

# **Applying the Emanuel Framework to explore the ethical issues raised in a participatory visual research project in rural South Africa**

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## **Abstract**

Participatory visual research can offer critical insight into the experiences of those most affected by health issues. As participatory visual methods are increasingly used to research sensitive topics, there is a need for a clear ethical framework to guide best practice on the part of researchers and research ethics committees. Here we reflect on a project where we used digital storytelling as a participatory visual methodology to explore HIV treatment adherence in rural South Africa, with a focus on the ethical issues we encountered during the lifetime of the project. To ground our reflections, we use the framework for ethical research developed by Emanuel et al., and the adaptation of this framework for social science proposed by Wassenaar and Mamotte. We suggest that fellow PVM practitioners and REC members draw on this holistic framework to support the optimal application of PVM in health research.

**Keywords:** South Africa, participatory visual research, HIV, stigma, research ethics, digital storytelling

## **Introduction**

Globally, health research is becoming increasingly transdisciplinary as scholars strive to engage more with research communities and gain deeper insight into the psychosocial aspects of human health (Nyika et al., 2010). In this context, participatory research and other social science methods are gaining popularity (Gubrium, Hill, & Flicker, 2014; Mitchell & Sommer, 2016). In participatory research, the emphasis is on collaborating with participants to foster collective knowledge about key issues and accelerate social change (Minkler & Waallerstein, 2008). The agency and autonomy of participants are respected by involving them as partners in multiple steps of the research process (Minkler & Wallerstein, 2008). The premise of participatory research is that when those most affected “are involved in identifying the issues

they face and the possible solutions for addressing them,” then interventions are more likely to be successful (Moletsane et al., 2009).

Participatory visual methodology (PVM) is a form of participatory research which incorporates a variety of arts-based processes that help participants to create visual artefacts, such as drawings, photos, digital stories or participatory videos (Black, Davies, Iskander, & Chambers, 2017). PVM is emerging as a popular, people-centred approach in global health research (Mitchell, & Sommer, 2016). It is frequently used to engage individuals from marginalised and underserved communities in studies on local health issues (Gubrium, 2009; Moletsane et al., 2007). In these contexts, PVM can offer participants visual ways of articulating information that may be difficult to communicate verbally due to language obstacles, or topic sensitivity (Gubrium, Fiddian-Gree, Lowe, DiFulvio, & Del Toro-Mejías, 2016; Mitchell & Sommer, 2016).

Like other forms of social science research, PVM ostensibly carries lower risks of physical harm to participants than biomedical research (National Research Council, 2003). However, a variety of other risks can emerge. As Wassenaar & Mamotte point out, the risks of “invasion of privacy, loss of confidentiality, psychological trauma, embarrassment, deception, stigma, and stereotyping exist and need to be monitored and prevented” (6). These risks are accentuated in communities that are considered vulnerable, or when sensitive topics are addressed and stigma and discrimination arise as potential threats. Indeed, despite the perceived advantages of PVM, Gillian Black and colleagues (2017) have observed that these innovative approaches and their associated technologies can lead to new ethical issues. There is a need for careful consideration of how this type of research can be conducted with minimal risk to participants (Black et al., 2017; Gubrium, Hill & Flicker, 2014; Liebenberg, 2018). There is also a need for further research to guide research ethics committees (REC), because if committee members are not familiar with the workings of PVM, they may overlook important nuances, “such as limits of confidentiality” in participatory workshops (Wassenaar & Mamotte, 2012: 5). Reviewers may also choose to withhold their approval of well-designed and innovative projects if they are unfamiliar with the proposed methodology and want to minimize the potential risk of harm (Wassenaar & Mamotte, 2012).

In 2008, Emanuel, Wendler, and Grady published a framework to provide scholars and RECs with a broad, systematic and comprehensive structure for conducting and evaluating clinical research in developing countries. The Emanuel Framework offers pragmatic guidance on how to apply fundamental ethical concepts in specific socio-cultural, political and economic contexts (Molyneux & Geissler, 2008). It rests on eight key principles, which follow the

sequential development of a project. These include collaborative partnership, social value, scientific validity, fair participant selection, favourable benefit-risk ratio, independent review, informed consent and respect for participants (2008). It was originally designed for clinical research in developing contexts, however in 2012, Wassenaar and Mamotte (2012) adapted the framework for social science, illustrated how its key components are relevant to social science researchers globally, and advocated for its widespread usage.

