THE PRACTICE AND ETHICS OF PARTICIPATORY VISUAL METHODS FOR COMMUNITY ENGAGEMENT IN PUBLIC HEALTH AND HEALTH SCIENCE

BY GILL BLACK AND MARY CHAMBERS

WITH CONTRIBUTIONS ON METHODS
FROM ALUN DAVIES AND SONIA LEWYCKA

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Photo cover: A young participant in the image-led digital story telling project Place of Change practises taking photographs with a simple digital camera.
Photo credit: Fact & Fiction Films 2012

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Pots of paint used for body mapping exercises in the Bucket Loads of Health project.
Photo credit: SLF 2018

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Patients recovering from brain infections can be left with ongoing disabilities. A participant from the OUCRU project Beyond the Hospital shows how he practises walking by holding onto his wife.
Photo credit: Annabelle Audier 2016

Foreword

This handbook provides guidelines on the practice and ethics of participatory visual methods (PVM) with emphasis on their use in low and middle income countries (LMIC) for community and public engagement in health and health science. The guidelines are drawn from the hands-on experience of the authors and the insights they have gained as PVM practitioners working with these methodologies in LMIC for 10 years or more. The handbook has been developed for use by engagement practitioners who are relatively new to the field of PVM and want to learn more about what they are and how to work with them. It also aims to support health science researchers who wish to include visual methods when engaging local communities and wider publics in their work. The handbook does not explore the theory behind PVM or provide an in-depth review of the literature. For each method that is described the pioneering work in the field is cited, along with other suggested reading, should you wish to learn more.

The content of this handbook is also available as an online course on The Global Health Network site:https://globalhealthtrainingcentre.tghn.org/practice-and-ethics-participatory-visual-methods-community-engagement-public-health-and-health-science/.

1. Introduction

A number of different terms are used to describe engagement between non-researchers and health research including public engagement, community engagement, public outreach, and public and patient involvement. This handbook focuses on facilitating 'internal engagement' processes with groups of community residents to generate creative visual materials and foster discussion and learning about health and health research. It also provides guidelines on how these visual materials can potentially be shared with other members of the public through external engagement activities and events. In addition, the handbook explores other avenues of engagement including the use of PVM to facilitate knowledge exchange between community residents, other members of the public, and scientists.

Internal engagement refers to engagement that happens with and between primary participants during a PVM process.

External engagement refers to the use of PVM outputs to engage people other than the primary participants of a PVM process.

Audience members interact during a Q&A session at a community engagement event in Delft, Cape Town. The Heart of The Matter - Photo credit: SLF 2016

A resident of the informal settlement of Enkanini in the Western Cape adds detail to her body map. Bucket Loads of Health - Photo credit: SLF 2018

The term ‘participatory visual methods’ encompasses a wide range of techniques that involve people taking part in the production of creative outputs that are used to convey their knowledge, experience, opinions and ideas. Examples of PVM products include dramatizations, drawings, paintings, maps, photographs, digital stories and films. As creative forms of expression, these products can enable participants and wider audiences to see and understand other people’s situations in new ways. The outputs of PVM can thus offer novel and exciting platforms for discussion and debate, and open up fresh channels for knowledge exchange and learning.

Many of the biggest global health challenges occur in the poorest and most marginalized areas of the world. Working with visual methods can enable those who are marginalized and often excluded from discussion and debate about medical research - such as women, youth, less-able people and the elderly - to take part meaningfully in community and public engagement.

Because participants express themselves mainly through performances or images, PVM can help to:

- transcend barriers of language and literacy
- foster interactions between non-researchers and researchers across creative platforms
- enable participants to show how they understand and experience health challenges and health-related research
- balance the dynamics of power and knowledge that are likely to exist when ‘non-expert’ community members and other members of the public are brought into discussion with scientists or other researchers
- allow community members to be seen and heard at engagement events without having to take part in live public speaking if they would prefer not to.

Empowerment:
The theoretical roots of “empowerment” as a critical element of community engagement can be traced back to Brazilian educator Paolo Freire (Freire, 1970).

As articulated by Kenneth Maton (2008: 5), empowerment is “a group-based participatory, developmental process through which marginalized or oppressed individuals and groups gain greater control over their lives and environment, acquire valued resources and basic rights, and achieve important life goals and reduced societal marginalization”.

Excerpt from the Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement.

In 2011, the Clinical and Translational Science Awards Consortium (CTSA) set empowerment as an important ethical goal of community engagement (CTSA Community Engagement Key Function Committee, 2011). Ideally, both the process and the outcome of working with visual methods for community engagement enables a form of empowerment for all participants. The final outputs of a PVM process should have the potential to bring recognition to the value of community knowledge and its place in research prioritization, design and practice.

Working with visual methods on health-related topics also has the potential to increase participant vulnerability in a number of ways. Examples of how this can happen are described in some of the case studies that form a component of this handbook (mini case studies can these can be found throughout Chapters 6 to 14 and fuller ethics case studies can be found in Chapter 15) . PVM facilitators need to be aware of these possibilities and, as far as possible, be prepared to mitigate or manage the eventualities.

The 15 chapters in the handbook fall into four sections:

Chapters 2 and 3 provide **general guidelines**, both practical and ethical, for planning and facilitating PVM processes. PVM processes can be complex and there are many considerations to be made in their design and implementation. These general guidelines summarize key practical or ethical factors to consider when planning and facilitating PVM workshops for community and public engagement in health research. Some factors (e.g. the language used in a workshop) require both practical and ethical considerations at the same time.

Chapter 4 suggests ways to **disseminate PVM outputs** with different audiences.

Chapters 5 to 14 give examples of some of the most well-known visual methodologies and suggestions about how to facilitate them. These chapters are grouped into visual methods that don’t require technical equipment (chapters 6-10) and visual methods that do require digital and other forms of technical equipment (chapters 11-14). Mini case studies are included for each method.

Chapter 15 comprises a collection of **ethics case studies** drawn from the global south. They describe some of the complexities that authors have experienced when facilitating PVM processes, explain how they navigated those challenges and discuss what they learned from doing so.

Suggested Reading

Friere, P. 1970. Pedagogy of the oppressed. [translated by Myra Bergman Ramos]. New York Herder and Herder

Maton, K.I. 2008. Empowering community settings: agents of individual development, community betterment, and positive social change. American journal of community psychology. 41(1-2): 4-21.

Ice breaking activities can help to bring health scientists and community members together.
Heart of the Matter - Photo credit: SLF 2016

2. General Guidelines For Planning A PVM Process: Practical And Ethical Points To Consider

Time

Practical tips: PVM processes are creative and enjoyable, but they can also be lengthy and challenging. Some require the focussed attention of facilitators and participants over multiple consecutive days, while others call for significant commitment over weeks or even months, especially in the case of participatory film-making and video. Rough guides to required timeframes for all the PVMs included in this handbook can be found in the relevant chapters (6 to 14) and can be referred to when designing and planning a workshop.

Which Method

Practical tips: If you are new to PVM, consider starting out with a method that aligns with your existing technical interests and skills. Alternatively, if you or your team already have substantial experience and abilities using a particular method, this may be a good practical reason for using it.

Always bear in mind, however, that the social and cultural context of your engagement setting will strongly influence the most appropriate type of visual method to work with. This means considering not just your participants, but also your intended audience for the visual outputs, including their age and what type of media they are most likely to respond to (see Chapter 4).

If possible, within your project framework, it is best to include the participant group in choosing a visual method. However, this can be challenging if a donor needs to know in advance what type of visual output(s) a project will generate. You may also need to consider the perspectives or concerns of ethics review committees, and the cost and availability of equipment.

Participants of Bucket Loads of Health show their collective film to fellow community members during an engagement event in Delft, Cape Town.
Photo credit: SLF 2019

Individual vs Collective Processes

Practical tips: Another factor to consider when deciding upon which visual method to use is the difference between individual and collective processes. In PVM processes, visual outputs are created by individuals, by groups or sometimes through a combination of individual and group. In general, an individual process involves each participant creating their own output, such as a body map or personal digital story – even if this happens in a group context. A collective process is when a whole group is involved in generating a visual output, for example in participatory video. Group size, group dynamics, the type of event that will showcase the visual output(s) and the main target audience are all key factors to consider when choosing between an individual or collective process (see Chapter 4 for guidance on identifying target audiences).

If time and resources allow, engagement can be strengthened by creating and sharing both individual and collective visual outputs. If you decide to take this two-pronged approach, it is important to think through in advance how you will facilitate the transition from group members working individually to create a personal product into working together to produce a collective output.

Group Size

Practical tips: With experience, most of the methods described in this handbook should be manageable with group sizes of up to 15 people. Choose a smaller group size of 5 – 10 participants if:

- You are using PVMs that require a lot of space (e.g. body mapping).
- You need to allow a significant amount of one-to-one time between facilitators and participants (e.g. personal digital storytelling).
- You are working with a visual method for the first time.

Participant mobilisation

Ethical considerations: Because they involve the visual expression of memories or lived experiences, PVM processes can be emotionally evocative and sensitive. This means you will need to think very carefully in advance about who to invite. It can be helpful if some members of the participant group are already connected in some way and have good relationships. When people know and trust each other, it's easier to develop and share visual materials, especially if they are related to personal health.

It's also important to know that one of the reasons that PVMs can be so powerful is that they enable the inclusion of marginalized people, whose voices are not often heard in a community setting but who bring an important dimension to engagement in public health and science. If you include only community leaders or the strongest local voices, you may limit the depth and breadth of experience and perceptions participants can convey.

Other factors that need to be considered as part of your mobilization efforts include:

- Time commitment and availability
- If participants are employed, will they need to take time off work to participate? If so, will they lose income and how will you compensate for that? (see Compensation section below).

If possible, ask well-known and trusted members of the community, who are familiar with the aims and objectives of the project, to help with mobilising participants. Depending on the context, topic and purpose of the project, aim for appropriate representation of gender, age, local languages and experience of the topic being explored.

Space

Practical tips: Different processes need different amounts and types of space – and in turn, the available space will influence participants' experience of the process. For example, body mapping needs enough room for all participants to work on a life-size body map simultaneously – if this is the method you choose, you need to book or hire a venue that can comfortably accommodate everybody. Participatory photography and video largely involve working outdoors in a local/community setting, but you will probably need a room for video or photography training, and to set up computers for the editing process. Also consider the physical requirements of your participants - for example, will the needs of less able people be accommodated in the venue you will be working in? It is also very useful to work in a space where you can leave the workshop materials and art works in place for the duration of the workshop. Clearing everything away at the end of each day requires additional time.

Ethical considerations: As far as possible, find a workshop venue that is private, quiet, comfortable and conducive to the specific visual approach being taken. Also consider group size and the length of the process. If a group of 10 to 15 people are going to be working together over a period of 4 or 5 consecutive days (or longer), it's helpful to have enough space so that participants have somewhere to get away for a few minutes. In some cases, you may need to take people outside of their community so they feel more able to speak freely, or they may not want to be identified with the project (e.g. if the project is known to be about a stimigmatised issue such as TB, or commercial sex workers).

Language

Practical tips and ethical considerations: Language is a top priority to consider when you are planning a PVM process. It is vital to be aware well in advance of the primary language that is spoken by the participants as project information sheets and consent forms will need to be made available in these languages. You may be in a situation where the participant group is multilingual in which case it will be important to know if there is a common language that all are fluent in. You will also need to consider whether a translator or translation support is needed. Translation can take a lot of time, so it is absolutely essential to build enough time into the programme for sufficient translation if it is required. Make sure that at least one member of the facilitation team shares a language with participants.

Facilitation

Practical tips: As for all participatory processes, PVMs need strong facilitation skills. The best way to develop these is through experiential learning under the guidance of a skilled practitioner. You do not need to have great artistic ability, but some creative flair and an appreciation of the diversity and power of art are definitely assets. Think ahead about how you are going to nurture a safe and trusting space for disclosure, and encourage a strong sense of respect and confidentiality for private matters.

A PVM facilitator and participatory photography group discuss different types of shots and angles. The Heart of the Matter - Photo credit: SLF 2016

Team work

Practical tips: Most PVM processes involve multiple steps and the availability of equipment or other accessories so it is important to build in efficient technical and logistical support. You will need co-facilitators to support participants working at different paces and help to monitor the process. Things will run more smoothly when each member of the team understands their roles and responsibilities, so work these out in advance. Beware of having more facilitators than participants, however, as this tends to cause an imbalance in the dynamics of the process. Before the workshop begins, develop a programme of activities or agenda and discuss and allocate roles and responsibilities between facilitators. Allow flexibility and "wiggle room" in your programme, and be prepared to make changes if needed.

Who to include

Ethical considerations: In general, the only people involved in a PVM process should be the core participant group, the facilitation team, a counsellor (if necessary) and possibly someone who is being trained in the method. Bringing in others will probably change the interactive nature of the workshop and influence the content of the visual outputs.

However, sometimes it may be culturally or politically necessary to include additional people. For example, in some places a facilitation team may not be welcome or allowed to conduct a workshop, or any process that involves community members, unless a community leader, a government official, the police, or a representative of the project funder have been invited. If this is the case, take time while planning the workshop programme to consider what can be done to minimize the impact of these visitors on the participation of the core group.

Flexibility

Practical tips and ethical considerations: Before you start, be aware that visual methods do not always go entirely to plan. Include some wiggle room when developing a workshop programme to allow for changes that may become necessary during a PVM process. Flexibility can be

An inception workshop in the Heart of the Matter project, bringing together community participants and health scientists Photo credit: SLF 2016

challenging, so it is crucial for a facilitation team to consider in advance where the boundaries of reflexivity lie, and to understand how flexible a PVM can be without compromising the aims of the engagement. This is especially important when a change in the programme would mean a significant reallocation of the budget.

Inception Meeting

Practical tips: A good PVM process should begin with an inception meeting a few days before the actual PVM workshop starts. This gives participants time to decide on whether they want to commit themselves to the programme or opt out, and plan their schedule and make any necessary arrangements. An inception meeting is useful because it gives potential participants and the facilitation team an opportunity to meet and get to know each other. It provides an important opportunity to discuss the project aims, objectives and wider project context before the creative process begins. An inception meeting allows facilitators to gain early insights into group dynamics and expectations and enables participants to make an informed decision about their involvement in the PVM workshop. This introductory meeting can usually be completed within half a day.

Compensation

Practical tips and ethical considerations: The issue of compensating or remunerating participants for taking part in a workshop (or an entire engagement project) is certainly not limited to visual methods processes. Compensation is a vital element to be considered in every type of participatory process. Important considerations when thinking about compensation include:

- It is common practice for participants to be provided with a stipend that covers the cost of their transport/travel to and from the workshop/engagement venue, communication (cell phone calls) and child care if it is needed.
- If the workshop is running over meal times, and meals are not being provided, the stipend should also cover these costs.

- If participants are formally employed, participating in your PVM process may have implications for their salary payments.
- If participants are not formally employed, participating may result in lost opportunities to earn income.
- During the planning process, work out what form the remuneration will take (e.g. cash, vouchers) and how the remuneration process will be done.
- If participants will not benefit financially from the process it is important to provide something else in return for participation that is considered to be a benefit by those that take part.

Consent

Practical tips and ethical considerations: Negotiating informed consent is an essential element of every PVM described in this handbook. Broadly speaking, the informed consent process has two core elements:

i. Requesting participant consent to take part in the PVM workshop that will produce visual outputs. This will also include asking consent to take written notes and photographs during the workshop, and explaining what this documentation will be used for.

ii. After the workshop, requesting participant consent for their final visual outputs to be shared with other people.

In practice, consent requirements vary according to the specific visual method that is being used. Regarding the second aspect of consent (ii) described above, individual methods such as body or hand mapping will require a different process compared to a collective method such as participatory video wherein participants are required to give consent collectively. Consent forms need to be developed as part of the PVM planning process. It is vital to ensure sure that consent materials are made available to participants in their home languages.

Third Party Consent

Ethical considerations: In general, there are two situations in which you may need to request consent from people who are not participating in the PVM process themselves:

iii. When participants are minors, they may need the consent of their parents or guardians to participate. This is also known as a process of 'assent'. In the case of projects involving school learners, the school principal may also need to consent (see Methods/Participatory Video/Ethics for an example of what this can involve). The Nuffield Bioethics Report Children and Clinical Research: ethical issues provides further information on the topic of assent.

iv. If non-participants appear in the outputs of a PVM process – for example if they can be identified in a photograph or video – they will also need to be asked for consent before their picture is featured in the final product.

Dangerous Contexts

Ethical considerations: PVMs can potentially involve taking audio-visual gear into public settings to obtain images. This may put participants at risk of being robbed for their equipment, especially in areas that are known to have high crime rates. This is dangerous for participants, and may also mean that expensive and irreplaceable equipment is lost or broken. This is to be circumvented at all costs. If working in unsafe contexts is a relevant and unavoidable issue for your PVM process, plan ahead in order to mitigate the chances of a dangerous event e.g. ensure the presence of security guards and select places that are busy and well-lit for the photography/film-making activities.

Support and Counselling

Ethical considerations: Before the PVM process begins, find out about established and reliable organisations or individuals, such as counselling services or support groups, who can provide appropriate support if needed. If the topic is especially sensitive in a given context, consider inviting a counsellor to attend workshops, and ensure that participants know from the outset why that person is there. Alternatively, a community member who is known and trusted by the participants (but is not actively participating) can be requested to attend with the aim of providing encouragement and personal support both during and after a PVM workshop. Ring-fence resources within your project budget so that a programme of counselling can be provided should it become necessary.

Open Enquiry

Ethical considerations: Because of their non-prescriptive nature, participatory methods have the ability to surface latent, rich and diverse experiences, even when a small number of participants are involved. To enable a wide array of responses, keep the core prompt question that guides a visual methods process open, straightforward and easily translatable into the locally spoken language.

Before the workshop begins, think carefully about the prompt question that will guide the engagement process. A good prompt question aligns with the health or health science research theme of interest, but avoids being rigid or trying to steer participants in a specific direction. Leave the prompt question sufficiently open so that participant perspectives can be seen through a wide lens.

Examples of good (open) prompt questions are:

- What is the impact of water scarcity in your life?
- What foods do you choose to eat during the course of a normal week in your life?
- What makes TB better in your community?
- What are the biggest risks you face in your farming life?

Examples of leading (poor) questions are:

- How does water scarcity negatively impact your well-being and livelihood?
- What are the healthy and unhealthy foods that you eat during the course of a normal week in your life?
- What have you learned from the clinic about how to treat TB?
- What are the health risks of handling farm animals?

