data protection, and responsible dissemination throughout the project
- Navigate ethical dilemmas such as participant anonymity, cultural sensitivities, and photo usage with context-specific solutions

Analysis Must Align with the Chosen Qualitative Framework

To ensure the research remains meaningful and addresses the intended research question, data analysis should:

- Follow a qualitative framework that aligns with the study objectives
- Remain true to participant perspectives rather than impose researcher-driven interpretations
- Integrate both visual and narrative elements to strengthen advocacy and policy influence

Challenges and Opportunities in Photovoice Research

This section outlines key challenges encountered in Photovoice research and the corresponding opportunities to enhance its impact, particularly in low-resource and diverse cultural settings.

We group the insights into three main areas:

- Overcoming Participation Barriers
- Scaling for Policy Impact
- Integrating Digital Innovations

Each section presents a challenge-opportunity pairing for clarity and practical reflection.

Overcoming Participation Barriers

Challenges	Opportunities
Limited access to cameras, smartphones, or electricity	Offer alternative methods like disposable camera or loan camera
Low literacy affecting caption writing or discussions	Provide training and guided support to interpret and capture visuals
Ethical concerns around privacy, representation, and consent	Adapt ethical safeguards to fit local norms and community contexts

Overcoming Participation Barriers

Challenges	Opportunities
Research findings remain within academic circles	Engage policymakers, NGOs, and advocates from the outset
Difficulty translating qualitative insights into actionable recommendations	Use accessible formats: photo exhibitions, videos, and policy briefs
Limited sustainability beyond initial funding	Collaborate with grassroots organisations for long-term impact

Integrating Digital Innovations

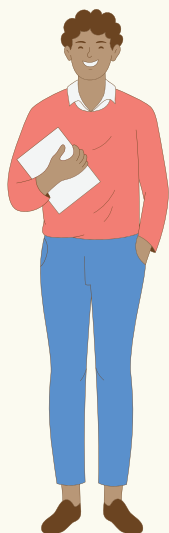
Challenges	Opportunities
Data security concerns with online platforms	Use secure, consent-based digital tools for sharing
Ethical dilemmas on social media dissemination	Develop clear protocols for digital ethics and participant control
Limited access to in-person sharing spaces	Create interactive online galleries to widen engagement

Final Thoughts: A Call to Action

Photovoice can drive policy change, challenge social inequalities, and empower communities, but its impact depends on how it is implemented. As you consider using Photovoice in your work, reflect on:

- How will you integrate Photovoice into your research, advocacy, or community initiatives?
- How will you keep participant voices central to your dissemination efforts?
- What steps will you take to ensure Photovoice is sustained ethically and effectively?

This toolkit has laid the groundwork. Whether you are a researcher, advocate, or policymaker, your next steps will shape the future of participatory research and community storytelling.



How will you use Photovoice to make a difference?

We'd love to hear from you, scan to give feedback



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Thank You

This toolkit is the product of many hands, hearts, and perspectives. What began as a method has grown into a movement, one that places cameras in the hands of communities and brings stories to the centre of global health research.

To the individuals living with chronic respiratory disease who chose to share your world through photographs and reflections, your honesty, creativity, and trust have shaped not just this resource, but how we understand illness, care, and community.

To those who stood alongside this process, facilitators, fieldworkers, caregivers, and quiet champions, your presence and patience have made this work ethical, grounded, and real.

Photovoice is more than a technique; it is a way of seeing, listening, and learning. Our sincere thanks to all who embraced this vision, not just to contribute to a project, but to reimagine what research can look like when it centres lived experience.

As you explore this toolkit, we invite you to carry forward the spirit in which it was created, with humility, curiosity, and deep respect for those whose stories are so often left untold.

— **Hani Salim, Universiti Putra Malaysia and Jayakayatri Jeevajothi Nathan, Universiti Malaya**

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