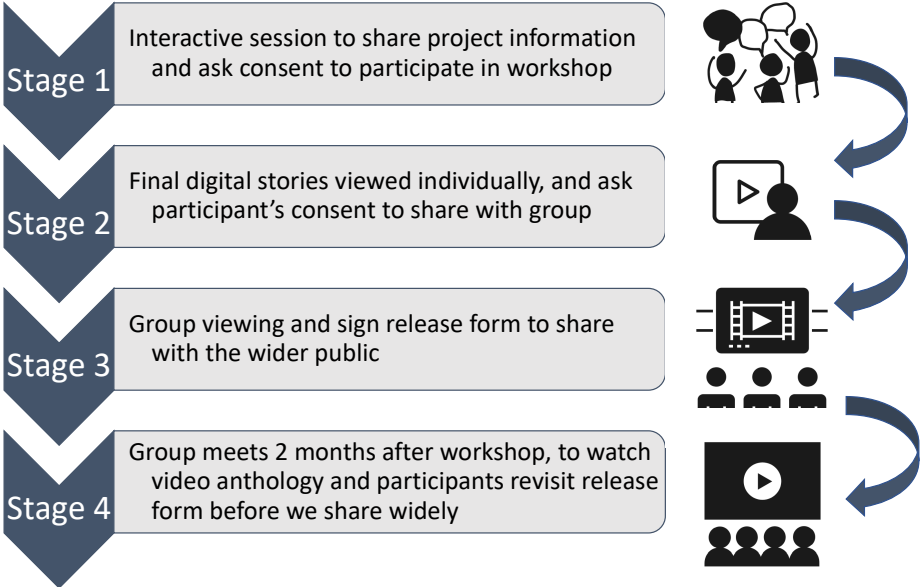
In this paper, we build on Emanuel and colleagues' pioneering work by investigating how the eight ethical principles are relevant to the application of PVM in a rural South African context. To ground our analysis, we reflect on a project that we conducted in 2013, where we used digital storytelling, a popular form of PVM, to learn more about HIV drug adherence from participants and to stimulate community engagement with this pertinent health topic. Our aim in this paper is to stimulate dialogue about the interplay between ethical principles, ethical decision-making and the application of PVM in health research in order to develop safe methods of applying PVM in developing communities and to guide REC members in their review of PVM proposals.

*Introduction to Digital Storytelling.* Digital storytelling is a narrative form of PVM that combines storytelling traditions with computer and video production technology. This method has been employed in a variety of settings to provide insight into health experiences and to assist with the design of culturally meaningful interventions (Gubrium, 2009). It is based on Paulo Freire's theoretical framework of empowerment, and is reported to increase community members' participation in research on local issues 2000, encourage creative self-expression and promote a sense of independence, agency and ownership (Burgess, 2006).

*Project Background.* Our interest in using digital storytelling arose when thinking of ways to engage community members in discussions about adherence to antiretroviral therapy (ART) in a hyper epidemic, rural setting in South Africa. Life remains difficult for many families living in this region, where over half of the adult population are unemployed (53% in 2011) (National Census) and HIV prevalence is high (37%) (Vandormael, Akullian, Siedner, de Oliveira, & Tanser, 2019). At the time of this project, we were engaged in clinical research and we were documenting high levels of HIV drug resistance in people whose ART was no longer working (Manasa et al., 2013, Lessells et al., 2014). Through our interactions with community members, we became aware that people face compound issues people in maintaining long-term adherence to ART in a rural setting (Lessells et al., 2014; Mills et.al., 2006), including the devastating impact of HIV stigma on health and wellbeing (Famoroti, Fernandes, & Chima, 2013;

Maughan-Brown, 2010). The aim of the project was to gain deeper insight into context-specific challenges to adherence through a narrative-based approach. We also wanted to share digital stories about adherence to ART to stimulate dialogue among the wider community and to encourage reflection on the contextual factors that influence adherence in this setting, including HIV stigma.

**Figure 1:** Phased consent process



**Method**

*Community Approval and Ethical Review.* Before submitting our proposal for ethics review, we presented it to the Community Advisory Board (CAB) to gain their approval and hear their suggestions. This board comprises approximately 30 local citizens, including representatives from the local traditional authority and local municipality, and members of the general public. Their role is to safeguard the community voice in the research process and to educate research teams on local cultural values, circumstances and social practices. The CAB made specific recommendations, outlined below, which we incorporated in the proposal before submitting it for ethics review. Below we provide a table to summarise the ethics review process.

**Table 1:** Digital Storytelling Workshop Structure

<b>Workshop structure</b>	
Day 1	Introduce project, gain consent, share story ideas with group, photo tutorial
Day 2	Run drawing tutorial, create artwork and audio recording of stories
Break	Facilitators create a first draft of stories
Day 3	Share first draft with participants, incorporate suggestions to create the final draft, record songs to use as sound tracks
Day 4	Share final draft with each participant, gain consent to share with group, share final digital stories with group, discussion, gain final consent to release films.

