

A Situated Practice of Ethics for Participatory Visual and Digital Methods in Public Health Research and Practice: A Focus on Digital Storytelling

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This article explores ethical considerations related to participatory visual and digital methods for public health research and practice, through the lens of an approach known as “digital storytelling.” We begin by briefly describing the digital storytelling process and its applications to public health research and practice. Next, we explore 6 common challenges: fuzzy boundaries, recruitment and consent to participate, power of shaping, representation and harm, confidentiality, and release of materials. We discuss their complexities and offer some considerations for ethical practice. We hope this article serves as a catalyst for expanded dialogue about the need for high standards of integrity and a situated practice of ethics wherein researchers and practitioners reflexively consider ethical decision-making as part of the ongoing work of public health. (*Am J Public Health*. 2014;104:1606–1614. doi:10.2105/AJPH.2013.301310)

Emergent digital methods are changing the field of public health and opening new possibilities for collaborative approaches. These methods encourage repositioning participants as coproducers of knowledge who partner “in the definition of problems, formulation of theories, and the application of solutions.”^{1(p253)} The simplification and affordability of technology has led to a rapid and diverse expansion of participatory video strategies.^{2–4}

In the early 1990s, the nonprofit Center for Digital Storytelling (CDS; <http://www.storycenter.org>) codified a process to create compelling 3-to-5-minute short films that synthesize still images, video, voice recordings, music or sound, and text.⁵ Digital stories privilege participant subjectivities: participants construct narratives, choose images and music or sound they feel best represents their experiences, and are guided through hands-on computer editing tutorials. The method is similar to Photovoice^{6,7} as both methods are visual and participants are central to the production of knowledge. However, as it is described in the literature the Photovoice approach codifies an explicit action component,⁸ whereas digital storytelling may not. However, we readily acknowledge exceptions as not all Photovoice projects contain action components,⁹ although many digital storytelling projects do.¹⁰

Digital storytelling has multiple aims. Stories can be used to: empower participants through personal reflection, growth, and the development of new literacies^{11–13}; educate and raise awareness among viewing audiences about issues presented in the stories^{14,15}; inform public policy, advocacy, and movement building¹⁶; and provide visual, narrative, and multisensory data to support public health research and evaluation efforts.^{17,18}

Increasingly, digital storytelling is used in public health community-based participatory research and practice. Analysis of 250 digital stories produced with Northwest Alaska Native youths explores identity construction highlighting “sites of achievement” in young peoples’ lives.¹⁹ These findings can be used to inform the development of assets-based interventions that more closely align with local community values.²⁰ Digital storytelling has also been used as a mechanism for youth empowerment in the context of diabetes prevention²¹ and as part of a participatory food security policy development effort.²² In another study,^{23,24} child participants showed increases in sustained asthma knowledge, as well as improvements in attitude scores after watching a composite digital story and writing their own. At the other end of the life

spectrum, positive changes were observed with early stage dementia participants, including increased confidence, connection, sense of purpose, and improved speech.²⁵

Although digital storytelling has the potential to contribute to a participatory dimension of public health research and practice, these innovative approaches open up space for new ethical issues to emerge.^{26–28} Those adopting a principle-based approach,²⁹ or an overly legalistic framework that focuses merely on risk mitigation, may not be adequately prepared to reflect on this new terrain. Drawing on the work of Clark et al., we advocate for an approach in which

ethical decisions are made on the basis of care, compassion and a desire to act in ways that benefit the individual or group who are the focus of the research. . . [where] ethical practice is appraised in the context of a particular case.^{26(p82)}

In this article, we follow the life course of several digital storytelling projects and highlight moments of ethical debate and tension. We begin by briefly describing the digital storytelling process, noting ways the approach has been applied in the context of public health research and practice. Next, we explore common situations, discuss the issues or complexities they create, and offer some considerations for ethical practice (summarized in Table 1). As we explore these situations through the lens of digital storytelling, researchers and practitioners using a variety of participatory visual and digital methods will benefit from a deeper consideration of the issues reviewed.