Including Health Researchers and Scientists as Participants

Practical tips and ethical considerations: Community engagement in health science research can be strengthened by bringing health scientists and community members closely together in engagement processes. The outputs created through PVMs can serve as platforms for engagement, enabling those who make them to explain their experiences of research and their understanding and opinions about specific topics or areas of science. Conversations about the content and meaning of visual outputs can also provide rare and important opportunities for reciprocal learning between researchers and the public.

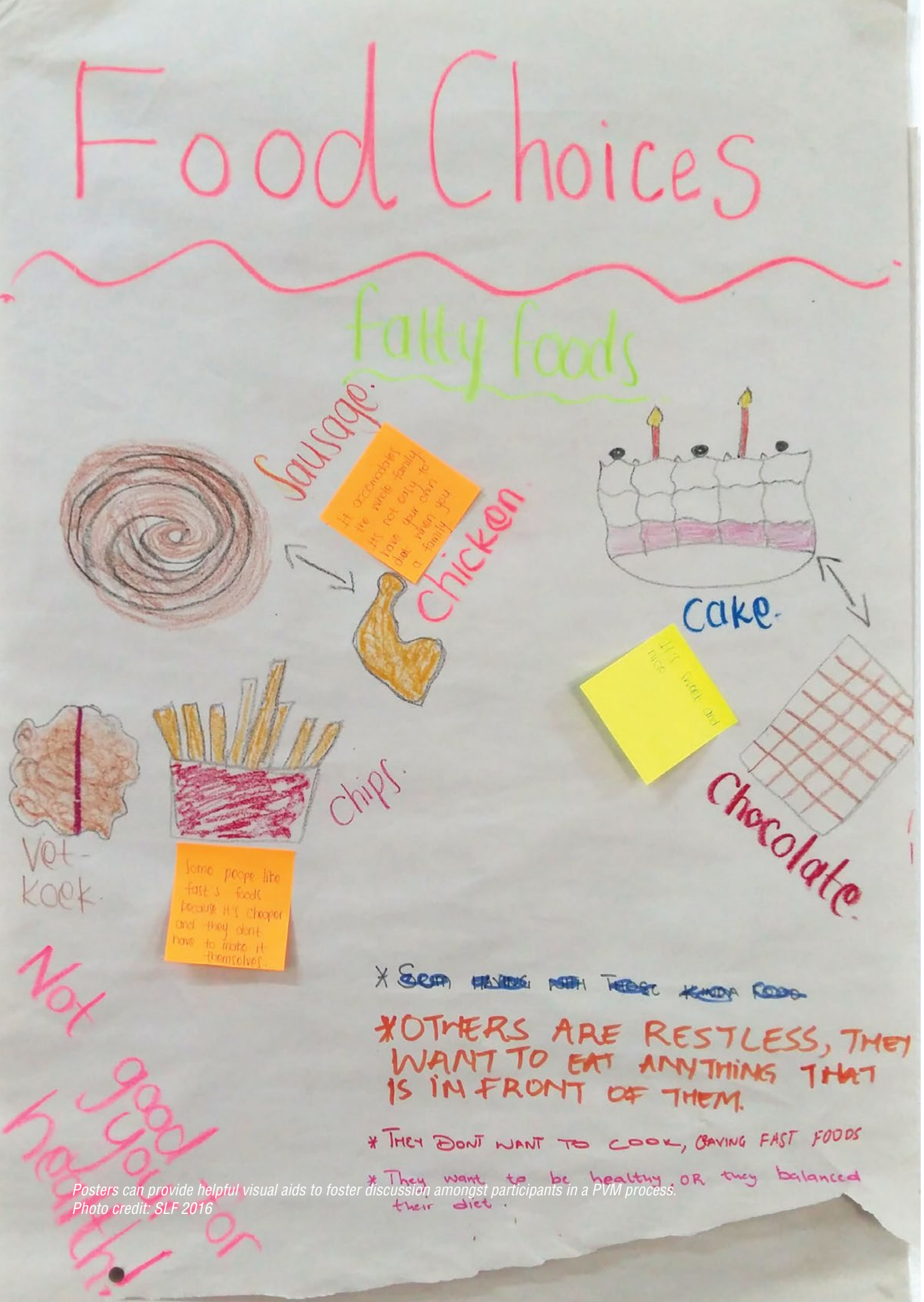
Participants in the science engagement project, The Heart of the Matter, watch as a researcher conducts an experiment in the cardiovascular disease research laboratory at Stellenbosch University.
Photo credit: SLF 2016

For researchers and scientists, taking part in PVM processes can enable them to see and show their research through a new lens and from a more grounded perspective. Engaging with members of the public in this way can ignite new ideas for research enquiry, as well as being enlightening and affirming for the community members and research teams that take part. Exchanging visual materials helps to level the ground between academics and community members, paving the way for a more balanced engagement experience.

Bear in mind, however, that close engagement with community members may be a novel and emotionally hard experience for a research group. This is something the PVM facilitation team needs to recognise and be responsive to. It may be necessary to work with researchers in advance so they are willing to accept and value a co-creation process which may be quite different from the scientific process they are used to.

There are different ways to include scientists in visual methods processes, depending on the depth of their interest in community engagement, and their availability. Here are some possible approaches:

- Organise an event at which community members present the visual materials they have created to a scientific audience. An example is The Heart of the Matter, a ground-breaking project that brought a team of cardiovascular disease scientists into a knowledge exchange process with residents of an urban township in South Africa through a participatory photography project.
- Scientists can also create their own visual outputs, either as a way to simplify and explain their science, or as a way to introduce themselves to community members. In The Heart of the Matter, the scientists developed colourful handmade posters to illustrate basic facts about heart disease, and to demonstrate the rationale, goals and scientific approach to their research. In another project from South Africa, Bucket Loads of Health, a team of microbiologists drew personalized hand maps to share their reasons for choosing to become water researchers in the context of informal settlements.



Posters can provide helpful visual aids to foster discussion amongst participants in a PVM process. Photo credit: SLF 2016

3. General Guidelines For Facilitating A PVM Process: Practical And Ethical Points To Consider

Time

Practical tips: Highlight and clarify the time requirements right at the outset of a PVM process, in early discussions with potential participants. Add a timetable to the project information or consent form so the participants are well informed about the time commitment involved (see Inception Meeting sections below and in Chapter 2).

Which Method

Practical tips: At an early stage in the PVM process, make time to provide participants with an explanation of what is involved in using the method of choice. Include a discussion about the possible implications of using the method, especially with regards to anonymity. This can be done as part of an inception meeting (see Inception Meeting sections below and in Chapter 2).

Ethical considerations: It's important to acknowledge that PVMs are not intended to produce perfect or highly polished visual products. PVM outputs are more accurate and powerful when they present first-person voices, raw images and original writing. With that said, taking part in creative, artistic exercises such as drawing, painting, photography, film-making and acting/role play can be intimidating for participants at first. The methodology may include activities they have never done before, or not done since childhood. Some participants may lack confidence, or be daunted by the artistic or technical abilities of the facilitators or other group members. Provide reassurance to participants that the PVM process is not competitive and involves no judgement over the quality of the end product.

If your process will involve editing participants' work in any way, include them and seek their input and approval as far as possible – and try to keep editing to a minimum. If the outputs are to be shared with an external audience, consider how to manage the expectations of those audiences regarding what the output will look like.

Space

Ethical considerations: The course of a PVM process is strongly influenced by how relaxed and safe the participants feel so do everything you can to create those conditions throughout. Playing appropriate background music while participants are working individually on drawings or painting can help to make everyone feel more at ease. Make allowances to provide sufficient refreshments and offer enough breaks to keep the participants comfortable.

Language

Ethical considerations: During the workshop it is important to frequently encourage participants to speak and express themselves in the language they are most familiar with. In addition to making participants more comfortable, stories or experiences that are narrated in a first language are more accurate and powerful. If the participants are making a film or creating personal digital stories, you can work with a translator and/or video editor to insert subtitles – when this is necessary or helpful for external engagement.

Team work

Practical tips: Work with at least one or two co-facilitators, rather than trying to juggle everything on your own. It is important to check in with your facilitation and technical support team at several points during each workshop day to see how they are doing and monitor the progress of the participants. Keeping journals and holding regular debriefing sessions for the facilitation team will enable you to monitor and evaluate progress, and discuss any changes to the programme.

Flexibility

Practical tips: Participatory processes can take new and unforeseen directions as they unfold, so it is important for the facilitation team, and the programme, to be flexible. Remain open and willing to make (sometimes significant) changes in the programme if this is strongly requested or becomes an obvious necessity. Be sure to keep the whole facilitation team updated in good time about any changes to the workshop programme. This will strengthen and streamline the facilitation process, and help to avoid unnecessary confusion or tension amongst the team.

A PVM facilitator and participants work together in planning the presentation of a photovoice project for public engagement. The Heart of The Matter - Photo credit: SLF 2016

Inception Meeting

Ethical considerations: During the inception meeting:

- Explain the background, themes and aims of the engagement project, and the logistical and practical requirements for participation.
- Give a light introduction to the visual method or methods that will be involved, and show examples.
- Discuss any hopes and fears the participants have about the process you have explained.
- Ask participants to develop some 'rules' to guide workshop etiquette.
- Request permission for a co-facilitator to take written notes and photographs of the workshop proceedings. Clarify that each participant is free to refuse or revoke permission for notation and photography if that is their preference.

- Ascertain the need for translation.
- If appropriate, discuss potential audiences with the participant group. Knowing who is going to engage with the final outputs is likely to influence what participants are willing to share and what views and opinions they are prepared to express.
- Raise the importance of privacy, confidentiality, respect and trust for all who are involved throughout the PVM process (see section on Anonymity and Confidentiality below).
- Provide time for questions and answers about the process and methods, so that potential participants can make an informed decision about their interest and availability to participate.
- If some members of the group don't know each other, include some ice-breaking activities.
- Give participants a take-home information sheet, written in their home language, about the aims of the project and an overview of what participation will mean for them. Include information about the commitments the facilitation team is making to the participants.
- Include a timetable so that participants are very clear about the time and commitment needed.
- Include a consent form for people to sign if they agree to participate (see Consent section below, and the sample information/consent forms in the Appendix).
- Give participants time before asking them to sign a consent form as they need a chance to reflect on whether they can (or want) to be involved. It might be necessary for participants to take the consent form home after the inception workshop as they may need to seek permission from somebody else.

Navigating Expectations

Ethical considerations: An inception meeting provides a valuable opportunity to begin understanding and exploring expectations among the participant group. It is important for the facilitation team to understand what the participants expect to gain or want to achieve through their participation. Discussing the expectations of the facilitation team is equally as important, so take time to explain what you (and your team), and the organisations or institutions involved are aiming to achieve by creating visual materials. Also explain why a specific visual method has been chosen, if the participants were not involved in choosing which method to use.

Discussing the scope of the process, or the wider engagement project that a PVM process is part of, will clarify the limitations of a project. For example, when a project involves participants using equipment like cameras, earphones, microphone or digital tablets, they may expect to be able to keep the equipment permanently. This is often not possible, and it is best to be clear about this from the very beginning.

Explain to participants that you do not expect them to produce an artistic masterpiece or highly polished end product. Emphasise that the aim of the creative exercises is to provide new and different ways to illustrate experiences and perspectives instead of just talking or writing.

Involvement and Ownership

Ethical considerations: When participants are fully or closely involved at each step in the development and dissemination of their visual product(s), they are likely to feel a greater sense of their ownership of that product. This is easier to achieve for some PVMs than others. For example, in the case of body mapping it should not be necessary for anybody apart from the participant to be involved in creating his or her body map. On the other hand, participatory video often requires

A water microbiologist describes her journey into science by presenting her hand map to participants in the community engagement project Bucket Loads of Health - Photo credit: SLF 2019

the skills of a video editor to assemble the final product. How closely involved participants can be will depend on their availability as well as the timeframe and resources of a project.

In order to support the intent for participatory methods to be empowering, it is crucial to allow participants to identify the experience and images that they feel are the most significant and important to share. The facilitation team should avoid trying to influence participants when it comes to making these decisions. It is likely that participants will disengage if they are not given the freedom to make their own choices. Include moments for analysis and interpretation in the process, so that participants have an opportunity to reflect upon the meaning and message of their visual product.

If and when it comes to disseminating and sharing visual outputs with the public, participants may need support in preparation and presentation. This is especially the case because of the power dynamics that often exist when 'non-experts' come into discussion on a research topic with scientific 'experts' or other professionals. Before presenting a visual output, build in rehearsal time so that participants can distil, articulate and practice what they want to say when engaging with their audience(s). By 'owning' visual outputs in this way even very inexperienced participants can gain confidence in presenting and explaining them. Confidence building can contribute to the capacity development of a participant group by enhancing group cohesion, fostering movement building or enabling the transfer of hard skills.

Give participants the option of taking away the original versions or copies of their visual products to keep and to use as they wish. This is an important point for discussion in an inception meeting, with a timeline agreed for handing over the completed outputs. Note that participatory video is a special case and it is very important to consider the implications of giving copies of the finished film to every participant. This is a decision to be made at the discretion of the project leaders or facilitation team, taking into account the topic of the film, the context in which it has been made and the perspectives of the participants.

Confidentiality and Anonymity

Ethical considerations: PVM participants often describe the process as being similar to therapy, or being in a support group. Some individuals share experiences that are deeply private, or disclose information that can potentially put them at risk in some way. They may choose not to include this information in the final product, and may ask that it is not discussed beyond the workshop. The facilitation team needs to create a safe and trusting space for disclosure, and encourage a strong sense of respect and confidentiality for private and sensitive matters.

Using drama or role-play as visual methods can help to circumvent concerns around confidentiality and anonymity as they enable participants to share sensitive views and experiences by portraying fictional characters.

Being identifiable in visual outputs that are targeted at wide audiences can have implications for the individuals or groups who appear in them, or their entire communities. This is especially relevant for personal digital storytelling, participatory video and photographic methodologies. Being seen in the context of particularly sensitive public health or scientific research topics can invade privacy, reinforce damaging stereotypes or introduce stigma and discrimination into someone's life. Depending on the context, there may also be serious risks involved if participants disclose anti-government sentiment or illegal activity.

Anonymity in PVM processes can be complex. If people do not have the option of staying anonymous, they might withhold opinions they really want to express, share 'made up' stories or experiences, or even choose not to get involved at all. On the other hand, some participants may feel very strongly that they want to appear and be identifiable in the final disseminated product.

Working with young people can be especially challenging, because they may not foresee the implications of being recognizable in a visual output. Consider bringing in an older/ experienced person who is liked and trusted by the participant group to support them in reflecting on the implications.

Participants can tell a story without showing their faces.
Photo credit: A Place of Change project participant 2013

Understand that different people may have different preferences, and allow for these differences in your planning. Discuss issues of anonymity and confidentiality early on in the planning process, because they may affect the choice of PVM and will certainly affect the nature of the content. If a participant suggests a story or image that the facilitation team or other participants consider to be risky (for example an image that might compromise the safety or security of an individual or the group), these possibilities need to be carefully discussed with insight, discretion and sensitivity. Consider using drama or role-play as a method for a light touch approach to de-identification as they enable participants to share sensitive views and experiences by portraying fictional characters. If participants choose not to be identifiable at all, offer a range of alternatives. These might include using:

- footage that has no people in it;
- drawings, paintings, models or symbols;
- open access images from the internet;
- photographs of a person's shadow or back;
- photographs that convey ideas abstractly, metaphorically or through mood; or
- figurines that can be creatively placed into scenes representing individuals or groups.

Compensation

Ethical considerations: It is imperative to discuss the financial implications of participation with a group of participants at the outset of any participatory process. Be very clear about when any payments will be made and how much those payments will be. If it is possible, it usually works best when stipend payments are made to participants by someone who is not in the facilitation or technical support team.

Consent

Ethical considerations: It is crucial for facilitators to give participants the option of remaining anonymous in the final visual outputs, as being identifiable may have unwanted repercussions for individuals and/or communities (see section on Confidentiality and Anonymity above). Most PVM processes involve different steps and stages, so it is best to take a dynamic approach to consent. A dynamic consent process involves asking participants to consider their agreements for sharing their creative materials at each stage, as their understanding of the project deepens and their visual outputs are developed and disseminated. Give participants enough time to consider their consent carefully.

Third Party Consent

Ethical considerations: If it is applicable in your PVM process (e.g. participatory photography or participatory video) explain to the participants what is meant by third party consent. Discuss how they might go about requesting consent from people they want to photograph or film, and explain that it is an essential to obtain consent if a person can be identified in a photograph or film. Work with your participants to develop a consent process that is suitable for the context and the project. This may involve participants developing written consent forms in the most appropriate languages, or working out an alternative approach to consent (e.g. video recording verbal consent) when literacy cannot be guaranteed.

Dangerous contexts

Ethical considerations: If participants are working in their own communities, discuss with the group which areas are safe and which are high-risk. Participants may well choose to avoid high-risk areas. If participants want to enter a high-risk area, discuss the implications with them and make sure that there are measures in place to protect them. These might include working during daylight hours only, having at least one person as lookout, and having a reliable emergency contact number. Make it clear that people are more important than equipment, and tell participants that they can let the equipment go if they find themselves in any danger.

Health Risks

Ethical considerations: If your project involves photography or video, participants may jeopardize their health by exposing themselves to infection to capture compelling images or footage. Before participants go into the field to take their photographs or make their film be sure to discuss potential risks with them. This is especially relevant for PVM processes that explore communicable diseases and is crucial when working with participants that may be immune compromised including young people, people living with HIV and the elderly. Emphasize that they should not risk their health for the sake of obtaining an image. Suggest alternatives such open-access images from the internet, drawings, paintings or magazine cut outs and provide opportunities for participants to create these.

Support and Counselling

Ethical considerations: While you are facilitating, keep your eyes and ears open for signs of distress among the participant group. During your regular check ins with your facilitation and technical support team, make sure that the participants are coping with the workshop emotionally as well as practically. Be prepared to bring in counselling support at any point and be aware that the need for counselling may extend beyond the scope of the PVM workshop. Remember that facilitators can also be vulnerable; make room in the daily debriefing sessions for the facilitation team to decompress.