*Participant Recruitment and Selection.* Once ethical approval was granted, over one week, we recruited participants for the digital storytelling workshops from seven of the local primary healthcare clinics (PHC). We approached all adults at these clinics on a given day, told them about the project and completed application forms for those who expressed interest. We received 96 applicants in total. We worked independently to purposively select twenty participants, including 19 women and one man, with a mean age of 30 years. Originally we planned to include both men and women in each workshop and to achieve a wide age range. However, only eight men applied to attend the workshops and although we invited all of them to participate, when we called them to notify them of their selection, only one was free to join a workshop.

*Digital Storytelling Workshops.* We held the workshops at the conference facilities of the local country club in a northern rural district of the KwaZulu-Natal province. Each workshop was four days in length, and we ran one during the week and the other over two weekends. Over the four days, each of the 20 participants produced a digital story of two to three minutes in length. A team of seven women facilitated the workshops, including the principal investigator (PI), a facilitator trained in DST, a qualified HIV counsellor, a health educator and three research assistants. The counsellor, health educator and research assistants were from the local community and the PI, who had a good working knowledge of isiZulu, was present at both workshops to ensure that the process was in line with the project proposal and that key ethical principles and processes were adhered to.

At the workshops, the participants received tutorials in narrative storytelling, photography and drawing. During these tutorials, they learnt how to use visual techniques, such as drawing and symbolic photography to mask their identities. To avoid voice recognition,

participants were also given the option of having one of the project team read the recorded narrative on their behalf. We kept all participants' names private and codified all personal details for research purposes. Nevertheless, the participants remained the owners of the intellectual property rights of the digital stories and we were able to use their anonymous visual products for research and engagement purposes with their signed permission.

**Table 2:** Digital Storytelling Workshop Structure

<b>Details of Ethical Review Process in 2013</b>	
29 April	Proposal submitted to the Biomedical Research Ethics Committee (BREC) for review.
4 July	Provisional approval letter received. Sixteen queries regarding participant confidentiality and unintended HIV disclosure needed to be addressed.
15 July	Revised protocol submitted for review. We provided further details about the proposed use audio and visual techniques to protect participant identities.
30 July	A second letter was received from the REC with four outstanding issues to address, which pertained to concerns about disclosure and confidentiality.
15 August	We submitted the revised proposal for review.
20 Sept.	BREC granted full approval provided that digital stories were not shared publicly.
21 Sept.	We contacted the Ethics Chair, explaining that we needed to include a dissemination strategy to support community engagement with this pertinent health topic.
25 Sept.	We submitted a revised dissemination strategy and supporting documents for review.
15 Oct.	BREC provided full approval to proceed with the project activities in accordance with the revised dissemination strategy.

*Informed Consent.* In the project, we engaged in a multi-staged informed consent process. The potential risks and benefits were delineated at each step of the research process and participants granted consent accordingly (see Figure One above). The consent forms received by participants at each stage were written in isiZulu and before they signed, an isiZulu-speaking co-facilitator read through the form and gave each person an opportunity to ask questions before they decided whether or not to proceed.

*Sharing the Stories and Evaluating Impact.* Through the dynamic consent process outlined above, we sought permission from the participants to share the digital stories they had produced with community members at seven local PHCs, on our university website and at other community settings. Nineteen of the twenty participants allowed us to share their visual stories in this way. We compiled these stories into a video anthology with a brief introduction to the project and English subtitles. We evaluated the impact of using PVM to support engagement with HIV research through a mixed methods approach: quantitative surveys of community

members' knowledge and understanding of HIV and ART, focus group discussions (FGD) with people who had viewed the video, and observation of practice during the audio-visual screenings. For further details of this evaluation and our results see a previous published manuscript entitled, "Community engagement with HIV drug adherence in rural South Africa: a transdisciplinary approach" (Treffry-Goatley, Wiebesiek, de Lange & Moletsane, 2017).

## **Findings and Discussion**

In this section, using the eight principles of the Emanuel Framework to structure our discussion, we highlight the ethical issues that arose in our project. We draw on Wassenaar and Mamotte's 2012 publication and the wider literature to reflect on the interplay between ethical principles, ethical decision-making and the application of PVM in health research.