THE DIGITAL STORYTELLING PROCESS

Digital storytelling workshops are often organized into 3 phases.⁵ Phase 1 is introductory: facilitators share examples and present brief

TABLE 1—Summary of Situated Ethical Issues When Using Participatory Visual and Digital Methods

Challenges	Situation	Issues	Considerations for Ethical Digital Storytelling Practice
Fuzzy boundaries	DST falls at the nexus of public health practice, research, and advocacy.	Confusion between where priorities lie (research vs practice) can lead to very different implementation approaches.	All partners should be in agreement about specific goals, objectives, policies, and procedures.
Recruitment and consent to participate	Sponsors want to recruit diverse participants to share their stories.	There is a fine balance between protecting individuals who are in the midst of trauma from further harm and patronizing potential participants through exclusion.	Critically engage with potential participants about the realistic benefits and potential risks of participation. Provide cultural safety and supports (e.g., counselors or elders).
	Consent to participate is sometimes indirect: a story may feature people (voice, images, names) other than its author.	Those featured in the digital story may be unaware of or upset about their inclusion.	Optimally, oral or written consent is received from all of those featured in a story.
Power of shaping	Storytellers are encouraged to tell their own personal stories; however sometimes tensions arise between emphasizing processes versus products.	Facilitators may help “shape” the narrative to produce stories that will resonate with audiences, inadvertently imposing their own agendas. Sharing power often means losing control over messaging.	Reflexive attention to issues of power and a sense of cultural humility are key to excellent facilitation. Storyteller’s well-being and autonomy of voice should be at the center of a project.
Representation and harm	Participants sometimes tell stories that make us uncomfortable or expose themselves to harm through the process.	Digital stories can misrepresent communities or reify stereotypes. Exposing illegal or illicit activity might endanger storytellers or participants.	Storytellers’ well-being should be at the center of a project. Supports should be in place. Guidelines should be established and implemented for risk management and harm reduction. Facilitators can engage in critical dialogue with storytellers or audiences to challenge messages.
Confidentiality	Confidentiality may not always be possible or appropriate.	Stories are sometimes so distinct that it is impossible to guarantee confidentiality. Often participants want to be credited by name for their contributions.	Wherever possible, storytellers should be credited for their work by name (or chosen pseudonym) and maintain ownership over their stories.
Release of materials	Consent to participate in a digital storytelling workshop is not the same thing as release of materials: giving permission for your story to be shared in a variety of manners.	Release of materials needs to be negotiated on an ongoing basis. Some stories reveal very personal issues (e.g., HIV status, a history of violence) that can make participants vulnerable to stigma and discrimination. Storytellers might want to change their stories or to change their minds about dissemination over time.	Workshops should include a session on the ethics of videography, which considers the power of images and the spoken voice. Where, why, how and by whom stories are released needs to be negotiated. Options range from publicly posting stories online, to sharing media files only for the purposes of education, research, and advocacy in closed workshop forums, to a decision not to share them at all. All options need to be discussed, and agreed upon on a case-by-case basis. Release of materials ought to be an iterative and ongoing process.

Note. DST = digital storytelling.

lectures on core elements. Phase 2 focuses on script drafting. Facilitators lead the group through a Story Circle, a group process for sharing and receiving input on story ideas or scripts. Scriptwriting supports are provided to participants as needed. The final phase of the workshop focuses on the mechanics of story production. Facilitators lead tutorials on basic digital editing, then participants audio record

their voiceovers and use software to piece their stories together. With consent, digital stories are screened at the end of the workshop, to storytellers and facilitators.

Many digital storytelling projects take their lead from Freire’s process of building critical consciousness.³⁰ Workshop participants are given the space to reflect on the world they live in and on their position within that world. They

are encouraged to imagine and be part of a shifted power arrangement that increases personal and social agency³¹ by producing and sharing stories that represent their individual experiences. The workshop is also a group process, where a reflective and collaborative space for analyzing injustice and oppression and articulating a more hopeful future is created.³²

RESEARCH AND PRACTICE APPLICATIONS

Digital storytelling offers a wealth of possibilities for public health research and practice. Gubrium has used digital storytelling as an ethnographic research tool in her work on sexuality, health, and well-being among marginalized women and youths.^{17,33} She writes field notes of workshop activities, records discussions between participants and facilitators, and uses the produced stories as elicitation devices during interviews and focus groups with participants and viewers. She has documented how participants reflect, shape, and make sense of their experiences through digital storytelling.