Suggested Reading

Margolis, E. & Pauwels L. Eds. 2011. The Sage handbook of visual research methods. London, United Kingdom: Sage Publications Ltd. ISBN 978-1-8478-7556-3

Mitchel C. 2011. Doing visual research. London, United Kingdom: Sage Publications Ltd. ISBN 978-1-4129-4583-7

Panos London. 2012. Beyond consultation: a guide for commissioners. Available: http://panoslondon.panosnetwork.org/resources/beyond-consultation-a-guide-for-commissioners/

Black, G., Davies, A., Iskander, D. & Chambers, M. 2018. Reflections on the ethics of participatory visual methods to engage communities in global health research. Global Bioethics. 29(1):22-38. DOI: 10.1080/11287462.2017.1415722
Available: https://www.tandfonline.com/doi/full/10.1080/11287462.2017.1415722

A member of the Delft Water Clan shares her body map with local residents at an external community engagement event in Cape Town.
Bucket Loads of Health - Photo credit: SLF 2019

4. Product Dissemination

External engagement

Product dissemination is not a prerequisite of PVM. In many cases a PVM process can be a valuable form of 'internal' community engagement in its own right because it promotes understanding and builds consensus for action or change amongst a group of participants. However, PVM outputs can also be disseminated to engage people who did not participate in a PVM process but can relate to the images and narratives produced through it. In this handbook we refer to this as an external engagement approach.

Facilitating external engagement through the dissemination of PVM outputs can be an effective means of enabling stakeholders to see situations in new ways and from different perspectives. It can raise awareness, spark discussion and foster new and reciprocal learning. For some engagement projects, a wider dissemination of the outputs is required to fulfil the desired project outcomes and impacts. Whether or not PVM outputs are disseminated externally depends on the aims of the project and the sensitivity of the PVM topic. The possibility of product dissemination resulting in stigmatisation or jeopardizing the safety of a group or an individual needs to be discussed in-depth with the participants before any material is released (as took place, for example, in the project Place of Change).

Aims of product dissemination

Before choosing a dissemination approach you will need to be clear about the purpose of sharing the PVM outputs. Plush (2009) describes the three central aims of PVM in the context of research.

1. Awareness/Knowledge

i. Amplifying the voices of community members who may usually be under-represented in order that their needs are considered by others in the community.

ii. Amplifying voices of people involved with, or impacted by research, so that researchers and funders can learn from their experiences and reconsider their priorities.

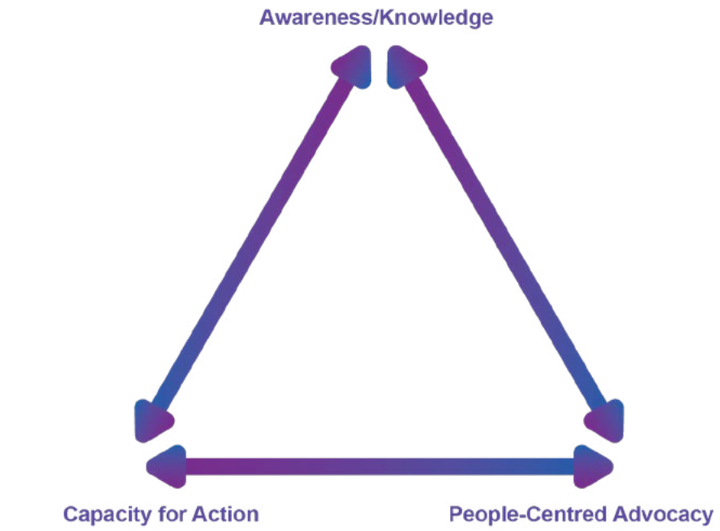
3. Capacity for Action

Encouraging community-led learning and discussion amongst peers and community members in order to promote changes such as safer practises on high altitude religious pilgrimages (for example in the project Mountain Views) or healthier eating choices (see the project The Heart of The Matter).

4. People-Centred Advocacy

To be used as a tool for advocacy by bridging the communication gap between less literate communities and decision makers, such as the need for safer neighbourhoods (project examples include Making All Voices Count; We Are Proud)

The same aims can be applied to the use of PVMs for community and public engagement in health and health science research. The first two aims may be met through the internal engagement process that occurs within a PVM workshop. External engagement has the potential to achieve all three of these aims.



Three central aims of PVM in the context of research (adapted from Plush, 2009)

Who makes the decision?

When it comes to the dissemination of a PVM product, collective decision making is ideal. However, there may be occasions when participants are unaware of a bigger picture. Where PVM outputs could implicate or endanger participants, facilitators must ensure they are made aware of possible implications and protected from potential risks (See case study 'Who Decides How to Disseminate Project Outputs?' in Chapter 15)

Audiences and forums

Audiences

Co-ownership and empowerment of participants should include joint decision making about audiences and forums for product dissemination. However, in some cases, the choice of audience might be pre-defined by the intended purpose of a PVM project, the funder or the pre-planned use of its visual outputs. If this is the case, it is essential that all participants are aware, before the project starts, of who the intended audiences are and the ways in which their visual materials will be shared with those audiences (see case study 'Managing Expectations' in Chapter 15). Knowing this may affect the stories that participants choose to tell or the narratives and images they decide to include in their PVM products. Alternatively, participants can opt out of the engagement project altogether if dissemination plans are not acceptable to them.

Potential audiences for external engagement are:

- The families or peers of the participants and other members of their community. In this case the production focus may be less on creating a polished product and more about conveying common experiences.
- Health researchers, scientists or more local stakeholders such as healthcare providers who will benefit from a deeper understanding of the communities they work with and their priorities. In this case the 'raw' (unedited) visual outputs can be very powerful.
- Policy and decision-makers. In this case the audience is high level and the visual products may need to be further edited and more polished.

Reciprocal learning between community members and healthcare workers or scientists is best achieved when the engaging groups are all included as participants in a PVM workshop (see section on Including Health Researchers and Scientists as Participants in Chapter 2). If scientists and researchers are unable to find sufficient time to participate in PVM workshops, effective engagement can also happen after the PVM process through face-to-face interactions at facilitated meetings or events.

Consent

It is vital to ask for consent at the start of an engagement project with regard to sharing the visual outputs with any predetermined audiences and to discuss explicitly who this includes as far as possible. However, we suggest a 'dynamic consenting' process in which participants have multiple opportunities to consider their participation. It is vital to ask for permission at the end of a project too. Even if participants have agreed upfront to share their visual materials with certain types of audiences in particular ways, they cannot know in advance what narratives and images they will include or how the process of creating their visual outputs will affect them. PVM participants should always be given the opportunity to change their minds about who can see their PVM products prior to the dissemination process. As a facilitator you must respect participant decisions about this, even if it means you can't publicise the project outputs in the ways that you hoped to. Consent for collective pieces is more complicated, as views might vary across the group (see Chapter 13).

Mini case study: In a digital storytelling project with a rural community in Vietnam, participants initially agreed to show their films to any audience. However, after creating their films they changed their minds. They felt the films portrayed poverty and ignorance and asked that they were not shown within a 20km radius of their village to prevent recognition.

Forums

The type of product or output that is created through a PVM process will determine the ways in which that product or output can be disseminated. Possible forums for dissemination are:

- Staged drama performances
- Exhibitions
- Film-screenings

Art-based and photography projects lend themselves well to exhibitions and can be very effective as a means to foster engagement between community members and researchers (see Chapter 6 and mini case study). Be aware that exhibitions need detailed planning and can be expensive.

Engagement venues

When PVM products are to be disseminated for external engagement, the format of the visual outputs to be shared and the intended audiences will determine the type of venue and equipment or accessories needed. For example, visual materials that are intended for viewing by the PVM participants and their fellow community members can be shown in local venues such as schools, village halls and health centres. The display of artworks or posters will require access to easels or suitable wall spaces that you are given permission to use for this purpose. A film screening will need access to electricity, a projector, a screen (or a suitable wall space) and speakers. A drama performance will need a stage area and seating. Depending on the venue and the size of the

audience, a drama performance may also require access to lighting and sound equipment. These types of resources can be difficult to find in rural settings.

When the audience includes policy-makers or senior government officials it may be necessary for an engagement event to be held in a government office or a high level venue outside of the participants' community. In this case it might not be feasible for all participants to attend and the group should choose some members to represent them. However, if at all possible, hold your engagement event in the community that is shown through the PVM outputs. Participants tend to be more confident in presenting what they have made when they do so in their own community. The impact of an external engagement process is likely to be more powerful when an audience learns about personal experiences whilst in the context where those experiences were lived and from those who have experienced it.

Timing is also a central factor to consider when planning an engagement event. If key members of the intended audience are busy during the working week, consider holding your exhibition, screening or drama performance at the weekend or in the evening. Ensure that participants are able to attend so that they can present and discuss their own stories. In some cases, this may require the provision of transport.

'Beyond the Hospital' provides an example of a PVM project that:

- Fostered external engagement through the dissemination of participants photostories in a hospital setting
- Engaged health researchers and healthcare workers as well as hospital patients
- Enabled People-Centered Advocacy through the dissemination approach (see Beyond the Hospital case study)

Mini case study: Beyond the Hospital was a Vietnamese project that aimed to understand the experiences of patients who had suffered from brain infections and were left with long-term sequelae. Using a participatory photography process the patients described their experience of returning home from hospital and the, often slow, road to recovery. The last step of the project was to show these photo stories to researchers and intensive care ward medical staff in order to:

- Raise awareness of the ongoing struggles that patients experience after discharge from hospital (Awareness/Knowledge)
- Advocate with hospital management for a stronger discharge process (People-Centred Advocacy)
- Encourage current patients/carers with stories of recovery and examples of activities that helped (e.g. daily exercises; Capacity for Action)

The photos were incorporated into graphically designed posters that were shown at an exhibition in the hospital. Participants from the PVM process, healthcare workers (HCW), researchers and current patients/carers were all invited to the exhibition.

An unexpected outcome of this dissemination approach was that clinical trial researchers and HCWs who had cared for these patients when they were very sick and often unconscious

in ICU were able to see their recovery and speak to them about their experiences. The audience members reported that this interaction was emotional and encouraging in a way that they or the project team were not expecting. As a result of this external engagement activity the discharge process at the hospital has been changed and now includes the provision of support information about living with disabilities in the discharge material. This outcome fulfils the People-Centred Advocacy aim of a PVM approach.

Disseminating PVM products via the internet

If the project outputs lend themselves to being shared online this can enable access to a very large and very broad audience. It is important to consider carefully whether sharing via the internet is an important aim of product dissemination as there are potential pitfalls with making the material so widely and openly available (such as viewing by unintended and potentially harmful audiences). In many cases online sharing is not an effective means of reaching the participants' own communities.

Ethical implications around consent become increasingly important when using the internet to disseminate media. It is imperative to adhere to the preferences of the participants with respect to the online sharing of their material. Increasing access to technology and internet literacy means many populations are comfortable with technology and the concept of putting information into the public realm. However, in communities which are less familiar with the web you should take time to ensure participants have a solid understanding of how the internet works before asking permission to disseminate their visual outputs via an online platform. This can include a demonstration of how a web search works and a question and answer session (see mini case study below).

Mini case study: As part of a PVM project in Vietnam on zoonosis (infections that transmit between animals and humans and vice versa), the facilitators showed rural participants with little experience of the internet how a search on "pig farms" returned 37 million hits and "pig farming in Mekong Delta" returned 286,000 hits. Typing in "films about pig farming in Mekong Delta" showed the project third on the list of search results. Only after that demonstration did the project team consider participants could give informed consent to have their films uploaded to the internet.

If online dissemination of PVM products is feasible and appropriate, consider how to most effectively publicise the media and how its impact and reach might be evaluated. Some websites have the capacity to gather that information (e.g. on-site web analytics such as Google Analytics or Adobe Analytics).

Suggested Reading

Plush, T. 2009. Video and voice: How participatory video can support marginalized groups in their efforts to adapt to a changing climate. Unpublished master's synthesis paper. Available:https://www.participatorymethods.org/sites/participatorymethods.org/files/PV_ClimateChange_Plush_April2009.pdf

Photovoice/World Vision. 2011. See it our way: participatory photography as a tool for advocacy. Available: https://photovoice.org/methodologyseries/method_05/ppforadvocacy.pdf

A participant and facilitator review the pictures and voice over in her image-led digital story. Health in the Backyard. - Photo credit: Fact & Fiction Films 2015

5. Introduction To Visual Methods Presented Here

The following chapters (6 to 14) provide guidance on how to facilitate nine relatively well known PVMs. The guidelines are primarily aimed at practitioners and researchers who are working with a method for the first time, but they may also be useful as a point of reference for those who are more experienced in the field of PVM. Mini case studies are included for each method.

The ladder of participation: As with all participatory approaches, the extent of participation in PVM depends on a number of factors including the timeframe of your project or programme, the budget you have to work with, the availability of the participants and any intended audiences for external engagement.

The complexity of a method in regards to the inclusion of technical equipment and the need for editing will also have implications for how closely involved participants can be. PVM that involve the use of digital technology or other forms of technical equipment tend to be more complex in terms of participation than those that don't have these requirements.

Chapters 6 to 10 describe visual methods that don't require the use of digital technology or other forms of technical equipment for their implementation. Chapters 11 to 14 describe more complex methodologies that do involve working with digital and other forms of technical equipment: participatory photography, digital storytelling (DST) and participatory film-making. There is significant overlap in the facilitation and implementation of these three methods. Many of the initial steps described for participatory photography are required for DST and film-making so we suggest you read the participatory photography chapter (Chapter 11) even if you are choosing to work with one of the other two methods.

All of the visual methods described below contain interchangeable elements. With some imagination and creativity on the part of the facilitators and participants, the methods can be modified to suit different participant groups and contexts of engagement.

The artist Lena Bui introduced her 'Flat Sunlight' project to school students and facilitated a discussion about what is 'natural'.
Photo credit: OUCRU PE 2016

6. Art To Stimulate Engagement

School students were invited to join interactive tours of Lena Bui's 'Flat Sunlight' exhibition.
Photo credit: OUCRU PE 2016

There is a long history of using art in development and as a tool for therapy. Art can also be used as a tool for engagement in biomedical research and there are two main ways of approaching this:

i. as a stimulus for discussion and reflection, or

ii. through the participatory process of creating art.

In Chapters 6 and 7 (Picture Card Games) we describe methods that enable community and public engagement through art that is created by a professional or expert artist to stimulate discussion. In Chapters 8 (Participatory Art) and 9 (Body Mapping) we describe methods that foster engagement through art that is created by the primary participants of a PVM process.

Typically, art to stimulate discussion will be created by a professional artist after engagement with a research community. The art may reflect the artist's perspective (for example Art in Global Health: Lena Bui) or it may illustrate the community's perspective (for example Sacred Waters). Wider engagement comes from bringing community members or members of the public to view and discuss the art work. The depth of engagement will vary from relatively shallow in an exhibition setting, to much deeper, if used in a facilitated discussion group.

Requirements

The main requirement for this method is an artist! Relationships will vary depending on whether you have a predefined idea of what they should create, or whether you can allow them artistic license. Most artists will prefer the latter arrangement. In larger funded projects consider working

with a curator to help project manage the artist and any exhibitions that you may be planning. The resources required will vary depending on the form of art, and should be determined by the artist you are working with.

Plan for the artist to meet the community or observe the research programme. This may be through an organised meeting in a community, or home visits for the artist to speak with community members. In some cases, artists have accompanied researchers into labs or on sample collection trips to observe. It may be possible to have an 'Artist in Residence' scheme which may give the artist more status with the researchers. It's important to involve researchers early in the project to help ensure acceptance and involvement (see case study).

Plans for engagement around the art and your target audiences will dictate whether you need a formal exhibition space (which may be expensive), or a smaller, public community space.

Participants and facilitation

There is a lot of flexibility in this method, and participant numbers will vary depending on the nature of the project. An artist may want to meet just 2-3 community members, patients or researchers, or more. A facilitator should accompany the artist to help with explaining the project, recruiting people and obtaining consent if photographs are taken or if their words will be used in the art. In the final engagement phase, more facilitation will help ensure that audience members are encouraged to reflect and discuss the art and its critique of the research.

Time and process

The time taken in each step of the process can be flexible, depending on the length of your funding. However, artists may want weeks or months to observe and immerse themselves in a research environment before creating their work. They may also need weeks or months to create the art. Where possible, be led by the needs of the artist.

Step 1. Recruiting and briefing an artist.

It is essential that the artist understands the requirements of the project and the participatory engagement that you are working towards. If you can afford a curator, they should be involved in this step.

Step 2. Briefing the researchers

Again, it's essential that researchers understand the aims of the project, and are open to having the artist observe their research. Be clear that the artist is not illustrating their science. Not all researchers will welcome this scrutiny; so select research groups who welcome the artist and project.

Mini case study: In one of the Art of Global Health projects, the artist was quite critical of the relationship of the research institute with the local community, observing it as paternalistic. The resulting artwork portrayed this perspective and was quite uncomfortable for the researchers. However, in terms of inviting an 'outsider' to give a different perspective and challenging reflection it was considered successful!

During a visit to the OUCRU laboratories, school children drew pictures of 'a scientist'. Along with the postcard sets, these images were used to promote conversations between the children and researchers.
Photo credit: OUCRU PE 2019

Step 3. Artist residency or observation of the research

Facilitate the artist to spend time with a research group or research community. If they are going into a community, you should take time to introduce them and the project. Be careful to obtain permission from community gatekeepers or authorities. Consider whether you need to ask consent from community members (e.g. for photography or interviews).

Step 4. Creating the art – led by the artist

This step may take months or weeks. Discuss with the artist what the time frame is and what they can create in that period.

Step 5. Engaging with the art

The type of engagement activity will vary depending on your target audience and aims. A public exhibition may reach a larger number of people, but the level of participation may be low. You can plan for interviews with attendees, or focus groups to increase discussion and contemplation about the art, or follow-up events. More participatory activities may be based in the community with less formal discussions around the artwork. These should be carefully facilitated with careful prompt questions to encourage the participants to discuss and reflect on what the art is representing.

Mini case study: In The Art of Global Health project in Vietnam, the artist Lena Bui observed research taking place in the laboratories and fieldwork on farms. Her resulting art included painting, sculpture and film. Much of the work was abstract, inspired by her observation that the distinction between humans and animals is small. The project culminated in a public exhibition and a facilitated evening for artists and scientists to meet each other, with the prompt question "what similarities are there between art and science?" However, for some researchers the link between Lena's work and their science was too tenuous and one stated "I can't see my science here."

Things to consider

The cost of using a professional artist and hosting a public exhibition can be quite high.

Community members interacting with installation artwork by Mahima Singh, Sacred Water project, Nepal.
Photo credit: Lena Bui 2015

7. Picture Card Games

By Sonia Lewyck

Women playing picture card game for maternal and newborn health problems, Bangladesh.
Photo credit: Sonia Lewycka.

What are Picture Card Games?

Picture card games are collective visual learning techniques that facilitate discussion about health issues without requiring a high level of literacy. The pictures can aid collective understanding about the relationships between different health challenges through the creation of visual links between the cards. The main aims of picture card games are to enable people to:

- reflect upon common health problems in their community
- promote dialogue and group discussion about these health problems
- explore underlying causes of these health problems
- suggest potential solutions that are relevant and appropriate in their setting.