*Collaborative partnerships.* Collaborative partnerships between researchers, participants and research communities have long been considered essential for the conduct of ethical health research and the development of effective health interventions (Tindana, Singh, & Tracy, 2007). Collaborative approaches can help investigators to develop projects which respond to the needs of the community, consider prevailing local values, cultural practices and traditions (Molyneux et al., 2005), and are also beneficial to the community concerned (Lairumbi et al., 2008). The increasing incorporation of participatory methods in health research brings exciting new possibilities for collaborative approaches. For example, through our participatory visual approach, we repositioned participants as coproducers of knowledge through their creation of digital stories, evaluation of the project, and analysis of the digital stories.

Our participatory approach extended beyond the methods adopted in the workshops, since local residents, community leaders, and representatives from local health services partnered in different stages of our project design and execution. For example, the CAB members played a pivotal role in shaping our proposal before review, and were also involved in project evaluation, analysis of digital stories and the dissemination of research results. When we first presented our proposal to the CAB, we were planning to run the workshops at our Institute, which employs hundreds of people from the local community. Yet CAB members immediately identified the risk of HIV disclosure as an ethical concern. They were concerned that if community members heard that the workshops were about ART and HIV, they might assume that all of the participants were HIV positive, and this could lead to stigmatization. Consequently, they suggested we hold the workshops away from the Institute at a private venue.

Once we had adjusted our proposal, and received official approval from the CAB to proceed, we sent it to the REC for review. Although the REC saw the value of applying PVM to learn more about HIV drug adherence and to stimulate community engagement with this pertinent health topic, they argued that sharing personal stories about HIV in a context where stigma and discrimination prevailed was too risky for the participants involved. As Wassenaar and Mamotte note, while some “might argue that the eventual benefits to knowledge outweigh the discomforts of a few participants, major research ethics guidelines since World War II have strongly emphasized that the ends of research do not justify the means” (2012:4). Consequently, we revised the proposal over three rounds of review (see Table One above), before proceeding with project activities. Below, we share further details of this revised proposal, highlighting the specific revisions suggested by the REC.

*Social value.* This ethical principle encourages researchers to conduct studies that are of benefit to society or to specific populations (Wassenaar & Mamotte, 2012; Emanuel et al., 2008). We designed our project to benefit several different groups. Firstly, we focused on the topic of ART adherence, which we knew from our ongoing research to be relevant to society at large and to local health needs (Manasa et al., 2013). Through our multi-level thematic analysis of the twenty digital stories (visuals, narratives and songs), we offered the research community unique insight into personal experiences of HIV and ART adherence in this context and illuminated several opportunities for further research. In addition, we increased the social value of our study by including an intervention component, where we used the anthology of the digital stories to support community engagement with this pertinent topic. We shared what we learnt through this intervention in a peer reviewed and open access journal article (Treffry-Goatley et al., 2017).

*Scientific validity.* This ethical principle requires that the sample and methods adopted in the research study are justifiable, rigorous and feasible given the social, political, economic and cultural setting (Emanuel et al., 2008; Wassenaar & Mamotte, 2012). The scientific aim of our project was to learn more about HIV drug treatment adherence from individuals with relevant lived experiences and to engage community members in discussions about ART adherence in a hyper epidemic, rural setting in South Africa. Our qualitative results suggest that it is not just the stories themselves, but also the information that emerges when the stories are shown and discussed that contributes to the scientific value of PVM as a research tool (Treffry-Goatley et al., 2015; Treffry-Goatley et al., 2017). Yet, when we attempted to explore the impact of the



digital stories on health literacy around HIV and ART, we found that our quantitative research design was not feasible given the socio-cultural impact of HIV stigma in this environment. For example, given the risks of unintended HIV disclosure, we did not ask participants to share stories about HIV. Therefore, many people chose to share a family or community story rather than events from their own lives, and the topics covered were broad and varied (see Treffry-Goatley et.al. 2016).

The varied topics affected the scientific validity of our project since complications arose when it came to impact evaluation (Treffry-Goatley et al., 2017). For example, our survey questionnaire was designed at the beginning of the process and assumed stories about ART adherence. Since we could not change the survey instrument after the workshops without undergoing another round of ethics review (and we were reluctant to delay the project with further rounds of ethics review), some of the questions became redundant and the measure was less effective at testing the impact of the intervention. Therefore, in hindsight, a cost-benefit analysis suggests that it would have been better if we had requested an ethics amendment and used a more appropriate survey instrument.