The stories can help shape others' health behavior.^{34,35} A model of culture-centric narratives in health promotion indicates that certain story characteristics are more likely to influence attitude, belief, and behavior changes.³⁶ Personal-level factors in a narrative, such as the perceived likability of characters and the appeal of storyline, and sociocultural level factors, such as the cultural embeddedness of characters, events, and language, are narrative characteristics that affect intended behavior change. These characteristics are mediated by narrative elements such as transportation (i.e., getting carried away by the story), identification with characters or the storyteller, and social proliferation (i.e., generate discussion, rehearsal, and reciprocal support for behavior change). Mediating factors can affect behavior change directly or via changes in attitudes and perceptions of social norms. These digital story characteristics can be used as preliminary data to support the development of health promotion programs, and as evaluation criteria for pretesting narrative-based health messages.¹⁵

As a culture-centered approach in health communication,³⁷ digital stories are intrinsically linked with cultural identity, thereby creating meaning, belonging, and guidance through shared understandings.^{38–40} Digital storytelling dovetails with the culture-centered approach used in indigenous research methodology because it “is a way to link individual stories and community narratives, while inciting and eliciting dialogue between and among diverse peoples and groups.”^{41(p7,42–44)}

Researchers may glean a wealth of data from audience feedback during screenings of digital stories. Such conversations allow for participatory content analysis and for the assessment of digital stories as part of a health messaging campaign. Indeed, the dialogue that typically occurs between audience members and storytellers can help researchers to key in on storytelling as a process for building and supporting cultural norms and developing culture-centered health promotion programs.^{37,45–47}

Digital storytelling also has an important place in public health advocacy. As of 1999, Amy Hill has led the CDS Silence Speaks initiative (<http://www.silencespeaks.org>), which positions digital storytelling as a tool for promoting gender equality, women's health, and human rights. For example, the initiative partners with the South Africa-based Sonke Gender Justice Network to address the twin epidemics of gender-based violence and HIV/AIDS by conducting workshops in urban and rural settings with a range of participants.

The Sonke digital stories are being distributed in a number of ways. Hill created a series of 5 discussion guides that Sonke staff use to facilitate conversations about issues raised in stories, and carry out action planning activities to address these issues. To date, more than 200 screenings have been held in community and professional settings, reaching approximately 5000 individuals. Hill also designed a formal training curriculum to educate men about how to support women survivors of sexual assault within the parameters of South Africa's Sexual Offenses Act. Digital stories are framed as case studies for a number of interactive learning activities, and linked to abridged radio versions that share how survivors and allies can find help. Beginning with the project's initiation in 2009, the radio stories have aired 120 times (10 stories across 12 radio stations), reaching an estimated 16 million viewers a week. The project has also reached 500 000 people by airing stories on broadcast health channels in clinics and schools. As such, the digital stories and accompanying materials serve as tools for health promotion and advocacy.

FUZZY BOUNDARIES

Although conventional public health research and practice applications have been clearly articulated, the ethical implications of using audio, visual, and digital methods like digital storytelling remain fairly muddy. Ethical conduct goes far beyond merely obtaining participant consent or fulfilling the expectations of an institutional review board (IRB). Researchers may find it particularly difficult to remain within the constraints of preformatted IRB requests, which rarely allow for flexibility in the informed consent process or take into account the fuzzy boundaries of research, practice, and advocacy that are common in participatory multimedia approaches.²⁷

Some have noted that the IRB process tends toward “methodological myopia” when it comes to human participants issues,^{48(p206)} placing multiple purposes in a monolithic context that may present extra hurdles for those using these approaches. This requires new approaches to ethics.⁴⁹ Calling for an “academic intervention,” medical anthropologist, Marty Otañez, who uses digital storytelling as a method for research, advocacy, and strategic communications, suggests hyper-transparency when addressing a human subjects board.¹⁸ Researchers must educate boards about their methodologies and practices to proactively shift expectations according to the approach used. Those using participatory visual approaches might also benefit from referencing The Ethics Application Repository (TEAR; <http://tear.otago.ac.nz>), an online archive of IRB applications donated by international scholars. TEAR contains separate collections of best practice IRB applications focused on community-based participatory research, youth populations, and innovative methodologies.⁵⁰