There are a range of ways of using picture card games that will depend on the context and needs of the participants, and where along the “ladder of participation” you want to be (See Degrees of Participation section in Chapter 15). At one end of the spectrum, picture cards may be used as a participatory education tool, and used as the primary source of stimulus for group discussion, supporting groups of participants to share their knowledge and experience on health topics as they learn more about specific issues. In this approach, picture cards can be used like a ‘game’, where participants are asked to match problems with contributing factors and preventative and treatment options. At the other end of the spectrum, picture cards may be used as part of a community-led problem-solving process, where the group independently identifies problems and solutions, and the cards are used to

summarise the discussion. Alternatively, they can be used more like prompts once particular health issues, contributing factors and preventative and treatment options have been raised in group discussions.

Picture cards can be used in participatory learning and action cycles with many community groups simultaneously, to stimulate change on a larger scale. These are group processes that engage participants in the identification of local health problems and in thinking about strategies for the prevention and management of these problems.

Applications of picture card games

Picture card games are mostly used for the purposes of internal engagement. The learning that is gained through picture card discussions can be shared more widely through external engagement with other members of the community and other local stakeholders such as health care workers and educators.

Picture card game and manual for maternal and newborn health problems, Nepal.
Photo credit: Sonia Lewycka

Requirements

A set of picture cards needs to be developed before beginning the group process on a larger scale, and this development process may also involve the participation of a smaller group of participants or a community advisory group. A local artist can work with the participants and a community engagement facilitator and/or health care professional to design the pictures. Hand-drawn pictures on pieces of card can be used for the purposes of co-design and piloting. The level of involvement of the community participants in decision making about picture design will depend on the timeframe of the project. Once decisions have been made about which pictures will appear on the cards, the artist can produce the final pictures. The cards can then be printed in bulk. If the purpose of the activity is to work with just one or two community groups the cards do not need to be printed in bulk and pictures that are hand-drawn by participants during the discussion process may be sufficient.

Examples of topics that can be represented on picture cards include: specific health problems; possible contributing factors; potential preventative activities; suggested management strategies/activities and healthcare requirements. These topics can be grouped by colour. Notes can be written on the reverse side of the cards to give more information about the pictures on the front. These notes may serve as helpful points of reference for participants and reminders for facilitators.

Participants

Picture card games can be played with small groups (5-10 people) or large groups (11-50 people). An advantage of playing with a smaller group is that each participant can play a more active role in the discussions. A disadvantage is that there will be a limited range of personal experience to share and learn from. When working with a larger group, different approaches can be used to foster the engagement of all of the participants. For example, each participant can take part in a voting process by placing a pebble/seed on top of the picture card that they think is the most relevant to the topic under discussion. Another way of managing the picture card process with a large group is to facilitate some small group sessions for reflection and discussion and follow these up with feedback from a small group representative for discussion and learning with all participants. Participants are typically those whose knowledge and health behaviour are the focus of the project. Groups may be of mixed gender and comprise participants with a range of ages, social status and other factors, depending on local social norms. Active discussion during the inception meeting around how to include particular marginalised or vulnerable groups may be useful (see Degrees of Participation section in Chapter 15).

Facilitation

One trained facilitator is sufficient to run a picture card game workshop. It can be helpful to ask a community participant to act as group secretary, to keep track of the discussions and play a role in motivating the group members. The facilitator does not need to be a trained health-worker as the picture cards can include notes to support learning. Discussions can be more open when the facilitator is perceived as a peer rather than a health expert.

Time

There are no definite rules about how long it takes to play a picture card game. A game can be played as a short, one-off activity over 1-2 hours. Alternatively, it can be spread out over several group meetings, allowing time for more in-depth reflection on each step of the process (outlined below). The time taken will depend on the availability of the participants and may vary according to their work commitments, the context of the community where the workshop takes place (urban or rural) or the season.

Process

As described above, there are a range of ways of using picture card games that will depend on the setting and needs of the participants, and whether they are used as a participatory education tool, or as part of a community-led problem solving process. As far as possible include all of the following steps:

Step 1 – Inception meeting

See Chapters 2 and 3.

Step 2 – Identifying problems

When used as a participatory learning tool, the group will first be shown all of the cards with problem pictures. These are passed around the group members to stimulate discussion and reflection. When using a community-led approach, group participants are asked to independently identify problems they see in the community in relation to a specific health issue. Other participatory visual methods such as body mapping and visual timelines can also be used at this stage to engage participants in identifying parts of the body affected or when these problems happen. Picture cards depicting these problems are then shown.

Step 3 – Prioritising problems

In this step, the picture cards showing the problems are laid out in front of the group. If using the participatory learning approach, all problem cards can be laid out. If using the community-led approach, only those problems identified by the participants are laid out. Participants can then use other participatory methods to decide which problems are the most important in their community. These methods include activities such as preference ranking (blind ranking with each group member able to vote for the problem she feels is most important); pair-wise ranking (the group systematically compares each problem to every other problem); diamond ranking (the group sorts the problems into an order of importance).

Step 4 – Understanding causes

When following a community-led approach, additional participatory discussion tools can be used to facilitate the identification of contributing factors. For example, developing a cause and effect diagram can support participants in assessing each problem in terms of input arrows (causes) and output arrows (effects). The collective drawing of a problem tree can also help to identify the causes and effects of community challenges. The problems are visualized in the tree trunk, the causes of the problem (inputs) are shown in the roots, and the consequences of the problem (outputs) are shown in the branches and leaves. Another participatory tool for problem assessment is the 'But why? approach. With this method the group assesses each problem by asking 'but why' did it arise, until they are satisfied that the root factors contributing to a problem have been identified.

Step 5 – Identifying solutions

Most picture card sets will include a group of pictures showing preventative activities, as well as a group of pictures showing treatment options. Treatment options may be divided into those that can be done at home and those that require seeking help at a healthcare facility. As in previous steps, when using a participatory learning approach, the picture cards may be shown initially and used as a tool for discussion, and then a matching game played to link problems with the most appropriate preventative and treatment activities. Alternatively, when using a community-led approach, additional participatory discussion tools can be used to facilitate the identification of preventative activities, solutions and resources, such as:

- H-exercise
- Bridge the gap
- Balloon.

All three of these tools are different visualizations of the same process which enables groups to illustrate where they are in relation to an issue, where they want to be and how they plan to get there – the strategies. These tools also allow groups to explore the factors that might facilitate or hinder the implementation of the strategies. Once preventative activities and treatment options are identified, the corresponding picture cards can be shown.

Step 6 – Sharing learnings with the wider community

Participants in the picture card game are usually selected because they are the target group for increased knowledge and behaviour change, and their health is the focus of the discussion. However, in order to transform the learning from this first phase into action, it is useful to engage with the wider community to begin to think about collective solutions. A community meeting can be held, during which the group explains what they have discussed, share what they have learned and seek input and ideas for possible solutions. Picture cards can be used again during this community meeting as a way of summarising the key learning points, but this will depend on the size of the audience.

Suggested Reading

Howard-Grabman, L., Seoane, G. & Davenport, C.A., 1994. The Warmi Project: a participatory approach to improve maternal and neonatal health. An implementor's manual. Arlington, Virginia, John Snow, MotherCare. [6], 194, [43] p.[SL1]

Bradley, D., & Schneider, H. 2004. VSO Facilitator Guide to Participatory Approaches: Tools. Available:https://issuu.com/raquelzabala/docs/vso_facilitator_guide_to_participatory_approaches_tools

Morrison, J., Tamang, S., Mesko, N., Osrin, D., Shrestha, B., Manandhar, M., Manandhar, D., Standing, H. & Costello, A., 2005. Women's health groups to improve perinatal care in rural Nepal. BMC pregnancy and childbirth. 5(1): 6. DOI:10.1186/1471-2393-5-6. Available: https://bmcpregnancychildbirth.biomedcentral.com/track/pdf/10.1186/1471-2393-5-6

Rosato, M., Mwansambo, C., Lewycka, S., Kazembe, P., Phiri, T., Malamba, F., Newell, M.N., Osrin, D. and Costello, A., 2010. MaiMwana women's groups: a community mobilisation intervention to improve mother and child health and reduce mortality in rural Malawi. Malawi Medical Journal, 22(4): 112-119. DOI:10.4314/mmj.v22i4.63947 Available: https://www.ajol.info/index.php/mmj/article/view/63947

Participants in the Sacred Water project in Nepal use art forms to illustrate their connection with water. The project culminated in an exhibition in their neighbourhood. Photo credit: Lena Bui 2016

8. Participatory Art

What is Participatory Art?

Participatory art engages participants in creating art for the purpose of reflection and expression. The form or quality of the art is less important than the engagement that happens during the process. The resulting artwork may or may not be used to stimulate wider external engagement with others outside of the creative group.

Applications of Participatory Art

Participatory art engagement may be used as a platform to allow participants to express themselves in non-verbal ways. This may be important with less literate communities, when the topics of discussion are sensitive, or to allow participants to illustrate perspectives in a less formal way.

Mini case study: Lena Bui - Sacred Waters. Lena and Nepali artists - Bidhata KC and Mahima Singh, used 4 different art forms over 8-10 weekly sessions. The final engagement was through a public exhibition in their neighbourhood, with an opening which included talks from research scientists about water safety.

Participants in the Sacred Water project in Nepal use art forms to illustrate their connection with water. The project culminated in an exhibition in their neighbourhood. Photo credit: Lena Bui

Mini case study: Nayreen Daruwalla and David Osrin: Dharavi Biennale. This was a two-year process leading to an exhibition, the Alley Galli Biennale, in 2015. It blended art and science to share information on urban health and to showcase the contribution of the people of the Dharavi slum area to Mumbai's economic and cultural life. With four themes – art, health, recycling and vitality – the Biennale invited Dharavi residents to meet, educate themselves on urban health, learn new skills, and produce locally resonant artworks that are authentic, honest and relevant.

Mini case study: Oxford University Clinical Research Unit and Lena Bui: Art Meets Science – tours for school children. Artist Lena Bui was inspired by working with researchers studying antibiotic usage in farming. On the back of her exhibition, scientists contributed interactive activities for children (microscopes, creating bacteria out of play-doh etc.) to create a 2-hour programme for school children. After a guided tour and talk with the artist the children were invited to create large mandala-style pictures of the relationship between nature/non-nature.

School students were invited to join interactive tours of Lena Bui's 'Flat Sunlight' exhibition. Photo credit: OUCRU PE 2016

Requirements

Creative engagement processes require space for art making. Ideally the space will be large enough that facilitators and participants can freely move around and discuss with each other. If possible, use a space with furniture that can be moved around, and avoid rigid layouts.

With more technical art forms, you may need a professional artist or artisan to help facilitate the art making. If specialist help is not available, choose a creative form that is less technical or perhaps familiar to participants already. The equipment and supplies you need will vary between art forms, budget and accessibility. For example, working with clay requires access to a kiln and the process takes days or weeks.

Mini case study: A project from Plantlife International engaged women's groups in the UK and Eastern Europe to identify locally important plants and flowers. They encouraged participants to embroider pictures of the plants as it was an activity many already had skills in. 'The patchwork meadow: Tapestries for our time' exhibition was held in 2015.

Women from all over Europe embroidered images of local plants to add to a large collection. Photo credit: Mary Chambers 2015

Participants

Typically, a group of 8 – 12 participants is manageable for an intensely hands-on participatory method such as this. If you are working with school children, you may be able to facilitate bigger groups if there are more adults (teachers or facilitators) to work with them.

Facilitation

You will need at least one artist or facilitator with a grasp of the art form, plus other facilitators (1 for 3-4 participants) to assist the creative process and drive the discussion and engagement. One person should be nominated as the observer to take notes of the process, group dynamics and any learning and reflection that occurs.

Time and Process

Refer to Chapter 3 for tips on briefing your facilitation team and developing prompt questions for participants.

Step 1. Briefing the facilitators and artist

Facilitators need to be aware that the main aim is not to create masterpieces, but to make space for discussion during the process and enable the participants to express their views.

Time: Facilitator training: 1-5 days depending on their previous experience. Recruiting the artist may take weeks. Briefing the artist: 1 day.

Step 2. Recruiting and introducing the project to participants

Similarly, let the participants know that the artwork is a form of expression, and they don't need pre-existing skills to take part. It's also important to manage expectations: participants should be aware that in most cases they will not come out of the project with a high level of skill. If one of your aims is local capacity building, you will need to spend more time on the art instruction phase and frame the subsequent engagement differently.

Time: Recruiting and introducing the project to participants – ½ -1 day.

Step 3. Running art workshops

Framing the workshop and developing the prompt questions are as important as the art creation, so plan this carefully. Plan the inception meeting to include introductions and a group discussion about the matter (for example beliefs and practises about water). Where possible, invite a researcher or healthcare worker to introduce the health or science that is the focus of the project. Work with them to ensure that they present in an interactive way and explain any scientific words. Introduce the idea of disseminating to a wider audience for the group to consider (see Chapter 4). Then allow the artist/facilitator to introduce the artform. Some participants may have skills already; depending on group dynamics, encourage them to demonstrate those skills (without dominating the group). Throughout the workshop, observe the dynamics and the learning and sharing from participants. These may occur through casual conversations and not just during the formal feedback times. If possible, have a nominated note taker.

Time: Art sessions – may be a single session, or a series of workshops e.g. one day per week for many weeks.

Step 4. Planning dissemination
As the art creation continues, raise the question of who should see the art, and what further engagement should be stimulated by it (see Chapter 4). Be led by the participants' wishes. If they wish, hold one exhibition in the local area so they can showcase their work to their families and community. Encourage them to introduce the project and their work and their learning to other community members. Similarly, if you hold a more public exhibition and the participants are comfortable, encourage them to speak to their work. Practise with them so they are confident when speaking. If the project focuses on a topic of research, invite the researchers to that event too.

Time: An exhibition (if part of dissemination plan) may take weeks to prepare. The exhibition itself can be held for 1-2 days or for longer.

Step 5. Project end
Meet again after the public events to collectively reflect on the exhibition and the project. Ensure participants have their art to take home, and mementos of the project (e.g. photographs).

Time: Project closeout – ½ day

Suggested Reading

Aggett, S. 2016. Art in global health: insights and considerations for future artist residencies in health research programmes.
Available: https://wellcome.ac.uk/sites/default/files/art-in-global-health-wellcome-jun16.pdf

Austin, K. 2016. The art of health: exploring creative engagement with research.
Available: https://wellcome.ac.uk/sites/default/files/Art-of-Health-Mumbai-Wellcome-Oct2016.pdf

Body maps created by youth participants from Delft, Cape Town. Bucket Loads of Health – Photo credit: SLF 2019

9. Body Mapping

What is body mapping?

In body mapping, each participant creates an individual life-size map of their own body. The methodology involves first tracing the outline of each participant's body; then, in response to a set of prompt questions, participants progressively add content to the centre and background of their maps to illustrate their experience of a situation or event. This is usually done by drawing, painting and writing short narratives to explain the meaning of images or add additional information. Body mapping allows participants to show their thoughts and feelings, and illustrate if and how different parts of their bodies were affected by the situation or event being explored. Because people's bodies are inextricably linked to their health, body mapping lends itself particularly well to an exploration of health and well-being.

Applications

Body maps can be used for both internal and external engagement (see Chapters 2, 3 and 4 and). Although the end product of a body mapping exercise is a life-size drawing or painting, the accounts that are developed through the exercise can be used in story-telling or other narrative processes like personal digital storytelling. Because they are colourful, large and original works of art, body maps can provide striking exhibition pieces for the purposes of external public engagement. However, body maps are highly personal and, as for all PVM outputs, it is essential to undertake a careful process of informed consent with the participants before exhibiting body maps to external audiences.

Requirements

Body mapping needs large single sheets of white paper that are long and wide enough to contain an adult body: we recommend sheets 2m long by 1.5m wide, with a minimum weight of 80gsm. A thick black permanent marker pen is needed to trace the body outline.

Other essential items for body mapping are:

- Paintbrushes of different sizes;
- Poster paint in various colours (get the best quality you can afford);
- Palettes, bowls or plates for mixing paint;
- Polystyrene or plastic water cups to clean paint brushes;
- Rags for cleaning paint brushes;
- Buckets to dispose of dirty paint water.

Plastic sheeting can help to protect floors and carpets. Additional useful items include scissors, coloured fibre tip pens, glue sticks, various colours of wool, sponge pieces (as another tool for applying paint to a body map, glitter and other arts and crafts supplies. When participants are using paint to decorate their body maps it is very useful to work in a venue that provides the opportunity to hang them up to dry.

Participants and facilitation

It is manageable to facilitate a body mapping process with groups of 10 to 15 people, but space is a very important factor to consider for this method. As a rough rule of thumb, body mapping needs 4.5-6.5 square metres per person. With groups of this size, a body mapping workshop can be facilitated by 2 experienced PVM practitioners. It is important to note that bending over a table or working with paper on the floor for long periods of time can be physically taxing, so build in time for stretching and moving about. Having room to hang the maps up to dry when paint is being used

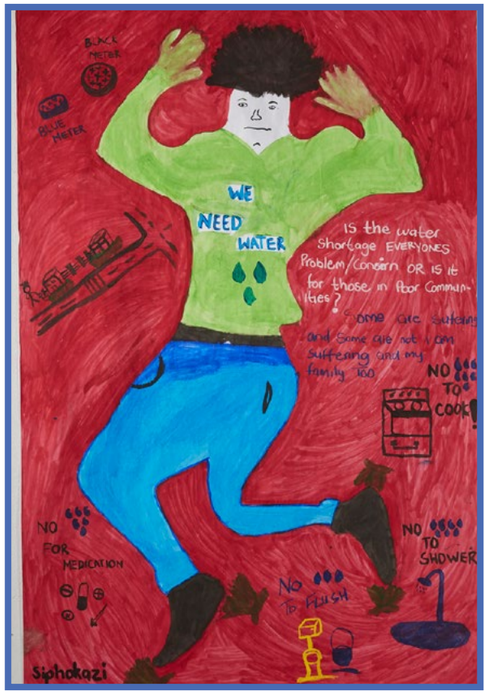
It is always helpful to have some good logistics/technical support in addition to the core facilitation team. It is not necessary for the facilitation team to have strong artistic ability, but this can be helpful if participants are finding it hard to unlock their own creative talent.