Our experience links to the difficulty that many participatory researchers encounter when attempting to use quantitative methods to evaluate the impact of a research process which is in a constant state of flux and transformation through the collaborative relationship between the researcher and the participants (Gubrium et al., 2016). In addition, the anonymity of the stories might have influenced their power as a health promotion tool. For example, while many FGD participants responded positively to the faceless and nameless digital stories, some argued that adults could never take these child-like drawings or photographs seriously, while one healthcare worker noted that the anonymity made the stories less believable: “The confidentiality thing they will spin it around and say that they are hiding people because this is all false and the whole film will be dismissed” (An anonymous, male healthcare worker). These limitations indicate some of the ethical complexities PVM researchers encounter when using visual products to support community engagement with a sensitive topic, such as HIV (Moletsane, Wiebesiek, Treffry-Goatley, & Mandrona. n.d.).

*Fair participant selection.* According to this principle, “the population selected for the study should be those to whom the research question applies” (Wassenaar & Mamotte, 2012: 15). Yet, while our focus was on gaining deeper insight into ART adherence, due to the risks of asking PLHIV to share personal stories of adherence, we made the workshops open to all, and did not ask anyone to disclose their HIV status at any point. Our REC argued that implementing

these safeguards was particularly important, since the individuals engaged in the project might be considered vulnerable based on the prevailing social marginalization, economic deprivation and the high rates of HIV in this community (Department of Health, 2015).

The gender imbalance in our workshops may reflect a flaw in our preliminary community engagement strategy and in hindsight, we can see that our choice to advertise the study in PHCs may have inhibited male involvement in our study (Sallee & Harris, 2011). Existing work on gender, health access and health research in this context shows that both practical barriers, such as opening times (Myburgh, 2011; Peacock et al., 2008) and social constructions of masculinity contribute to men's poor engagement with local health services, in particular HIV services (Fitzgerald, Collumbien, & Hosegood, 2010). Yet, while we recognise that it is critical to involve men in more targeted and male-friendly community engagement activities, we also know that the female-dominated workshops offered a safe space for the (mostly) female participants to engage in discussions about HIV, which is crucial given the high rates of HIV prevalence amongst women in South Africa.

*Favourable benefit-risk ratio.* A favourable risk-benefit ratio requires that scholars fairly distribute the burdens and benefits of research across the project (Lie, 2010). When distributing these benefits and risks, researchers need to be aware that the benefits to society, while important to consider in determining risk-benefit ratio, should always be viewed as secondary to the benefits to participants (Wassenaar & Mamotte, 2012). Below we discuss how we worked to inflict minimal harm and bring maximum benefit to the participants of this study.

One of the important aspects of increasing the benefit of a project is to reduce the risk of adverse impact on the participants and community concerned (Emanuel et al., 2008). For example, in our interactions with our REC, re-traumatization arose as a potential risk to participants, since retelling stories about HIV and ART adherence might trigger painful memories and appropriate support needed to be available at all times. Accordingly, we hired a trained HIV counsellor from the local area to provide support at both workshops. This individual was also available for post-project support upon request as advocated by Black and colleagues (2017). A further step that we took to reduce the risk of re-traumatization, was to keep the subject of the stories open and we did not attempt to coerce participants into telling a potentially painful story about HIV.

HIV disclosure arose as an ethical concern in this project, since we were planning to create stories about HIV in a context of stigma, which could lead to harm should a participant's identity be exposed. Moreover, given the densely layered social networks that characterize this

small community (Reynolds, Cousins, Newell & Imrie, 2013), it was possible that local people might identify not only participants, but also members of their social networks, including family members, partners or friends discussed in the stories. This might lead to exposure of the health status of people who had no control over this disclosure. We took multiple steps to prevent harm through unintended disclosure. For example, we taught workshop participants to use visual techniques to mask their identities and withheld their names to anonymize the stories.

Yet many of the participants were very proud of what they had created and were keen to read their own stories. In fact, more than half of the participants asked to have their names, or at least their initials, listed in the end titles on their films to give them official credit for their creative input. Unfortunately, given the potential risk to participants and members of their social networks, we did not to grant this request. The fact that workshop participants were not given the opportunity to be publicly recognized as authors of their story exemplifies one of the most challenging ethical decision-making processes we faced as researchers when attempting to navigate through our dual obligation to protect participant wellbeing and our commitment to respect participants and support power sharing and agency through participatory research. This is an ethical dilemma that many PVM researcher grapple with, particularly those who work with participants from communities that have been deemed vulnerable (Moletsane, Wiebesiek, Treffry-Goatley, & Mandrona. n.d.).