Experience has shown us that multiple perspectives—including those of workshop participants, facilitators, community members, field-site and partner organizations, funders, and researchers and their supporting institutions—must be considered as ethical practice standards are being developed for any given digital storytelling project.⁵¹ Relationships must be established to (1) address the impact of power differentials on methods, knowledge production, and outcomes; (2) build rapport, reciprocity, and trust; (3) ensure transparency

about potential risks and benefits of digital storytelling; and (4) acknowledge the complex politics of representation surrounding visual media. Because digital storytelling can fall at the nexus of public health research, practice, and advocacy, it is essential that the entire project team is clear about project goals and objectives, and where priorities and resources lie.

RECRUITMENT AND CONSENT TO PARTICIPATE

Digital storytelling projects may focus on stigmatized health issues (e.g., violence, drug use), and project sponsors will likely want to recruit diverse participants to share their stories. Workshop recruitment can take a variety of forms—including partnering with pre-established groups or putting out a call for participants. It can sometimes be challenging to find participants who are at the right stage for engagement. The experience can be triggering as participants may choose to tell painful stories. These emotional tales often create very powerful products, but can raise tensions around the ethics of naming perpetrators of violence, ensuring that participants do not remain victims of these experiences, and providing appropriate support and care (i.e., having on-hand elders, social workers, or other professionals who are trained to help with emotional work). Workshop organizers may need to screen potential storytellers to exclude individuals who might still be in the midst of “experiencing their stories” (particularly survivors of traumatic experiences) and could be put at risk for harm if asked to construct a coherent narrative about these experiences.⁵²

It is also important to consider the personal and structural dimensions of consent to participate, particularly in resource-poor settings. Although a participant’s social position should not disqualify her from taking advantage of the opportunity to participate in a project, sponsors are obligated to provide thorough information about the potential risks, limitations, and benefits of participating. Hill has found in her work with members of impoverished communities in rural South Africa 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.⁵³

There is a nebulous line between protecting and patronizing potential storytellers. As a once novice digital storytelling researcher, Gubrium conducted a workshop with women about their experiences with injectable contraception (Depo-Provera). A participant, who was living in a homeless shelter, expressed interest in being included. Gubrium was concerned about the woman’s capacity to provide consent-to-participate given the insecurities she faced in daily life. Gubrium balanced the participant’s everyday exigencies with the potential benefits she might realize from participating in a workshop, including: learning new technical skills, receiving remuneration for her time, and participating in a process that could promote well-being. Ultimately, Gubrium reckoned that well-being might be enhanced through the participant’s ability to give voice to her difficult life experiences and turn them into a tangible object (a digital story), rather than continuing to be objectified by the experiences of homelessness. In the end, the woman did not complete her digital story and could not be reached for further contact. Gubrium questioned whether she had inflicted more harm on this woman, who possessed little structural agency and was largely disenfranchised by public health and social support systems, by encouraging her to participate in a digital storytelling workshop.

Two other examples highlight the issue of navigating the disclosure of traumatic experiences. In her work as a more seasoned digital storytelling facilitator with Sonke Gender Justice, Hill encountered a situation in which workshop organizers tried unsuccessfully to recruit local leaders and advocates to address gender-based violence and HIV/AIDS prevention. Instead, other more vulnerable women participated. Several produced stories that were quite difficult and raw in detailing ongoing abuse at the hands of their partners. Hill consulted with participants repeatedly about whether they felt safe disclosing certain information but, short of urging them to tell different stories altogether, she felt uncomfortable with the idea of pushing repeatedly for certain script edits.

Although these women did complete their digital stories and gave consent for the stories to be released, Hill did not include their work as part of a compilation DVD that, according to a contractual agreement with the project funder, was to be widely duplicated and distributed. Clearly, the risk of harm outweighed the women’s willingness to have their stories shown publicly, especially because legal remedies and counseling for domestic violence are in short supply in the region.