Time

The amount of time that is required to facilitate a body mapping workshop depends on what the final output of the process is intended to be. If the intention is only to generate body maps and to enable some reflection and discussion among the participants about their content, 2 full days should be sufficient. Note that this does not include an inception meeting (see Inception Meeting sections in Chapters 2 and 3). If the project intends to extend the methodology by, for example, including a story-telling component, it may take a further 3 days to fully develop (and film) the stories. When paint is being used to decorate the body maps, sufficient time will be required to allow the paint to dry before the maps are removed from the workshop venue.

Process

The steps described below provide guidelines for a 2-day body mapping workshop that includes a light touch story-telling component.



Body maps created by youth participants from Delft, Cape Town.
Bucket Loads of Health, SLF 2019
(Click on the image for more detail)

Two young men from Enkanini informal settlement add detail to their body maps.
Bucket Loads of Health, SLF, 2019 (Click on the image for more detail)

Day 1

Step 1. Introductions

Begin the workshop with introductions.

Step 2. Consent

Give participants a copy of the project consent form and facilitate an informed consent process in a step-by-step manner. This includes:

- providing an overview of the aims and objectives of the engagement project
- discussing the confidentiality of the PVM process
- discussing the ownership of the body maps
- asking permission to document the workshop in writing and to audio record the discussions
- asking permission to take photographs during the workshop if this is considered ethically appropriate
- giving participants the opportunity to ask clarification questions.

This consent process can also be carried out during the inception meeting if there is time and it is appropriate.

Step 3. Summarize the method

Describe the concept of body mapping to the participants and summarize what is involved in a body mapping process. Explain why body mapping is being used as an engagement approach in your project. It is very helpful to show digital projections of body maps that have been produced through other projects. The film Our Water Challenges demonstrates how body maps can be used as visual platforms to convey the embodiment of lived experience with respect to a health-related issue. Encourage participants to speak in the language they are most comfortable with and explain what will happen with regards to translation if it is required.

Note that steps 1, 2 and 3 can also be carried out during the inception meeting if there is time and it is appropriate to ask for consent at this early stage.

Step 4. Workshop rules
Include a session on workshop rules to give participants an opportunity to state their ground rules for working with the facilitation team and with each other.

Step 5. Discussing the health topic
Describe the research project and/or health topic that the participants will be responding to through their body maps. Allow time for their inputs, questions and answers.

Step 6. Asking the prompt question for engagement
Introduce the prompt question (see Open Enquiry section in Chapter 2). Ask participants to discuss the question in small working groups. Ask each participant to think about how the prompt question relates to a personal experience they have had and to record these reflections in their notebooks.

Step 7. Conceptualizing the body maps
Ask participants to think about how they might show their individual responses to the prompt question as embodied and sensory experiences on their body map, i.e. how they might convey the stories and experiences they shared in Step 6 on their body maps by populating them with drawings, symbols, written words, magazines cut outs and/or other craft materials.

Step 8. Set up for body mapping
While the participants are responding to the above task, the facilitation team can set up the body mapping accessories i.e. the arts supplies including paper, paints, paint-brushes and other craft supplies.

Step 9. Body map demonstration
Enrol two members of the facilitation team to give a floor demonstration of how to draw the outline of a body map. Using scrap paper, give participants a chance to experiment with the paints, brushes and different amounts of water for painting. This enables participants to get a feel for working with the arts materials prior to working on their actual body maps.

Step 10. Body map development
Ask participants to get into groups of two and draw the life-size outline of their workshop partner on a large piece of paper on the floor, with a thick marker pen. Encourage the use of a dark colour of paint to complete the outline, so that it stands out.
Each participant can then proceed to develop the content for their own personal body map by painting, drawing, writing or placing arts materials at any place on their map. Reassure the participants not to worry about their artistic abilities.

Step 11. Clean up
End the day with a clean-up. If possible, hang the body maps up to dry.
Ask participants to bring any pictures that they have at home and would like to include on their body map (e.g. printed photos, magazine images, other pictures) for Day 2.

Day 2

Step 12. Check in
Facilitate a 'check in' and ask the participants to share their reflections on Day 1. Find out if any clarifications are required with regards to the aims or activities of the workshop.

Step 13. Body map development ii
Participants continue to work on their body maps with one-on-one facilitation support as required. Make sure that all body maps are anonymised in accordance with the stated preferences of each participant.

Step 14. Body map presentations
Facilitate the presentation and whole group discussion of the body maps. Make a collective decision about who will present first, second, third and fourth etc. Take audio/visual recordings of the individual presentations if you have been given the consent of a participant to do so and it is required for your engagement project.

Step 15. Check out
Clean up, discuss next steps and check out.

The Bucket Loads of Health (BLH) project, which was facilitated by SLF in South Africa, provides an example of how body map story-telling has been applied to health science engagement. The short film Doing It Differently describes the BLH project process. Health, Stress and Sanitation is one of the story films created through the BLH body mapping approach.

Suggested Reading

MacCormack, C.P. 1985. Lay perceptions affecting utilization of family planning services in Jamaica. Journal of Tropical Medicine and Hygiene. 88;4 281-285.

Solomon, J. 2008. Living with X - A body mapping Journey in the time of HIV and AIDS: Facilitator's Guide. Available:http://www.comminit.com/africa/content/living-x-body-mapping-journey-time-hiv-and-aids-facilitator's-guide

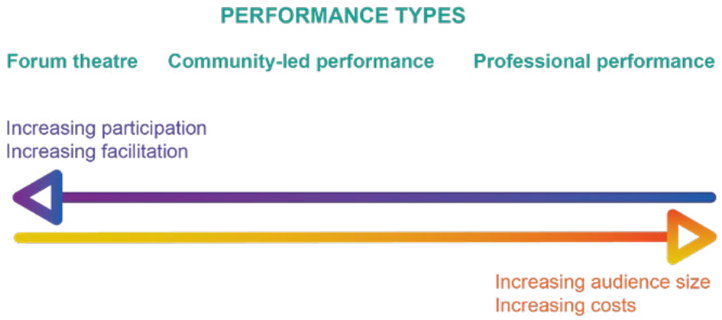
Gastaldo, D., Magalhães, L., Carrasco, C., & Davy, C. 2012. Body-Map Storytelling as Research: Methodological considerations for telling the stories of undocumented workers through body mapping. Available: http://www.migrationhealth.ca/undocumented-workers-ontario/body-mapping

Orchard, T. 2017. Remembering the body: ethical issues in body mapping research. Springer Briefs in Anthropology. 1-22. DOI: 10.1007/9783319498614.

Professional actors engage the students watching the science theatre performanceby using games
Photo credit OUCRU PE 2016

What are Performing Arts?

Performing Arts describes multiple genres of performances including spoken-word drama and comedy, music, song, dance and mime. When used for engagement with biomedicine the topics of the performances relate to research or health. It encompasses a spectrum of performance types from the professional to the amateur and from stage shows to role play. The level of community or public participation will differ depending on the approach that is taken when performing arts is used as a method of engagement. In a professional show, where professional actors perform for a public audience, engagement is likely to involve a one-way flow of information. On the other hand, when a performing arts project takes a community-led approach, community participants take a leading role in plot development, script writing and acting. In this handbook we concentrate on discussing the more participatory types of performing arts, in particular the use of spoken-word drama, but sung music could be used in a similar manner.



Applications of Performing Arts

Performing arts has been widely used a method of engagement in the development sector and there is a rich literature describing its potential for health messaging, promoting activism, therapeutic intervention and action research. It has been recognised as a means to communicate health messages to less literate communities and as a more memorable and effective means of engaging children. Participatory or 'forum' theatre is a form of role play drama which invites the audience to contribute or re-enact scenarios. Theatre of the Oppressed (also referred to as Theatre for Development) was developed by Augusto Boal in the 1960s as a platform for collective learning and for communities to explore tensions and develop strategies for change. It can be a powerful tool in health engagement to encourage participant interaction and explore inequalities, barriers to accessing health or issues that arise in research.

During a forum theatre session exploring health worker-patient communication, a nurse from the audience explains to the three actors how they could re-enact a scene.
Photo credit OUCRU PE 2016

An actor, wearing black, acts as the man's emotions in a participatory or forum theatre session.
Photo credit OUCRU PE 2016

Requirements

Performing arts with the community as an audience, and the 'show' as a means of conveying a message will require performers, stage, sound equipment etc. If aiming for a more participatory approach (right hand end of the spectrum in Image x) you will require:

- **Space:** When the process is highly participatory it works best in a space with chairs in a circle or semicircle around the actors ('in the round'). The play can take place on the floor. A stage and formal theatre setting is usually unnecessary and, unless it is a low one, a stage may hinder the interaction.
- **Props:** Props and costumes may be an asset, but are not always necessary. If your biomedical research comprises a wide range of approaches used in diverse contexts for many different purposes.
- If you are using actors to portray emotions or thoughts, you may want them to dress in black, perhaps with a mask, to distinguish them from the characters.
- **Script:** See Time & Process section.
- **Permissions:** In some settings the script will need to be reviewed by authorities in advance (e.g. Department of Education, hospital management, local authorities). This may be a lengthy process so include time in your planning.

Participants

A more professional theatre show can be used with a very large audience, or even filmed for television. In this case, the show is educational (or 'edu-tainment') and tends to have one-way communication. Engagement would be through workshops with community members to identify the issues and develop the script, or post-show as a prompt to discuss and feedback on the issues raised.

A forum theatre or role play approach can be used with a community group of up to 40 people, although less than this will allow for more people to contribute. Because we are asking them to participate and express themselves, it is important that the group feel comfortable with each other. Consider whether men and women should be in separate groups, or whether power dynamics may stop some people from taking part.

As part of the OUCRU science theatre programme, professional actors perform a play at a rural primary school to raise awareness about mosquitoes and dengue transmission.
Photo credit: OUCRU PE 2016

Facilitation

- **Facilitator:** A participatory performance approach is highly facilitated and requires an experienced facilitation team with one lead facilitator.
- **Actors:** These may be performing artists or members of the project team. If the process is highly community-led, the actors will take more of a training role to enable community members to build the script and perform. In forum theatre sessions the actors (whether professional or project team) must be immersed in script and process so they know how to respond when an audience member participates in the role play.
- **Observer:** An observer who can take notes of discussions and decision-making within the group whilst supporting with workshop activities.

Time and Process

Participatory performance projects vary tremendously in implementation time. A forum theatre (role play) process depends on having participants available for 1.5-2 hours, however the development of an accurate script may require numerous interviews and iterations. The facilitation team will need time for rehearsals. In a more formal theatre session, the rehearsal time will be longer. In a hybrid process such as described in the Cambodian example below, the facilitation team developed a loose script and songs (taking 1 week), and then toured rural areas spending three days in each community.

The process again will vary depending on the aims and type of performance, but the basic steps are:

Step 1: Recruiting project team, including a strong facilitator.
Professional actors may not be necessary if you are aiming for a less formal presentation.
Time**:** variable.

During a forum theatre session exploring health worker patient communication, a doctor in the audience explains to the three actors how they could re-enact a scene.
Photo credit OUCRU PE 2016

Step 2: Inception meeting
This is a necessary step if community members are developing the script. (See Inception Meeting sections in Chapters 2 and 3 above). In a less participatory project, this step may involve meeting community leaders to discuss their needs, logistics and ask for their support. **Time: 2-4 hours.**

Step 3: Developing the script
Regardless of whether you want a loose script (for a more community-led process) or stricter script, the key messages and components need to come from community-generated needs or ideas. This may be developed through qualitative research methods such as in-depth interviews or focus group discussions, or less formal discussions with community members ('researched-based script'). As you work on the script, it is very important to have regular feedback from participants about its accuracy and relevance. Time will vary from a ½ day workshop to 1-2 months of interviews. (See Capacity Strengthening for Healthcare Workers case study).

Step 4: Rehearsals
For an actor-led performance, rehearsals may take 1 week. When community members are involved in the performance the timing should be based on their availability but two 2-hour sessions may be sufficient. For forum-theatre performances, the project team/actors should rehearse and be very clear about the points when the audience may contribute or join in acting, and possible scenarios they might suggest.

Step 5: Performance
The key is to invite your target audience and so consider the timing which is most convenient for that community. In open air performances consider whether there is shade or cover from rain.

Step 6: Engagement
In most cases your aim will be for engagement rather than a polished performance and without consideration, performance can be unidirectional. However even in actor-led performances, the audience can be included with quizzes and games before or after the show. Workshops after the performances can be used to engage communities and gather their views on the topics in question.

These three mini case studies show performance used for engagement across the spectrum of participation.

OUCRU's science theatre show toured rural primary schools in Vietnam. Sometimes over 700 children attended a show.
Photo credit OUCRU PE 2014

Mini case study: Science Theatre Vietnam: With the aim of promoting science in primary schools and contributing to the wider research communities, OUCRU public engagement team developed theatre scripts around some of the Unit's main research topics: dengue, antibiotic resistance and transmission dynamics (i.e. how hand washing can reduce bacterial infection) but the final decisions about which topics to include were based on feedback from teachers and school health workers. Learning points for each script were developed in a workshop between doctors, researchers and teachers – this was a point of engagement. The script was developed by a professional theatre producer, with numerous iterations as researchers and doctors reviewed it. The play was performed by a professional theatre group to primary schools in rural Vietnam, in full costume and with a large sound system. Before the play started the Director interacted with the children through quizzes and action songs. In the weeks after the play, members of the team visited each school to take part in classes to reiterate the health messages. Over 7 years, Science Theatre has reached over 100,000 school children. Each show was filmed and shown on national television. Although evaluation shows that the project had a huge reach, and was highly valued by schools and health workers and much enjoyed by the children, the level of engagement and participation is low. The cost was quite high because of professional actors' fees, costumes and transportation costs.

Mini case study: Village Drama Against Malaria: A research team (MORU) running a large, multi-site trial of mass drug administration to reduce malaria transmission in rural Cambodia worked with local health authorities and professional actors to develop a loose script about malaria transmission, early diagnosis and the clinical trial. They toured rural villages, staying for three days at a time. On days 1 and 2, the group ran after school workshops for children who wanted to participate, teaching them songs and dances which were incorporated into the play. On the 3rd night, the team set up a stage in a public area and invited the whole community. Adults were invited to perform a song or local dance to encourage participation. The play was introduced by the head of the health services who endorsed the clinical trial. The play, which was humorous and in a local style of theatre, included the children actors alongside the professional actors. In most villages, over 70% of the community watched the shows and evaluation showed an overwhelmingly positive response. The cost for this project was high because of transportation costs of touring the project team, stage and sound equipment for 20-30 days. Two short films, 'Cambodia -Village Drama against Malaria' and 'Village Drama Against Malaria 2018' provide further information on this topic.

Mini case study: Capacity Strengthening for Healthcare Workers: To explore the tensions that healthcare workers (HCWs) experience the public engagement team at OUCRU interviewed a number of HCWs and carers of patients in the intensive care unit. It became clear that certain points of communication between them were potentially highly stressful. The PE team worked with Life Art group, a professional participatory theatre group, to draft a script based on these interviews. The script was reviewed by a doctor for accuracy. The story was based in a hospital and had three parts: admission of a woman in a coma, explaining the diagnosis to the husband, and a hurried discharge. This part of the process took about 2 months.

Three actors played the roles of wife, husband and doctor. Two other actors, dressed in black (to distinguish them as 'emotions'), represented the thoughts or emotions of the husband and doctor. A skilled facilitator led the session, stopping the play after each of the three scenes to ask for the audience's feedback. After the second scene, she invited members of the audience to take on the roles of husband and doctor and replay the conversations in an alternative manner and explore how those interactions might be handled differently. The OUCRU PE team had intended to invite the junior and senior doctors to separate sessions as we felt that junior doctors may be intimidated by their superiors, and the senior doctors would be reluctant to take part in 'demeaning' (our word) role play in front of their junior colleagues. Due to staff timetables they all came to the same session. To our surprise, the senior doctors were very engaged and junior doctors later reported that it was very insightful to hear how more experienced medics would handle complex relationships. Although they didn't report it, junior medics may have been more reserved in offering their opinion. The overall feedback was that it was a very useful forum to help HCWs understand and empathise with patients/carers, and it was requested we use this method in future training. After those sessions, Life Art actors trained members of the PE team to facilitate future participatory theatre sessions internally. The cost of the first workshop was higher because of the professional input but subsequent sessions run by the project team were very low cost.

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During the 'introduction to photography' session, Health in the Backyard participants learn some basic photography skills. Photo credits: Fact & Fiction Films 2013

11. Participatory Photography

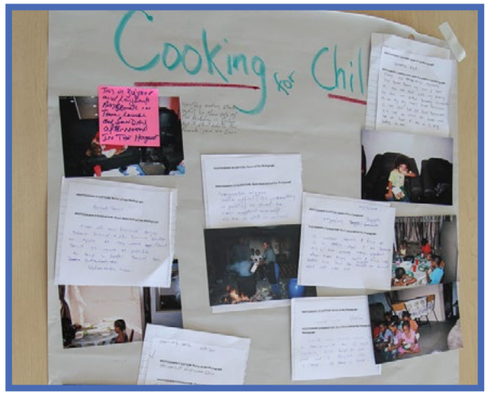
What is Participatory Photography?

Participatory Photography enables people to represent the places where they live and their everyday situations by taking photographs. Participatory Photography has three main goals:

i. To enable people to record and reflect upon the strengths and challenges of their communities or situations.

ii. To promote critical dialogue and learning about important issues through showing and discussing photographs in small or large groups.

iii. To reach wide public audiences as well as researchers and strategic decision makers.



Participatory photography: Thematic clustering and selection of images to appear in a photobook for public engagement on heart health and cardiovascular disease research. The Heart of The Matter. - Photo credit: SLF 2016

Participatory Photography can also form a key component of other PVM processes like personal digital storytelling and participatory video, both of which are discussed separately in the following sections.

Participatory Photography can be used for the purposes of internal engagement or external engagement (see Chapters 1 and 4). If the goal is external engagement, photographs can be incorporated into a number of different outputs that can be shared with diverse audiences:

- Hard-copy albums of original printed photographs;
- Hard-copy printed photo-books of digital images;
- Digital albums on websites;
- Posters with photographs and accompanying text for public display; or
- Exhibitions in community halls or wider public spaces.

Individual vs Collective Participatory Photography

Participatory Photography can be used either as an individual or as a collective method. In the individual approach, individual participants make decisions about which photographs they are going to take. The collective approach involves a group of participants working together to decide the subject matter of their photographs.
When choosing whether to work individually or collectively, consider:

- The number of participants in the group and their availability;
- How many cameras are available;
- How much experience the participants have with taking photographs; and
- How the participants would prefer to work.

If the group is fairly large, it may be best to take a collective approach.