In addition to the risks of re-traumatization and HIV disclosure, inducement was also viewed as a potential risk, since we were proposing to work in a resource-poor setting and knew that poverty could make participants more vulnerable to exploitation. Emanuel and colleagues argue that excessive inducement should not be a concern in research studies which have been through ethical review (2008). In this setting, research participants are used to receiving a modest stipend for participating in the Centre's activities. Therefore, we provided participants with transport from the local town, gave them R100 (approximately 7 US\$) per day (for six hours of participation), and offered refreshments at tea breaks and lunch time. Participant compensation was agreed with CAB and the REC and was in accordance with local guidelines based on the Time, Inconvenience and Expenses method of the time (South African Health Products Regulatory Authority (SAHPRA), 2018). Nonetheless, when we asked participants at the FGD "what attracted you to the workshop?" the immediate response from the group was "The R100!" (*laughter*) However, following this initial reaction, many participants went on to add that they found the project valuable. For example, one participant noted, "I feel elated, you don't know the way I feel about doing this film it was a dream come true." (An anonymous 33-year-old woman).

Our results echoed the writings of other scholars who have argued that offering participants commodities, particularly cash remunerations, may induce them to participate without careful consideration of the potential risks involved (Wong & Bernstein, 2011). Consequently, Molyneux and colleagues have suggested that in low-resource settings, non-monetary goods, such as medical screenings, food, clothing and books, may help to decrease the commercialization of research (2012). In addition, in relation to the application of digital storytelling in rural South Africa, Gubrium and colleagues have argued that “it is possible to reframe the expectations of potential storytellers from a desire solely for material support toward an interest in being part of local social-change efforts” (2014: 53).

In our project, we focused on enhancing the beneficence of the research process through an explicit focus on creating a safe environment, giving relevant support, boosting participant agency and imparting skills to those involved. A participant from the FGD provided some evidence of how this high level of support contributed to participants finishing the workshop with an increased sense of pride and self-belief:

With this workshop it made me see that if you aspire to do something, you can do it. Even when you think you cannot do it. You can do it. I never thought I would do something like this, but I did it. This made me see that maybe my dream came true. Since always my heart wish that I might tell people about this disease that they can get helped. (An anonymous 30-year-old woman).

This quote attests to the enjoyable and enabling process of story creation and relates to the work of Mertens (2009) and others, who attest to the transformative nature of participatory research. Yet Molyneux et al. have argued that the flexible and collaborative nature of participatory research can make it difficult to predict the benefits or risks of research in advance (2009). For example, originally, we had proposed to run the workshops at the Institute’s outreach computer centre and to impart computer skills in the process. Yet, through the collaborative involvement of the CAB, our venue changed, and we no longer had access to the computer facilities. Since we had not budgeted to hire or buy digital tablets or computers, we decided to rather support the participants to create paper edits of their stories and the PI and workshop facilitator conducted the digital edit on their behalf. This decision, while ethical, reduced the level of benefit for the participants involved and also limited the sustainability of the intervention since the participants did not learn all the technical steps involved in creating a digital story.

The collaborative nature of digital story production can also lead to unforeseen risks, since the content can potentially spread misinformation, reify stereotypes or trigger past trauma. Therefore, scholars and practitioners need to think carefully about which stories can be shared and how to share them. For this reason, in our evaluative FGDs, several participants suggested that screenings of the stories should always “be facilitated by a trained counsellor, who could dispel misinformation and provide emotional support if the stories triggered deep emotions” (Treffry-Goatley et al., 2017). This was a good suggestion and we followed this advice in the screening of the digital stories in the local PHCs.

*Independent ethics review.* This ethical principle stipulates that before data collection begins, all proposals are reviewed by an independent and competent REC (Emanuel et al., 2008). Our project protocol was reviewed and approved by the University of KwaZulu-Natal’s BREC, which is a registered REC linked to the University. This committee follows a transparent review process and became a critical partner in the development of this project as described above. While we believe that the collaborative development of our proposal with the REC was beneficial, it took several months to gain approval since our proposal went through three rounds of review before acceptance. This delay at the beginning of the project was particularly challenging since our research grant was only 24 months in length and it shortened the time that we had left to engage with participants, which is not ideal in participatory research, where building rapport with participants and communities is of key importance (Denith et al., 2012).