In Flicker’s federally funded digital storytelling work, focused on HIV prevention with First Nations youths in Canada, several youths spoke of being HIV positive, being survivors of sexual abuse, or recovering from serious substance use issues. This type of disclosure is a heavy decision for young people, yet at least 1 young woman has spoken of participating in the workshop as healing. A very real issue related to consent to participate is if and how a “vulnerable subject,”⁵⁴ such as an HIV positive youth or a woman experiencing intimate partner violence, particularly those in a fiduciary relationship with those organizing or sponsoring the workshop,⁵¹ should be encouraged to participate in workshops or share their stories, publicly or otherwise.

The visual subjects of digital media generated as part of a project, such as those individuals who are videotaped or photographed by workshop participants, make up another group of people whose rights and well-being must be addressed. Writing on Photovoice ethics, Wang and Redwood-Jones²⁸ strongly advocate obtaining secondary consent form releases from all visual subjects and state that this is essential when a project’s subject matter is highly sensitive or potentially stigmatizing. However, in Flicker’s digital storytelling work with Indigenous youths in Canada, written consent forms were interpreted as tools of colonialism. Rather than offend local cultural protocol, participants went through rigorous training on how to obtain verbal consent in a respectful manner. Part of the training included a discussion on the notion of ongoing consent, to consider how participants could negotiate the consent process if someone depicted in their story requested that they be deleted from the story long after it was

completed. Informed consent thus extends beyond participants to the subjects portrayed within.

POWER OF SHAPING

Participatory visual methods are sometimes chosen to promote an ethic of collaboration and accountability, with the goal of changing professional norms and practices. However, sponsors must also interrogate the notion of participation and how this concept may differ in relation to process and outcomes. Knowledge production is often framed as a “neutral activity rather than as a process through which economic structures and ideological meanings are reflected, reproduced, or transcended.”^{55(p128)} We encourage researchers and practitioners to thoughtfully reflect on the power dimensions inherent to the participatory process, which affects whose voices are privileged and whose may be silenced. These can be manipulated consciously or unconsciously to influence the decisions of workshop participants about whether to create a story, when to speak up, what to say, what story topics or visual images are viewed as appropriate, and how they feel their stories should or should not be shared.

Digital storytelling participants are said to actively construct their own stories. However, in descriptions of the process, the influential role of others (facilitators, funders, researchers) is often absent from reports, when in fact they may serve as more than just midwives to stories. For example, facilitators often help participants find a story that is neither too easy (i.e., formulaic or stereotypical) nor too painful to tell. They may also help shape participants’ stories into something that will resonate with and therefore capture the attention of viewers. Storytellers are asked to consider what they want to do with their stories and for whom they are telling their stories. In the midst of all this help, some participants may feel that their own voice gets lost.

In the limited existing digital storytelling literature, authors rarely write candidly about how workshop facilitators can significantly influence the content of the stories produced. (Notable exceptions include the work of Davis and Weinshenker⁵⁶ and Hull and Katz,¹² which includes transcripts representing dialogue among participants and facilitators during the production process. Of course, one

limitation is that participants might not consent to audio or video recordings of interactions during the digital storytelling workshop, which would obviate this possibility.) This may be shaped by a disciplinary expectation of public health as an evidence-based science. Proposal reviewers may critique digital storytelling and other participatory media-making methods as being too subjective for scientific research because of the potential influence of a facilitator on the emergent media products.

By contrast, with Silence Speaks-Sonke projects, which are not framed as research but rather as community-based participatory media, Hill asks workshop participants and facilitators to consider how content decisions are made, in terms of writing and image selection, and how facilitators may influence stories by providing input and support during the story-making process.⁵⁵ For projects with explicit goals related to public distribution of stories, Hill frames story production as a joint effort between participants and facilitators. Participants understand from the outset the purpose of a workshop, the kinds of stories that will be produced, what their role will be, and what plans exist for sharing completed stories. Where possible, participants are engaged in discussion during the creative process about how their stories can be shown to maximum impact, what they would like viewers to learn or do as a result of viewing their stories, and when, if at all, they would like to participate as partners in story distribution. Participants are thus positioned as coauthors and coproducers of media pieces that will be shared as concrete tools for education, community building, or advocacy.