A young participant in the Place of Change image-led DST project practises taking photographs. Photo credit: Fact & Fiction Films 2012

The Participatory Photography Process

Group size and facilitation requirements

Participatory photography can be done with a relatively large group – depending on the space available for photography training, the process is manageable with up to 20 people.
A facilitation team of 3 to 4 people is recommended: a lead facilitator, technical and logistics support and a photography trainer.

There are no definite rules about how long the process should take: This will depend on many factors including the project context, participant availability, the level of training required, and how long participants need to take their photographs.

Choosing cameras

The type of camera participants will use will be a major factor in designing and delivering the photography training, so the facilitation team needs to make this decision before bringing participants on board. Some of the options include:

- Disposable cameras: These are the most affordable option, with the advantage that each participant can be given their own camera to use. There are disadvantages, however: participants can't see the photographs they have taken; they can only take a limited number of photographs; all the photographs need to be printed; and transferring printed photographs into digital format (e.g. for a photobook) is time consuming and has a cost.
- Simple digital cameras
- Simple film/video camera with photograph option
- Professional film/video camera with photograph option
- Participants' own camera phones. An advantage of participants using their own camera phones is that they are likely to be comfortable and familiar with their devices and will be used to carrying them around and taking care of them. A disadvantage is that the pictures taken for the engagement project may be mixed up with a participants own personal photographs and this can be tricky to navigate. This could also result in a wide diversity of photograph quality.

Key Steps

The following is a general outline of the recommended steps involved in a participatory photography process, with suggested timings:

Step 1: Inception meeting (half day)
See General Guidelines for more details on planning and facilitating an inception meeting.

Step 2: General introduction to photographs as media for engagement (half day)
This session and the following sessions are held with community members who have already consented to participate in the Participatory Photography (or Personal Digital Storytelling) workshop. If the general introduction to photographs is not held on the same day as the inception meeting, start with a refresher about the aims and objectives of the process and any wider public engagement that the photographs may be linked to. Then give examples of different applications of photography and show examples from (preferably un-related) participatory photography projects.

Step 3: Photography training and practice (1-3 days).
Depending on experience, it can take 1-3 days to complete basic training that covers the core aspects of taking and documenting photographs. The more time that is given to photography training, the better the photographs are likely to be.

The training is best led by a photographer with experience in participatory photography, or with good skills in basic photography and training. Depending on the size of the group, support/additional facilitation may be required. The training should include time for participants to become familiar with the equipment through practice and to review the quality of their pictures with the trainer.
It is helpful for the training to cover:

- Handling the equipment (reviewing pictures, flash, changing battery etc.);
- Technical photography tips (focus/framing/angles/lighting/shots (long range; mid-range; close up);
- Creative tips: using web images or hand drawn pictures can add creativity to a story;
- Symbolism: it is not always necessary to take photographs of people to say what you want to say. Images of objects, animals or places can symbolise and describe situations just as well as pictures of people;
- Anonymity: there are many techniques to showing a person without revealing their identity (photographing their shadow or hands, photographs from behind, blurring, backlit photographs);
- Titles and descriptions (accompanying narratives): photographs can be powerful and emotive on their own, but when a photograph is taken in order to convey a certain message, including a written description or even just a title can help to make a point;
- The ethical considerations of photography: Strong emphasis should be given to the consent process to be followed when taking photographs of people (See Session 4 ii below)

If the participants have no or limited experience of taking photographs, and there is insufficient time for photography training, it may be necessary to include a photographer who can work with the participants in the field to capture the images they want.

Participants can tell a story without showing their faces.
Photo credit. A Place of Change project participant 2012

Step 4: Planning (1 day)

i. Prompt questions and photograph planning

Prompt Questions

For guidance on framing the prompt question for a PVM process, see Open Enquiry section in Chapter 2.

Planning photographs

Participants will need time to think about and plan what or who they want to take photographs of, and where and when they will take these photographs. Ask participants to work by themselves or in small groups, with journals and pens, to identify key messages they want to share and what images they will need to portray these. Participants may want to take photographs of events that don't occur every day, or only occur at a certain point in the day, in which case they will need to think carefully about timing.

If possible, give each participant a journal to record the following details about their photographs:

- The main subject of each photograph, including who (if anyone) appears in it.
- Where (location) and when (time) the picture was taken.
- The main reason for taking the photograph (i.e. what they were wanting to show with it)

Be aware that some participants may not be literate or comfortable with writing. Pairing with a project buddy or family member to help with writing may be a solution.

ii. The ethics of photography and how to request consent from people in photos

Discuss the requirements for consent or assent for photographs in detail. Stress that *Participants must get written or recorded informed consent (or assent)* for every person that can be visibly identified in any photographs that are included in the final visual outputs. The team should develop a consent form specifically for this purpose. Whenever possible, develop the consent forms with the participants and translate them into local languages.

Farmers took photographs of their everyday activities in animal husbandry for the Health in the Backyard project.
Photo credit: Ms Nga 2013

iii. Final preparatory steps

- Give out the cameras. Including a check out / check in process helps to keep track of who is in possession of the equipment.
- Distribute journals and pens (for recording photograph titles and narratives) and informed consent/assent forms.
- Ensure that all participants understand the core aim of the photography process and have made a note of the prompt question.
- Confirm the timescale for taking photographs and agree when the next group meeting will be.
- Collect participants' phone numbers and give them the contact details of a facilitator in case any cameras break or get stolen. (See Dangerous Contexts sections in Chapters 2 and 3).
- If participants are going to take photographs in a remote location leave a spare camera and batteries with someone who lives in that area in case they are needed (if possible).

Step 5: Taking photographs (5 - 10 days)

This step typically takes 5-10 days, but if there are events that the photographers want to capture at a certain time or on a specific date, the time may need to be extended.

Step 6: Individual and collective viewing of photographs and image selection

After all of the photographs have been taken, bring the participants back together to collectively view their images, which allows them to analyse their pictures and surface any strong or recurring themes. Depending on the number of participants and the total number of photographs taken, this selection and discussion process may need to happen in multiple stages.

i. Image collection and pre-selection

If participants have used disposable cameras, you will need to collect the cameras and have all the photographs printed before the group assembles again. If there is sensitive content, give participants

A Health in the Backyard participant and facilitator review the pictures in his image-led digital story. Photo credit: Fact & Fiction Films 2013

a chance to view their printed photographs privately before sharing them with anybody else. If the group has used digital cameras, there may be a large number of photographs. In this case, before the collective viewing you will need to work with participants to choose 20-30 images each that most clearly show the situations or experiences that they want to convey. Image quality may also play a role in selection -- although depending on the intended audience(s) quality may not be important (see Which Method section in Chapter 2). This pre-selection process also gives participants a chance to filter out or delete any photographs that they don't want to be seen by other people. Once this process is done, the facilitation team can collect and check the equipment and download the selected photographs onto computers. If printing is not feasible, the selected digital images can be viewed using a projector.

ii. Collective viewing

Open the viewing session by giving participants time to talk about their experience of the participatory photography process. If possible, print the photographs out and display them using a wall or floor gallery. If participants used journals in the field, they can discuss this information while viewing their photographs. It is good practice for facilitators to document these discussion sessions. In some instances, after they review their photographs participants may want a second chance to take pictures.

If the aim of the overall photography project is internal engagement, it can end here. For external engagements, collective viewing provides an opportunity for the participant group to decide which photographs will be taken forward for wider public or community engagement, and to agree on the next steps in that process. If the final visual output is to be a photobook or an exhibition, participants can use this stage of the process to make decisions about the titles of their photographs and to further develop the narratives that will accompany them. Depending on the scope and scale of the engagement project, further reflection sessions can be held, with individual or multiple group members, if they want to take more photographs or spend more time working on their narratives and titles.

Step 7: Photo editing (1 week to 1 month depending on the type of output)
As far as possible, involve participants in decisions about the layout and content of the final visual outputs. The project team may need to work with a graphic designer or curator to prepare drafts for participants to review and comment on before final printing or exhibition. Before the final visual outputs are used for external engagement, make sure that an informed consent form has been submitted for any photograph that shows an identifiable person.

Step 8: The external engagement process (Open-ended - depends on the modalities of engagement)
See Product Dissemination for more details. Note that if the modality of engagement is a photograph exhibition or another type of event, additional time will be required for event planning.

Suggested Reading

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A healthcare worker using tablet technology to produce her digital story in the Participate-Engage-Prevent TB II project. Photo credit: SLF 2015

12. Personal Digital Storytelling (DST): Image-Led DST And Story-Led DST

What is Personal Digital Storytelling?

Digital storytelling (DST) is a creative, participatory audio-visual process that brings peoples personal experiences to life through the use of digital technology. A digital story is a short film sequence that conveys a memorable personal experience told in the first person narrative. The visual content of a DST is made up of static images that can be created through drawing, painting, photography or other arts based methods. DSTs can be used for the purposes of internal or external engagement (see Chapters 1 and 4). How the films are used or shared depends on the initial purpose of the process and the consent of the storyteller.

In this chapter, guidelines are provided for two distinct approaches to DST:

Image-led DST

This approach to DST has been followed by the public engagement team at OUCRU. It involves creating story images by taking photographs of places and people in a community or local setting.

Story-led DST

This approach to DST has been followed by the public engagement team at SLF. It involves creating story images in the workshop venue through arts based methods such as drawing and painting or the photography of objects.

Image-led DST

Requirements

For taking photographs it is best to use digital cameras or phone cameras (rather than disposable cameras) so that images can be quickly and easily uploaded to a computer. In order to involve participants in the film production, you will need a number of laptops and portable voice recorders to record the narrative/voice over. Ideally, provide one laptop or tablet and one recorder for each facilitator/participant pair.

The introduction and training phase can be done in any comfortable space, but with access to an outside area for participants to practice taking photographs in different lights during the photography training phase. If the participants want to use images off the internet they will need access to a computer and guidance how to download them, and avoid copyright issues. The storyboarding and editing process will require a space with tables, chairs and electrical supplies.

Participants and facilitation

Unless the participants that you are working with are skilled and confident in using digital technologies, personal DST requires a high level of technical assistance and at times one on one facilitation. The availability of facilitators will dictate the size of your group. With four facilitators you can work with a group of eight participants. You can have everyone together for the introductions and trainings but splitting the group for the story boarding and editing sessions to work with four at a time.

Time
The time requirement is similar to that of participatory photography (see Chapter 11), typically 2-3 weeks. The technical production stage (linking images and adding voiceover) is usually done by the facilitators, with input from participants before finalizing the films. This stage may add a week to the process. Allow for extra time if participants, on seeing the draft, want to add other images to support their story.

Process
When photographs are being used as the main image source for DST, steps 1-5 of the participatory photography process (described in the previous section) can also be used to start a DST process. Some additional steps are needed to create a film:

Step 6: Viewing the photographs and image selection
When all of the participants have taken photographs the group will reconvene. Facilitators should help download photographs from the cameras to a laptop. Ensure these are backed up regularly. Sometimes participants may choose an image (printed photos and pictures, web images) or artefacts or objects that relate to their story. These should be photographed and added to the picture collection. When working on personal stories it is important to do the initial image selection with participants individually because stories may be confidential. In the first instance, a facilitator should help a participant go through their images and make a rough choice of 40-50 pictures. Some may have taken hundreds of pictures so it's important to narrow them down. Prompt them to explain why they took those pictures and what story they want to tell.

Step 7: Storyboarding and adding a narrative
Some people may not have a clear story yet but at this point they should try to 'storyboard', or lay out the flow of their film story, reminding them of the prompt questions. Work with participants to diagrammatically plan their story. Once they have done this, they can select images which support their story. The facilitator can start putting the images in order on the software on a laptop. Typically, 15-20 images are sufficient for a 3-4 minute film.

In order to record the narrative, the participant should plan the voiceover. Generally, it helps if the participant can write out their script and practise it. With illiterate communities, facilitators should help write their script. Once comfortable with the narrative, record the participant telling the story. Reassure them that you can edit out 'mistakes' and they can re-record if they wish. In some cases, the participant may wish for someone else to speak, or just to use subtitles.

Two facilitators work with a participant of the Health in the Backyard DST project to add a voice over to his photographs. Photo credit: Fact & Fiction Films 2013

Step 8: Editing
If participants have the time and interest you can include them in the editing process, of creating a film and adding the voiceover. A quicker option is for technical facilitators to do the first cut before showing the participants for their feedback. They may want to re-record some more narrative or collect more pictures at this point, which will add a few more days to the process.

Step 9: Consent
This is also the point to discuss how the participants want to use the film and which audiences they are happy to show it to. This will influence the next steps and dissemination plan (see Consent sections in Chapters 2 and 3).

Step 10: Collective screening and project end
Even if participants don't want to show their films to a wider audience, screening the films in the project group (other participants and project team) can be an exciting event and an important part of the process of reflection. Show all the films (that you have consent for) in full and allow each filmmaker to introduce it and explain more if they are willing. It may be helpful to ask if their thinking around the subject has changed through the process. This event should celebrate their creativity and contribution. If possible leave them with a copy of their film, and a selection of their pictures. Whether you use the media further should be decided collectively (see Chapter 4).

The Health in the Backyard project which was facilitated by OUCRU in Vietnam provides an example of how image-led DST was applied to community engagement in public health. Mr Liem's story is one of the DSTs that was created by a participant of this project.

Story-led DST
This approach to DST has been followed by the public engagement team at SLF. It involves creating story images in the workshop venue through arts based methods such as drawing and painting or taking photographs of pictures (e.g. pictures in a magazine) or objects.

A clip from a digital story showing an image created using a digital drawing app. Participate-Engage-Prevent TB II. Photo credit: SLF 2015

A facilitator helps a participant of the Health in the Backyard DST project to practice taking photographs. Photo credit: Fact & Fiction Films 2013

Requirements

Space
For 12 participants you will require a spacious workshop venue with tables, chairs, good light for creating artwork and an electricity supply.

Image production
Provide an array of arts and crafts materials. This can include but is not limited to:

- Lead pencils
- Erasers
- Fibre tip pens, crayons, pastels and pencils in various colours
- Watercolour and/or acrylic paints
- Paint brushes in various sizes
- Scrap paper for practice drawings
- High quality art paper for final versions of drawings (also see step 11 in process outlined below)

Glossy magazines are useful for cutting out images that can be photographed or scanned. Pictures in magazines can also help participants to come up with ideas for images they might want to draw or paint.

Digital technology

- iPad tablets
- iPad apps including
- Drawing Pad for image creation

- Scanner Pro to scan pictures that have been drawn or painted by hand
- Evernote for script writing
- Audio Memos for narrative recording (for practice reading)
- Sonic Pics (video making software).

Participants and facilitators
The limiting factor for this tablet based approach is the number of tablets that are available. With a facilitation team of 4 people, a participant group size of up to 12 is manageable. The facilitation team should include a lead facilitator and sufficient technical and logistics support.

Time
The process described below takes a total of 6 days. This includes:

- 5 consecutive days for the production of the DSTs
- up to 1 day for the consent workshop (though this can usually be achieved in half a day)

Note that this does not include time for participant mobilization or an inception meeting (see Inception Meeting sections in Chapters 2 and 3).

Process
Follow steps 1 - 6 as described for the Body Mapping method (Chapter 9)
The remainder of the story-led DST process includes an array of creative exercises which help to:

- identify the core stories that participants want to share
- focus in on a key moment
- give shape and texture to the participants' individual stories
- develop the visual content to accompany the story narratives
- audio record the narratives and complete the digital stories

Examples of these creative exercises and a suggested order for their application are given below:
Step 7. Free-writing
Ask participants to write freely in response to the following prompts (i. I remember…. ii. I remember what I did when…. iii) I remember how I felt when….). This helps participants to open their minds and get out of their normal pattern of engaging with each other and the world through *improvised storytelling.*

Later on in the process, participants are asked to write out their stories, and so this exercise serves to kick start the creative writing process. This exercise also helps facilitators to identify any group members who have difficulty writing and may need one-on-one support for written story development.

Step 8. Story circle
Facilitate a story circle on the first and second day of the workshop. Story circles provide an opportunity for participants to tell their stories to the rest of the group, while sitting in a circle format. This process enables the storytellers to reflect on their stories and get feedback from a 'listening friend' (the person sitting to their right) - and the lead facilitators - regarding the theme, characters, position and strength of the key moment, emotions and clarity.

Step 9. Image association
Image association involves showing 20 – 25 selected images/photographs on a large screen to the whole group and asking them to write down (and subsequently tell the rest of the group) the first word that comes into their head when they see that image. Each image is shown for a duration of only 10 seconds. This exercise helps participants to understand how they can use symbolic images in their stories, i.e. that, in visual storytelling, a picture/image (such as a tree) can be used to represent and evoke thinking about many things in addition to just a tree.

Step 10. Visualizing the key moment in a story
Ask participants to close their eyes and feel their way to the most important point in their story where something highly significant and deeply memorable happened. Explain that this is a moment where they experienced a profound emotion such as fear, shock, anger, frustration, or relief, excitement, joy etc. Finding this point is a crucial step in story development and helps the storyteller to crystalize their story content and identify where their story begins and ends. Ask participants to create a drawing of this moment. This drawing (or a later version) is often used as an image in the final digital story.

Step 11. Story World
Story world is a creative exercise that supports participants in generating images to accompany their story narrative. It involves creating single scenes or friezes that illustrate a point or points in the story. These scenes are created using various craft items including modelling clay, paint, glue, plastic figures and figurines, colour and sliver-paper, string, wool, etc. Once built, these scenes are photographed (either in full or in part).

Step 12. Story dramatization
Story dramatization is a particularly useful exercise for identifying the main or most significant characters in the story and to find clarity regarding how the story starts, what happened in the beginning, and how/where it ends. The dramatization process especially helps participants who are struggling to find the story they want to tell, or to trim a big/long story down to a manageable size. Participants are asked to work in small groups to act out a single story (of a participant within the small group) in a maximum of 4 scenes, for a maximum of 5 minutes, without words (i.e. mime only). This exercise works best if the participant whose story is being enacted plays themselves in the dramatization.

Step 13. Story boarding
Give participants time to think about how they are going to visually lay out the order of their story. At this point it is useful to give a reminder of the prompt question. The facilitation team should support participants as needed to diagrammatically plan their stories on a story board. A story board is best developed using multiple smallish pieces of paper (e.g. half A4 size) which represent the images (or rough sketches of the images) that will make up the visual content. These can be moved around while participants work out the visual flow of their stories.

Step 14. Image creation
Participants spend time using the arts and crafts materials supplied to create images to accompany their stories. A guiding rule of thumb is 20 images for a 3 minute story.