We view these delays as symptomatic of the transdisciplinary nature of our project, where we adopted PVM to address a health concern. In addition, the non-approval of the first protocol reflects the PI’s unfamiliarity with biomedical research ethics as she had not conducted HIV research previously and had not clearly identified the potential risks of making the videos public, nor spelled out risk mitigation strategies in the initial application. As Wassenaar and Mamotte have argued, “if researchers themselves were more competent in the ethical aspects of research, their proposals would be less likely to be returned for revision” (2012: 7). The novelty of our proposed methods to the CAB and REC members, made them especially cautious, since we were proposing to apply an unconventional approach to address a sensitive health topic in a vulnerable community

*Informed consent.* This is one of the key determinants of ethical research. It is particularly important in participatory visual research, since at the “beginning of the process, participants do not know what the final content of their media will include, so they cannot always pre-empt

who they do or do not want to share them with” (Black et al., 2017; Mitchell, 2011). Accordingly, we adopted a dynamic and multi-staged approach to consent, where individuals determined what activities they wanted to participate in and the release of materials was an iterative process (Black et al., 2017).

In the first stage, on the first day of the workshop, we introduced participants to the project process, potential risks and benefits, and expected outcomes in an interactive session. The risk that we focused on at this stage was the risk of exposure to digital stories, which might trigger difficult emotions, or through the creation of one’s own story, which might also cause distress. We also spoke about the risk of sharing personal stories with the group, and the particular concern of HIV disclosure in this context. Each participant received a form where they consented to: (1) partake in the proposed activities, (2) keep the personal identities and information shared by other participants confidential and (3) confirm that they were aware that they could withdraw from the project at any point without any adverse consequence. In the second stage, on day five of the workshop, we shared final stories with each individual and asked each participant for consent to share their stories with the wider group. At this stage, we asked them to consider the potential risks of HIV disclosure and social stigmatisation should they decide to share their completed story with the group, the wider community and on the Internet, understanding that once digital media is released online it is not very easy to retrieve it. On the same day, after the group viewing, participants received a release form with the following options to consider: (1) not to share their story at all, (2) to share their story with research team members in a password-restricted section of our website, (3) to share their story on the public section of our website or (4) to share their story with the local community on the televisions at seven local primary healthcare clinics. Two months after both workshops were complete, we called the participants together for a final event, where we watched the film, distributed copies of the anthology and revised the potential risks involved in sharing the stories in the community and conducted a critical analysis of the workings of the project as a whole. After the discussion, we asked participants to revisit the release forms.

*Respect for participants.* In the conduct of ethical research, it is of key importance for researchers to ensure that participants are treated with respect during and after a study (Emanuel et al., 2008). Accordingly, in our project, we monitored the wellbeing of the participants during the workshops and responded to any ethical concerns that arose to minimize harm. We also informed participants of their right to withdraw from the research at any stage, without any penalty (Emanuel et al., 2008). We debriefed participants at the end of each day, counselled

them if required and then referred to local counselling services, which they could access beyond the life of the project. At the public screenings of the video anthology in clinics and at the FGDs, we also had a trained counsellor at hand, who could respond to any issues if they arose.

In research, it is considered best ethical practice to respect the privacy of participants and protect both their individual identities and the identity of communities in research (Emanuel et al., 2008). Therefore, we made all the digital stories anonymous and used the visual techniques described above to conceal personal identities. Nonetheless, many factors preclude the possibility of absolute anonymity in PVM. For example, Gubrium and colleagues note that “stories are sometimes so distinct that it is impossible to guarantee confidentiality” (2014). In addition, participants may be identifiable in the resulting visual media, particularly in small communities, through their clothing, their jewellery or their voice, for example. Moreover, participatory activities in social science research, such as PVM workshops and FGDs, (Black et al., 2017), challenge the enforcement of confidentiality, because researchers are unable to ensure that all participants will respect the confidentiality of information shared by other participants in group activities.

A number of scholars have questioned “the ethical assumption that confidentiality is always best” (Guenther, 2009). These proponents argue that when deciding whether or not to name participants, researchers and RECs need to consider the wishes of the participants involved, the potential risks, and whether naming participants will have any impact on the reporting of research results (Guenther, 2009). For example, Gubrium and colleagues state that wherever possible, the authors of digital stories should be credited as the authors of their work and remain the owners of the digital story (2014). Nonetheless, in some cases, scholars or RECs may refuse a participant’s wish to be named if the potential harms of identity exposure are too great in that context (Wassenaar & Mamotte, 2012). This was the case in our project, where we took the decision not to name the authors of the digital stories given the potential risk of stigma.

Nevertheless, stigma thrives on silence, and we often found ourselves questioning whether hiding the identities of the participants and using a secluded venue might entrench the problem. As Skinner and Mfecane ask, to what extent do silence and anonymity support a culture of HIV stigma and continue to drive “HIV out of the public sight, so reducing the pressure for behaviour change?” (2004:157). Therefore, we found it very difficult to make this decision in the context of a participatory project, and we found ourselves torn between an obligation to protect participants and a commitment to support power sharing and agency through research. We also thought it ironic that in a process deliberately intended to enhance

participant agency, in the end we overrode their own clearly expressed wishes by anonymizing their stories, albeit for sound reasons.