Participants can also use the *iPads* as a means to create some images for their stories. Images that are produced with Drawing Pad or scanned with Scanner Pro can be saved to the Camera Roll on the tablet device. Photographs (e.g. of story world scenes) that are to be included in digital stories can be uploaded to a cloud based platform (e.g. Google Drive) for subsequently download to specific iPads, as per individual story requirements.

Step 15. Producing the digital story
The facilitation team should provide one-onone support as needed to help participants in fine tuning their story narratives prior to audio recording. How much support is needed at this point depends on how easy or difficult a participant is finding it to finalize the narrative. Generally, it helps if a participant can write out the story scripts and practise reading it out loud a few times. If any of the participants struggle with writing, facilitators can help with the writing of the script. If any of the participants are illiterate, avoid using a script altogether and find other ways that will help them to remember the words of their story.

When it comes to audio recording the stories, the Apple app SonicPics is a simple video making tool that can be used to combine the spoken story narrative with its accompanying images. Another more recent video app is Shadow Puppet, which will work on Android and other tablet devices, as well as IPads. Reassure participants that 'mistakes' can be edited out later and they can re-record if they wish. The story-tellers should be given the opportunity to record their stories as many times as they want, until they are happy with a particular version. If requested or approved by a story-teller, a facilitator can be present during the recording process to help ensure that the images are placed at the correct position in the audio stream. In some cases, participants may wish for someone else to speak (e.g. if they are too nervous or wish to remain completely unidentifiable) or just to use subtitles.

Step 16. Story upload and download
When complete, a digital story video file can be uploaded from an iPad to a cloud based platform (e.g. Dropbox) and then downloaded for subsequent use.

If there is time, it is great to close the DST workshop with a collective viewing of the stories. Participants have worked very hard by this stage and a film show allows time to relax and celebrate the achievements of the week.

Step 17. Video editing
If it is necessary, the video editing process usually involves an independent video editor working with the digital stories to add subtitles and credits as desired by the story-teller or required by the project. A music soundtrack is an optional extra.

Step 18. Consent workshop
The aim of the consent workshop is to review all the stories collectively (possibly for a second time) including any edits (as above), and to request the story-tellers' permissions to show/share the stories with external audiences. A consent form will need to be developed in advance for this purpose (see Consent sections in Chapters 2 and 3).

The Participate: Digital Stories project which was facilitated by SLF in South Africa, provides an example of how story-led DST has been applied to community engagement in public health. Inkedama (Orphan) is one of the DSTs that was created by a participant of this project.

Suggested Reading

Gubrium, A., 2009. Digital storytelling: An emergent method for health promotion research and practice. Health promotion practice, 10(2), pp.186-191.

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Treffry-Goatley, A., Lessells, R.J., Moletsane, R., de Oliveira, T. and Gaede, B. 2018. Community engagement with HIV drug adherence in rural South Africa: a transdisciplinary approach. Medical humanities, 44(4), pp.239-246.

Oxford University Clinical Research Unit. n.d. Health in the Backyard.
Available: http://healthinthebackyard.org/index.php/films

Storycenter.
Available: https://www.storycenter.org

School Leavers' Attachment Scheme (SLAS) students on attachment at KWTRP Kenya assemble film-making equipment to make a film to share their experiences, which you can see here: https://vimeo.com/271420128.
Photo credit: Shadrack Baraka 2018

13. Participatory And Collective Film-Making

by Alun Davies

What is Participatory Video?

Participatory video (PV) comprises a wide range of approaches used in diverse contexts for many different purposes. Essentially, in this method, a group of participants, together with a facilitator, learn how to make their own videos to explore and describe their experiences, views and situations. The process has been described by many practitioners as being empowering in itself, but the approach can also produce a video product which can be used as a powerful tool to communicate important issues to different audiences.

Applications of Participatory Video

Used widely in community development across a wide range of age groups, PV has been described as having the capacity to enable participants to "take control of their destinies". PV approaches and methods vary widely, however the method described here draws from my experience of PV with school students, and was developed specifically to evaluate and communicate the experiences of secondary school leavers participating in a 3-month attachment at a research institution (the KEMRI-Wellcome Trust Research Programme (KWTRP), Kilifi Kenya). It has also been used as a research tool in a wide range of contexts including an exploration of school engagement with health research, and issues facing young people in deprived areas. It involves a combination of collaborative film-making and participant observation. As such, the process offers an opportunity to capture views through detailed notes as well as a video product to share experiences with broader audiences such as: institution staff; parents; schools; and the general public through the www. The advantage of this approach is that issues deemed too sensitive to share through video with broad audiences can be captured and documented anonymously through notes. PV has been used in many other contexts and with a range of communities, but this section describes work with young people in particular.

Requirements

Practitioners have used a wide range of equipment for participatory video

- Camera – can range from smart-phones and tablets to camcorders and SLR cameras. The higher the specification of the camera, the higher the potential quality of the video product, but high-spec cameras take a longer time to learn how to use. Camcorders are a good option when working with adolescents and young people as they are generally robust, produce good quality footage, have very accessible external controls (e.g. zoom) and are usually intuitive to use. A camera with a microphone and headphone socket is recommended to enable the use of external microphones.
- Sound equipment – An external microphone(s) such as a lapel or a shotgun microphone produces much better quality sound than microphones that are built into cameras, though they can be a little cumbersome to use and may require some practice. Shotgun mics can be attached to boom-stands so that they can be directed, outside the view of the camera, towards the person being filmed. A pair of headphones is essential when using external mics, to ensure good sound quality. A sound mixer may also be used which can be attached to the bottom of the camera. The mixer can then enable the use of a combination of a lapel and a shotgun mic together.

- Tripod – This essential component of the kit keeps the camera still and stable whilst filming.
- Editing software – this comes in various shapes and sizes. Generally speaking, the higher spec software tends to be more flexible, have a wide range of features and have faster processing speeds, but are more expensive. Having said this “imovie” and several free PC options work well on high-spec computers.
- Laptop – the higher the processing speed of the laptop, the faster the editing and rendering process will be.
- Miscellaneous extras – Deadcat wind protectors for mics; extra batteries and external battery charger; lighting lamps/reflectors; SD cards; external hard drives.

Participants

The specific approach described in this section has been developed to produce a collective video output with groups of 4-10 upper-high school students or school-leavers, however it has much wider applications.

Facilitation

Facilitation of a participatory video project requires a minimum of two facilitators:

i. A trained PV practitioner who has experience of facilitating workshops, is fully conversant with camera and sound equipment, and is able to edit film footage in the field (or in a workshop venue). A consultant editor could be brought in to do the latter, however this is usually an expensive approach.

ii. An observer who can take notes of discussions and decision-making within the group whilst supporting with workshop activities.

iii. The intention of PV is that during the process, participants have creative control in the scripting and editing and fully take over the filming and sound.

Time

Participatory Video projects vary tremendously in implementation time. This specific process depends on having participants available for 3-5 days, however, several factors will determine the duration of the project including: the depth of engagement required; the length and number of video products required; and most importantly, the amount of time participants can commit.

Process

The process developed for use with young people at KWTRP in Kilifi relies on alternate sessions of shooting and reviewing, with an emphasis on enjoyment, so that the sessions incrementally nurture confidence, and a good rapport between participants and facilitators. The process involves multiple steps:

iv. Getting to know the equipment: participants are tasked to assemble the camera, headphones, tripod and sound equipment, and to practice shooting, zooming, panning.

v. Reviewing footage: cameras can usually be connected directly to an LCD projector or a laptop to view the footage taken. Whilst reviewing participants are asked to reflect on the type of shots (close or wide), picture quality (steady/shaking), sound (including background noise) and to reflect on what makes good shots/clips.

vi. Storyboarding and shooting three scenes: Participants are asked to plan and sketch three consecutive clips (scenes) of a scenario they would like to depict, and then to shoot those clips with the camera and sound assembly. The total duration of the three consecutive clips must be no longer than 45 seconds. At KWTRP this has included: health and education promotion messages; adverts; and school descriptions.

vii. Group edit: The Facilitator loads the clips on to a laptop connected to an LCD projector, and asks participants to direct on: which clips to select; what order to place them; and where to cut in and out of each individual clip. An advantage of the ‘group edit’ is that it enables participants to select their preferred clips and omit clips that they are uncomfortable with sharing. As the edit is done, participants are encouraged to reflect on strengths and weaknesses of the clips. The note-taker records the main discussion points and the decisions made.

viii. Interviewing: Participants are invited to consider their experiences experience of the phenomenon/situation being explored (in our case, the attachment scheme) and asked to think of three questions which will elicit responses. They then proceed to interview each other on camera, taking turns at being interviewer, interviewee, camera person and sound engineer.

ix. Group edit: Whilst reviewing and group-editing, participants are asked to reflect on different styles of interviewing (facing camera, facing interviewer etc.), the angles and height of the camera in relation to the interviewee. Ideas about composition, such as the law of thirds can be introduced at this point, to help participants think about video conventions and how they help to tell a story. Whilst editing, participants are shown how additional media such as images, video footage and a soundtrack can be layered on to the interviews to make the created media more dynamic and appealing.

x. Creating media: Building on this experience, participants can then take on more ambitious projects such as short dramas or narrative stories, and can be encouraged to plan and storyboard and shoot short films to depict different aspects of their experiences.

xi. Processes 6 and 7 can be repeated giving increasing time for participants to be creative.

xii. Towards the end of the PV workshop, participants review all the edited media produced and discuss as a group: what further fine-edits are needed; what media they want to share; and which audiences to show the media to (unless this was agreed upon at the outset).

Ethics

Though hailed by many practitioners for being a method particularly suited for young people, very careful facilitation is required to ensure that pre-existing power dynamics within the group aren’t amplified through the PV process. For example, facilitators may be required to encourage quieter members of the group to actively participate. Further, in order to protect participants, whether young people or adults from potential harm or stigma which can arise through sharing their views and experiences, close attention must be paid to ensuring that films produced are acceptable at several levels. To address this a multi-staged consent/approval process is highly recommended:

<table>
<tr><th></th><th>School students (under 18, but this may vary from country to country)</th><th>Adults</th></tr>
<tr><td>Prior to filming</td><td>1. In a research context, PV projects involving young people in school may require national and institutional scientific and ethical review and approval.
2. The approval of the local education authority is likely to be required.
3. The school principal's approval is required.
4. Parental consent is required.
5. Student assent/consent is required.</td><td>1. Institutional permissions may be required and in a research context, PV projects may require national and institutional scientific and ethical review and approval.
2. Individual consent will be required for filming.</td></tr>
<tr><td rowspan="3">Post editing and prior to sharing</td><td colspan="2">The edited film is shared with institution staff (head of community liaison, communication officer, director) for editing suggestions and approval.</td></tr>
<tr><td>Consent to show the film to defined audiences, which may include websites or social media, is sought from:
1. Participating students.
2. Teachers (including school principal).
3. Local education authority.
4. Institutional media release forms may be used.</td><td>Individual participants are requested for consent to show the film to defined audiences, which may include websites or social media) using institutional media release forms (where appropriate). Audiences may include websites or social media.</td></tr>
<tr><td colspan="2">Media may be edited further to incorporate any amendments suggested by participants or stakeholders prior to wider sharing.</td></tr>
</table>

Table adapted from (Davies, 2017)

Often, where there is agreement across all participants and stakeholders, media may be uploaded to the worldwide web. Prior to consenting and uploading, participants must be made aware that once posted on-line, control of the media is essentially shared publicly. Combined with the group edit, where participants decide on what clips to discard from or keep in the final media, this process, though quite long, aims at ensuring that participants, and stakeholders are happy with any media being released.

Suggested Reading

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Acknowledgement

The Participatory Video method described in this section (Davies, 2017) was developed at the KWTRP with the support of Dr Chris High, Linneaus University, and published with the permission of the Director of the Kenya Medical Research Institute (KEMRI).

The Place of Change project involved community members living in rural areas at risk from malaria. This family lives in Binh Phuoc province, Vietnam. Photo credit: Mary Chambers 2011

14. Participatory Photo Postcard Sets

Researchers use photos of their work and research environment to compare with school children's drawings of their perceptions of a scientists' job, and elicit discussions. Photo credit: OUCRU PE 2019.

What are participatory photo postcard sets?

This method was designed to support researchers in engagement with school children about their area of biomedical research. Similar to photo elicitation, the images are used as prompts for conversation. When used by a Schools Engagement team (Vietnam), they asked researchers to show the 'human' side of their jobs – the team work and social activities as well as images of laboratories and pathogens. They also prompted the children (Grade 8-9) to draw a scientist and their activities. This way both sides had images to refer to and the differences between the children's perceptions and the reality of the photographs simulated conversation and laughter.

Applications

Health researchers illustrate their work through a series of pictures, which are used as conversation prompts when engaging with the public. These could be used during school or public visits to an institute, or as researchers visit communities to raise awareness of their work and build bridges. (See Including Health Researchers and Scientists as Participants in Chapter 2).

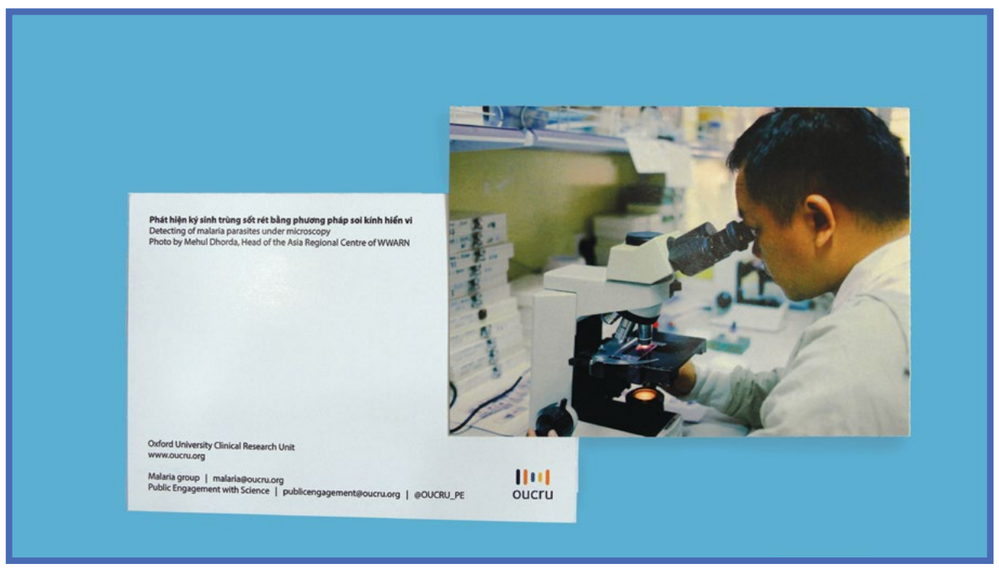
Requirements

You will require a fairly good camera and access to printing facilities. If possible, have the postcards professionally printed so that they are a nice take-home memento for the community and research groups. Engagement should occur in a space with tables that people can stand around and look at the photographs laid out in a 'table gallery' format. Or, if culturally acceptable, the cards can be spread out on the floor.

An example of a researcher-led picture for a postcard set. They captioned the image: "Interviews can be conducted anywhere as long as the interviewees feel comfortable."
Photo credit: OUCRU PE 2019

Participants and Facilitation

Since this method aims to facilitate researchers engaging with the public or communities, the size of the groups will vary depending on how many researchers are involved. Ideally one researcher can speak with 3-5 people at a time. If there is a group of researchers, the community members can rotate around them. You will need at least one facilitator to project manage and help conversations.



An example of a postcard with short explanation and photo credit on the back.
Photo credit: OUCRU PE 2019

Time and process

- Introducing the project to researchers: 1 hour. Discuss the image of their research that they want to portray to the public. Encourage them to include photos of people not just objects and equipment, and of researchers involved in social activities as school children (and public) often haven't met a scientist and don't imagine them as 'normal' people.
- Researchers taking photographs and writing narratives: Time will vary depending on the timeframe of the project, but 2 weeks may be sufficient. The researchers should choose 10-12 images and write 1-sentence titles.
- Editing and printing: 3-5 days. If possible, edit and print them to look like a postcard with size over 13x18cm so they are clear.
- Engagement process: 1 hour, unless you combine with other activities. Invite researchers to meet a community group or school group, either in the research institute or in a school or community space. Facilitate 3-5 participants to meet with a researcher and look at the photos, ask questions and discuss. If you are working with children, a nice addition is to have the children draw pictures of scientists and 'doing science' to have as a comparison.
- Evaluation with community and researchers: ½ hour. You can use a light touch evaluation to ask the community members about their experience and learning through the event. It's also important to have a feedback session with the researchers to understand what they found hard to explain what perceptions the public had.

Acknowledgement

This method was conceptualised by Thi Ha Le My and Vu Duy Thanh: Schools and youth engagement team, OUCRU-PE department.

A young boy watches ducks being slaughtered in the market. His mother was a participant in the image-led DST project Health in The Backyard, 2015.
Photo credit: Fact & Fiction Films 2013

15. Ethics Case Studies

Situated Ethics: Decisions about the Ethical Framework for a PVM Project

Engagement activities held in clinical settings require formal review by an Institutional Review Board (IRB) and must follow their ethical guidelines. Outside of these settings, there may be flexibility to encourage the participants to develop their own ethical code of conduct for the project (can be in addition to formal IRB guidelines).

Mountain View was a PVM project conducted in Nepal in 2016. It involved a group of 12 young people in making a participatory film about their experience of undertaking a pilgrimage to a high-altitude religious site. The aim was to understand more about the challenges they face and reasons that so many risk altitude sickness on these journeys. The participants had a facilitated discussion about scenarios they might encounter on the pilgrimage and came to consensus on how they should act in each of these situations:

- Needing to seek consent from other people they wanted to film;
- Coming across another pilgrim suffering extreme altitude-related sickness. Should they assist them? Was it appropriate to film them?
- What to do if someone was unconscious or couldn't give consent;
- What to do if one of their own group started to show signs of altitude-related illness. Would the whole group descend?

The outcome of the discussion was very similar to what an IRB would suggest - respecting agency and confidentiality of those they filmed and interviewed, and putting safety before the film-making process. The advantage of this approach is that participants actively discuss and agree on an ethical code of conduct, rather than being obliged to comply to externally generated guidelines they might not understand or agree with. Watch Mountain Views online.

Who Decides How to Disseminate Project Outputs?

Although we would advocate for participants to lead decision making about dissemination of media they have created, there may be cases when facilitators understand the wider context and need to step in.

This case study is from Kenya where a short documentary entitled 'Facing Our Fears' was created. The film was made collaboratively between a community engagement team and members of a local community. It aimed to disseminate information on how and why men who have sex with men (MSM) are involved in ongoing KEMRI HIV prevention research, and associated community engagement. Although not entirely participatory in nature, the film included candid interviews with community members and researchers and was based on feedback from numerous participatory events with those individuals and communities. In order to assess the potential of the film as a community engagement tool and its potential to put those who participated in the film at risk, the engagement team conducted a series of facilitated viewings and interviews with over 100 community members. Despite overall positive feedback, consent from those in the film to show it, and recognised potential to reduce stigma around homosexuality, several participants from across stakeholder groups expressed concern that the documentary could cause a backlash for members of the LGBT community in the film, other individuals appearing in the film, and for the HIV research clinic and broader research institution. Given these concerns, and the engagement team's awareness of the wider context of increasing religious tensions in neighbouring countries, the team made the decision not to release the film on the internet or use it outside of highly facilitated settings. While releasing the film with blurred faces was considered, the team opted against this option because it was felt this would undermine the intimacy of the stories and dilute the intended messages.

As far as possible decision making should be a collective process. However, decisions are not always clear-cut or unanimous, and in adhering to the principle of 'do no harm' you may need to consider the wider context and the impact that dissemination of the media might have on your participants or others implicated in the project. There may be occasions when interests and desires of participants and institutes conflict. As facilitators you need to find the common ground before proceeding. It also highlights that choice of format is important and there are situations when film or photography is not appropriate.

Kombo, B., Sariola, S., Gichuru, E., Molyneux, S., Sanders, E.J. & van der Elst, E. 2017. "Facing our fears": using facilitated film viewings to engage communities in HIV research involving MSM in Kenya. Cogent medicine, 4(1): 1330728. DOI: 10.1080/2331205X.2017.1330728
Available: https://www.cogentoa.com/article/10.1080/2331205X.2017.1330728.pdf

Participatory Photography and Consent

When photographs of people are used for external public engagement they may end up being seen by members of the local community where they were taken. Even if a person who is identifiable in a photograph has consented to be photographed and agreed on the ways in which the photograph may be disseminated, ethical implications may arise after the photograph has been publicly shared.

The Participate-Engage-Prevent TB II project was led by the Sustainable Livelihoods Foundation (SLF) in Cape Town in 2015. The project included a participatory photography component in which residents of a semi-formal settlement were asked to take photographs that illustrated 'what makes TB better' or 'what makes TB worse' in their community. One of the participants, X, took a photograph of an 18-year-old woman who was a close friend. In the photograph, the young woman – who could be easily identified - was smiling and looking relaxed and happy. She gave consent to the photographer for her photograph to be included in a photobook that was to be circulated within her community as a way of sparking local discussions about TB. During the photography process, the photographer decided that the caption for the photograph should be 'Overcoming TB'. The photograph and caption were included in the photobook which was graphically designed and printed for public distribution.

The facilitation team asked the project participants to share the printed photobook with all those who appeared in it, as well as their friends and family. The photographers planned to give out many more copies at a large-scale public engagement event that they were co-designing and participating in a few weeks later. The event was to be held in their community and was aimed at raising awareness about TB. Shortly after X had taken her copy of the photobook home, a member of the project facilitation team at SLF was contacted by the father of the 18-year-old woman who appeared in the 'Overcoming TB' photograph. He had seen the photobook and explained that he was angry because the photograph of his daughter implied that she had once had TB. In a project setting where TB was highly stigmatized, he was affronted that his daughter had been shown in this light, especially because she had never actually had TB, and he wanted the photograph to be removed from the photobook. Although the young woman pictured was an adult and had given her consent for her photograph to be included in the photobook, she was still living with her father and he was still involved in making decisions about her life.

The SLF team took the following approach: the facilitator who had been contacted by the father of the 18-year-old woman went to visit him in his home, apologised for the misunderstanding and explained that many copies of the photobook had already been printed and that some had already been circulated in the community. Together with the 18-year-old woman, the father and the facilitator came to an agreement about what should happen next and the SLF team took the following steps to fulfil that agreement:

i. All the participant photographers were contacted, informed about what had happened, asked to gather in the photobooks and return them to the project facilitator. A meeting place and time was arranged with each of the photographers for the collection of the photobooks.

ii. The recalled photobooks and those that were yet to be distributed were edited, using specially designed high-quality stickers, so that the caption ‘Overcoming TB’ was blanked out.

iii. The photobooks were redistributed to the participant photographers and the remaining copies disseminated at the community engagement event as planned.

Visiting the father in person was helpful. He recognized that his complaint was being taken seriously and agreed to enter into discussions to find a way forward. A solution was reached that was acceptable to the father. The young woman was enabled to appear in the photobook and contribute towards health promotion in her community as she had wanted to. The photobook was used to engage a large public audience about TB as all of the participant photographers had hoped for. Project resources were not wasted.
Even in a complex public engagement project that involves working with a lot of people, it may be ethically necessary to respond to an individual objection. Consent can be complex when working with young adults, especially when they are still living by the decisions of their parents. As PVM facilitators it is important to be reflexive and do what is possible to change visual outputs after they have been publicly shared if this is called for (see Working with Young People section in Chapter 13).

This image shows that a photograph of a person can communicate a clear message without the person’s face being visible in the image.
Participate-Engage-Prevent II. - Photo credit: SLF, 2015

In the end of project meeting for the Health in the Backyard project, participants considered which external audiences they wanted to see their films.
Photo credit: Fact & Fiction Films 2015

Managing Expectations

Each individual, project team and participants, will come to a project with different expectations of what they will do and what the outcomes will be. In some cases, it may be possible to leave the process and outcomes open and allow participants to lead those decisions. However, there are often (to a greater or lesser degree) predefined outcomes to work towards, whether defined by the project team, partners or funders. It is essential to discuss the expectations of everyone involved openly and very early in the process. If you are unable to offer much flexibility, that should be clear before participants agree to join the project.

This case study is taken from Health in the Backyard, a participatory photo project with small-hold animal farmers in Vietnam exploring their understanding of zoonotic risk (infections between humans and animals). The government structure is such that all contact with community members is tightly regulated. After obtaining permission to conduct the project with farmers, the project team (OUCRU) gave the project brief and criteria for inviting participants to local government vets who were responsible to recruit to the project.

In the first community, eight farmers volunteered and joined a full day of photo story introductions and training. By lunchtime it was clear that they were unhappy, and a few left. The facilitators stopped the training to ask the participants why they were discontented. It transpired that the local vets had recruited them by telling them that the project was offering training on farm safety and animal husbandry. The vets felt that no one would

volunteer for a participatory project which had little obvious benefits for the farmers. Instead of completing the first day of training, the facilitators went over the background to the project and then sent participants home. Those who wanted to take part came back to the second day of training.

In the second community, this time in North Vietnam, the facilitators wanted to guard against this scenario happening again so wrote a simple, 1-page project brief and planned a community introduction session. 10-12 farmers were given the project brief and invited to this recruitment session which took place a week or so before the project was starting. However, all the farmers had been told they were invited to join the project, and there were strong expressions of discontent when facilitators indicated they only wanted to recruit eight people. There wasn't an agreeable solution to this.

Our learning is that it is essential that the middle-men, in this case the local vets, responsible for recruiting must be included in early discussions and seen as part of the project team. Their misguided expectations of the project process and outcomes were passed on to potential participants.

It also raises a wider point about who benefits from projects and the ethics of asking people to participate in a process that has no clear benefit to them or their communities. This discussion is beyond the scope of this handbook but you should be aware of it, and consider it before embarking on a project. In this case, the farmers were not content with the photography outcomes alone, and wanted to receive training over and above that which happened informally as photographs were discussed by the group. Therefore, the project team decided to raise additional funding and conducted a follow-up project to offer training and create training literature which was given to farmers and the wider community.

Women playing picture card game for maternal and newborn health problems, Bangladesh. Photo credit: Sonia Lewycka

Degrees of Participation: An Example from Picture Card Games

As described in Chapter 7 there are a range of ways of using picture card games that will depend on the context and needs of the participants, and where along the ladder of participation you want to be. At one end of the spectrum, picture cards may be used as a participatory education tool, and used as the primary source of stimulus for group discussion. At the other end of the spectrum, picture cards may be used as part of a community-led problem-solving process, where the group independently identifies problems and solutions, and the cards are used to summarise the discussion.

In a women's group intervention study in Nepal, picture cards were used as a participatory education tool. During the identification of strategies to address problems, there was a tendency to mismatch prioritized problems and strategies. For example, one group suggested tackling the problem of post-partum haemorrhage by attending antenatal care. Another group considered that the problem of vaginal discharge during pregnancy could be addressed by training new Traditional Birth Attendants. There was an overwhelming preference for care within the community, in terms of place of birth and seeking solutions to health problems. Home practices with unequivocal allopathic clinical benefit were rarely mentioned. There was also little knowledge about what kind of problems could be managed at different health service institutions, and it appeared that communities define the "seriousness" of a problem in a different manner to the allopathic model. Therefore, the team concluded that perinatal health education would be useful during the development of the strategies. It was felt important to avoid turning the facilitators into educators, and therefore a participatory form of health education was developed, based around a picture card game.

In a similar women's group intervention study in Malawi, there was a much stronger emphasis on the community leading the discussion. For this reason, the picture cards were used to stimulate further discussion, clarify what had already been identified, visualize links and relationships, summarise and illustrate what the problems were, what caused them and how they could be prevented and managed. The cards were only presented after the issue depicted on the card had already been identified by the group, to allow for further discussion. They were not presented if the issue they depicted had not been identified or used to prompt the groups to identify the issues that they depicted. The range of maternal and child health problems included on cards were based on clinical and epidemiological knowledge of the most common problems, as well as a co-design process with pilot communities to ensure that these were locally appropriate. For contributing factors as well as prevention and treatment activities, a similar process was followed to develop a set of pictures, with the initial set of pictures based on known factors or recommended activities, and these being tested with a pilot community. Where there was no picture card for a problem, contributing factor or preventative or treatment activity, this could still be noted and included in further discussions where problems were ranked, or contributing factors, preventative and treatment activities discussed. However, facilitators were trained to keep the discussion focused on health problems that were medically recognised, and preventative and treatment activities recommended by the Ministry of Health.

Who to involve

Picture card games have primarily been used to generate collective solutions with groups of women in settings where literacy is limited and women's decision-making power and autonomy may also be limited. They are a powerful tool to get women to talk about problems and share their own experiences among peers, in an enabling environment. However, there has been much debate about male involvement in reproductive and child health, and whether and how men should be included in discussions about these topics. In order to create a safe environment for women to talk about sensitive issues related to reproductive health, it is preferable to begin discussions with women alone. But in order to mobilise the whole community to take action, community leaders and extension workers, who are often male, must also be included - as well as husbands and partners.

Another important group whose inclusion has been debated is adolescent girls. In some cultures, it is not acceptable for girls who have not yet begun childbearing to take part in discussions about pregnancy and childbirth. However, they can be most at risk from adverse reproductive health outcomes, and their participation needs to be considered. In Malawi the importance of involving adolescent girls in groups was discussed and encouraged, and groups were then left to establish their own membership rules.

Appendix

This is an example of an information sheet and consent form that can be used for a participatory workshop. More examples can be downloaded from the online course:

https://globalhealthtrainingcentre.tghn.org/practice-and-ethics-participatory-visual-methods-community-engagement-public-health-and-health-science/

INFORMATION SHEET AND CONSENT FORM

Name of project

Who we are
Brief description of the engagement/facilitation team

What we are doing
Brief description of the method and aims of the workshop

Your participation
We are asking you whether you will participate in a workshop exploring…[insert the topic that you are exploring with your workshop].

The workshop will involve a group/collective process that will take place over X days.

The programme will start at Xam/pm and end at Xam/pm daily.

We will either reimburse your travel or arrange your travel to the workshop venue.
During the process, you will use images, video, audio and/or photographs to develop a narrative or tell a story. [You will be provided with guidance and training in the use of digital technology to record your story – insert if appropriate].

Following the X-day workshop, you will be invited to participate in an additional [half-day] workshop to review your [type of visual material] and make decisions about the ways in which it can or cannot be used by the [name of organization].

Please understand that your participation is voluntary; the choice of whether to participate or not is yours alone. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to participate, you may stop participating in the workshop at any time and tell a facilitator that you don't want to continue. If you do this, there will be no consequences and you will not be prejudiced in any way.

Documentation
With your permission, we will audio record, videotape and take photographs of some of the workshop discussions and activities, and take some written notes. These recordings are done so that we can accurately document the conversations that take place and they will be used for transcription purposes only. If you would rather not be audio recorded, videotaped or photographed, please let a facilitator know. If you agree to being audio recorded, videotaped and/or photographed, but feel uncomfortable at any time during the workshop, we will turn off the recorders and cameras at your request. Or if you do not wish to continue at all, you may leave the workshop at any time.

Confidentiality
In group discussion settings such as this workshop, confidentiality will be strongly encouraged but cannot be guaranteed. The facilitation team will adhere to confidentiality and ensure anonymity of your [visual material] at your request. The engagement/facilitation team cannot guarantee that other workshop participants will treat the information that is revealed as confidential, but all will be urged to do so. Participants are thus advised not to disclose sensitive personal information in the group discussions if they do not feel comfortable in doing so.

Risks/discomforts
During the workshop, we will ask you to share a [personal story] about _____ (topic to be inserted, for each case). There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. You may stop the discussion at any time if you begin to feel uncomfortable.

Benefits
[Provide information about how you hope that participation in the workshop may be beneficial to the participants].

If you have any concerns after the workshop, please contact us on
[provide contact details of the engagement/facilitation team]

You may keep this information sheet

CONSENT

I understand that:

- my participation in this workshop is voluntary and I can stop participating at any point should I not want to continue
- if I decide to withdraw my participation it will not in any way affect me negatively
- this engagement project may not benefit me personally in the immediate or short term
- my participation will remain confidential should that be my preference

CONSENT FOR PARTICIPATION
I agree to participate in this [participatory visual methods] workshop

……..
Signature of participant Date:……..

CONSENT FOR DIGITAL AUDIO RECORDING OF WORKSHOP DISCUSSIONS
I agree to the digital audio recording of my participation in the workshop.

……..
Signature of participant Date:……..

CONSENT FOR VIDEO RECORDING OF WORKSHOP DISCUSSIONS AND ACTIVITIES
I agree to the video recording of my participation in the workshop.

……..
Signature of participant Date:……..

CONSENT FOR PHOTOGRAPHY OF WORKSHOP ACTIVITIES
I agree to the photography of my participation in the workshop.

……..
Signature of participant Date:……..

Links To Projects

Page	Suggested Reading and Links
14	**CTSA Community Engagement Key Function Committee, 2011** https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf
22	**The Nuffield Bioethics Report Children and Clinical Research** http://nuffieldbioethics.org/wp-content/uploads/Children-and-clinical-research-full-report.pdf
24	**The Heart of the Matter** http://livelihoods.org.za/wp-content/uploads/2018/05/The_Heart_of_the_Matter_Photobook.pdf
24	**Bucket Loads of Health** http://www.afox.ox.ac.uk/news/participatory-visual-methods-for-research-engagement/
35	**P(L)ace of Change** https://factandfictionfilms.com/engage/place-of-change/
35	**Mountain Views** https://www.tropicalmedicine.ox.ac.uk/news/oucru-nepal-nepali-pilgrims-to-gosaikunda
35	**The Heart of the Matter** http://livelihoods.org.za/wp-content/uploads/2018/05/The_Heart_of_the_Matter_Photobook.pdf
35	**Making All Voices Count; We Are Proud** https://www.youtube.com/watch?v=12Ccczp_tTU&feature=youtu.be
43	**Art in Global Health** https://wellcome.ac.uk/sites/default/files/art-in-global-health-wellcome-jun16.pdf
43	**Sacred Water** http://www.sacredwaternepal.com/about
55	**Dharavi Biennale** https://www.ucl.ac.uk/global-health/research/a-z/dharavi-biennale
56	**Art Meets Science: Flat Sunlight exhibition** https://factoryartscentre.com/en/event/flat-sunlight-a-solo-show-by-lena-bui/
63	**Our Water Challenges** https://www.youtube.com/watch?v=G0EPP4IpUyo

65	**Bucket Loads of Health** http://livelihoods.org.za/causes/bucket-loads-of-health-2/
65	**Doing it Differently** https://www.youtube.com/watch?v=-_7jAhOgGGU&feature=youtu.be
65	**Health, Stress and Sanitation** https://www.youtube.com/watch?v=5pyhtAoNb38&feature=youtu.be
72	**MORU** https://www.tropmedres.ac/homepage
72	**Village Drama Against Malaria** https://www.youtube.com/watch?v=ZD2oVgtaeM8&feature=youtu.be https://www.youtube.com/watch?v=h6IOeXaPAmc&feature=youtu.be
72	**Life Art Vietnam** https://en-gb.facebook.com/LifeArtVietnam/
87	**Health in the Backyard** http://healthinthebackyard.org/
87	**Mr Liem's Story (HIB)** http://healthinthebackyard.org/index.php/films?limit=10&start=10
91	**Digital Stories** http://livelihoods.org.za/causes/participate-digital-stories-2/
91	**Inkedama (Orphan)** https://www.youtube.com/watch?v=F82b0uZupYA
94	**School Leavers' Attachment Scheme (SLAS) at KWTRP Kenya:** https://vimeo.com/271420128.
105	**Mountain Views** https://www.youtube.com/watch?v=Mw2ZHrAkGVc&feature=youtu.be
107	**Participate-Engage-Prevent TB II** http://livelihoods.org.za/causes/pep-tb-ii-2/
107	**PEP TBII Photobook** http://livelihoods.org.za/wp-content/uploads/2019/05/SLF_Community_Participation_in_Action_for_the_Prevention_of_TB__HIV_in_South_Africa_-PHOTOVOICE-1.pdf
109	**Health in the Backyard** http://healthinthebackyard.org/

Abbreviations

BLH	Bucket Loads of Health
BTH	Beyond The Hospital
CTSA	Clinical Trials and Translational Science Awards Consortium
DST	Digital Storytelling
HCW	Healthcare Workers
HIB	Health In The Backyard
ICU	Intensive Care Unit
IRB	Institutional Review Board
KEMRI	Kenya Medical Research Institute
KWTRP	KEMRI-Wellcome Trust Research Programme
LMIC	Low and middle-income countries
MORU	Mahidol Oxford Tropical Medicine Research Unit
OUCRU	Oxford University Clinical Research Unit
PE	Public Engagement
PV	Participatory Video
PVM	Participatory Visual Methods
SLF	Sustainable Livelihoods Foundation
TB	Tuberculosis

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