## **Conclusion**

The purpose of this analysis was to stimulate further dialogue amongst researchers and ethics practitioners about ethical principles, ethical decision-making, and the application of PVM in health research. We used the Emanuel Framework as our analytical framework. The workshops in which the digital stories were told and recorded offered a beneficial and enjoyable experience for many of the participants involved. Yet using participatory methodology in the context of HIV stigma and poverty raised several key ethical issues. We attempted to address these issues by adjusting the project design and putting strategies in place to mitigate risks and increase benefit to participants. However, these strategies led to further ethical dilemmas and also influenced the project outcomes. For example, our efforts to support participant agency led to little control being exercised over story content. This meant that stories covered a broad range of topics and we learned less about ART adherence than we had originally anticipated. This also made it more difficult to investigate the impact of the stories on the local population. In addition, our decision to use local clinics as a primary research site attracted many local women but made it harder to attract men. While it is important that the project amplified the voices of female participants, given the prevailing patriarchal culture in this region, it is also important that men's voices are included in participatory HIV research, so that we can learn more about the psychological and social barriers to ART access. As participatory visual tools become increasingly used in HIV research and public engagement with HIV research, key stakeholders should consider the following recommendations to address the ethical considerations raised in this manuscript.

## **Best practices**

As health research becomes more participatory and people-centered, there is a need for clear ethical frameworks to guide best practices in project design, implementation and review. While the Emanuel framework of 2008 was developed for clinical research, like Wassenaar and Mamotte (2012), we found it to be an accessible framework which helped guide our reflections on the ethical challenges that the research presented. We suggest that fellow PVM practitioners and REC members draw on this holistic framework to support the optimal application of PVM in health research.



We also suggest that social science and PVM researchers engage in early and constructive engagement with their REC during study design to speed up the review process, and if possible, involve an ethicist as part of the research team to guide ethical decision making over the life course of the project. It is critical that PVM practitioners address risk mitigation directly to minimise the risk of causing harm through their work. For this reason, in our evaluative FGDs, several participants suggested that screenings of the digital stories should always “be facilitated by a trained counsellor, who could dispel misinformation and provide emotional support if the stories triggered deep emotions” (Treffry-Goatley, Lessells, Moletsane, de Oliveira & Gaede, 2018). We heeded this useful suggestion and ensured that a trained counsellor was present at all screenings.

We also recommend that scholars foster strong partnerships with members of the community so that they can learn more about the local context, and so that they collaboratively design and deliver projects, which bring maximum benefit to the participants and their community. These collaborative partnerships, particularly in the early stages of project design, can help health researchers to target hard-to-reach groups, such as men, out of school youth or sex workers.

## **Educational Implications**

We advocate that fellow participatory visual researchers engage with ethical research issues with intellectual and creative vigour (Wassenaar and Mamotte, 2012), and that they write about their ethical decision-making experiences so that we can learn from each other and REC members can become more familiar with what ethical issues commonly arise and how they can be addressed. This learning could be supported through the design and delivery of customized courses on PVM for both investigators and REC members. These modules could focus on the key ethical issues which are associated with the use of PVM in health research and can be integrated into existing international and national research ethics programs, including the South African Research Ethics Training Initiative (SARETI) (SARETI, 2017). Training material could potentially be hosted on the TRREE website (<https://elearning.trree.org/>). Investigators and REC members who are interested in community engagement could attend online training sessions, such as “The Practice and Ethics of Participatory Visual Methods for Community Engagement in Public Health and Health Science,” which was developed by the MESH Community Engagement Network (<https://globalhealthtrainingcentre.tghn.org/practice-and->

[ethics-participatory-visual-methods-community-engagement-public-health-and-health-science/](#)).

## **Research Agenda**

Our findings may pave the way for further research. One of the limitations of this research project is that we applied the Emanuel Framework retrospectively. Future studies could take a different approach and use the framework to guide the design and delivery of their research. They could also incorporate greater qualitative analysis with participants and community members to reflect on these ethical issues from their perspectives and to look at further ways of refining the Emanuel Framework for social science and participatory research. As PVM becomes more widespread in HIV research, it is important that REC members, scholars and practitioners develop a clear ethical framework to guide best practices in PVM as a health research tool. Refining the Emanuel Framework would allow further research to address key conundrums in PVM, such as the unresolved tension between participant agency and ownership of research and the need to protect personal identities in a context of stigma and discrimination.

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