Funding can also impact outcomes. For example, a workshop sponsored to produce health communication digital stories may have parameters different from one that is funded as a research project to ethnographically explore participants’ understandings of public health issues, or one that is unfunded or directed toward community building. Depending on these goals, those integral to the process may have difficulty refraining from urging storytellers to take up their overt or subtle suggestions about words, images, music, plot devices and editing strategies used.

Hill’s work with Silence Speaks serves as a useful example for how to proceed. Silence Speaks projects are informed by the agendas of

multiple funders and partners. Hill makes clear to potential funders in advance—including in proposals for funding—the limitations of predetermining story content, given the participatory nature of the digital storytelling process, as well as the likely homemade feel of productions and means of story distribution. Given her transparency over these issues, over her 6-year collaboration with Sonke, Hill has experienced no conflicts with funders.

REPRESENTATION AND HARM

Researchers and practitioners must also consider issues of representation and harm. Storytellers hold representational power when choosing how to tell their stories; they often talk about people other than themselves. Ethical issues may arise when a storyteller publicly identifies people, experiences, or events that others would prefer remain private. For instance, stories may depict images of violence, crime, or drug use and serve to reify existing stereotypes about marginalization. In this respect, those involved in a given project must maintain a responsibility to the story. This requires an acknowledgment of the seamier side of visual and digital technology—that “it can be used to spread ‘uncivil’ stories [and] create . . . its own forms of exclusion and risk.”^{57(p180)} Challenges arise from the tension over the potential for both emancipatory and oppressive outcomes.

As suggested in Photovoice ethics,²⁸ content on the ethics of image, voice, and representation should be emphasized in an orientation session and woven throughout the digital storytelling workshop. Specifically, a process of reflexivity should extend to workshop participants as they are asked to consider the potential malfeasance brought on participants depicted in their stories. Storytellers should be asked to consider the power that an image holds, the implications of how participants are presented, and the importance of clarity of intention when seeking people’s consent to be photographed or recorded. Facilitators must acknowledge the distinct possibility that local audiences might know, or assume they know, storytellers or other people discussed in a story¹⁰ and should have conversations with storytellers to explore potential implications. If any party feels that disclosing particular

information will put anyone at risk for harm, this information should be omitted.

Working with an alternative school for young pregnant and parenting women, Gubrium grew concerned with the way that some participants reaffirmed dominant negative narratives about “teen mothers.” The workshop participants spoke of some as “greedy and lazy recipients of welfare,” “partiers” who were “bad mothers,” and their own mothers who “were not in the picture.” Although the participants themselves could be classified as teen mothers, they used derogatory language during the workshop as a way to contrast themselves with other young women (as well as their own mothers) who had not risen to the challenge, to position themselves as good mothers despite the odds.⁵⁸ Gubrium found the workshop particularly difficult to navigate. In the context of research, the stories could be useful as data that illustrated how participants negotiated narratives on young motherhood and youth sexuality. However, for advocacy purposes, the stories might fail to dislodge conventional conversations.

An experienced cofacilitator worked with Gubrium to design and implement a second story circle-like activity, after participants had put together their first drafts of stories. Participants were asked to consider dominant representations of young mothers and youth sexuality in the mass media and then to reflect on their own stories in this regard. The activity provoked participants’ critical thinking and, in the end, produced stories that represented young mothering in a more considerate manner, at the same time also bolstering their capacity to reflect on their experiences in a public forum.

In her work with Sonke Gender Justice, Hill has handled similar challenges by weaving critical discussions of narrative representation directly into the story scripting process. By gently questioning participants’ word choices that have the potential to reinforce negative stereotypes or place the blame for systemic health problems on individual behaviors, participants explore the ways that their narratives are dialogically shaped by dominant discourses.^{59,60} This encourages participants to author stories that both acknowledge the external structures and discourses that shape

their perspectives and opportunities in the world, and put forward a coherent alternative vision.

Workshop scheduling can be daunting. It is tempting to stick to a strict schedule of activities so that all participants produce stories. However, means and ends should be balanced. Rather than mechanically proceeding with a workshop as planned, a flexible approach accommodates arising challenges and serves multiple purposes (i.e., developing participants’ critical capacities, serving as mechanism for advocacy, serving as an ethnographic research process that produces rich data).

CONFIDENTIALITY

Even though names can be omitted and visual images blurred, the audio component of digital storytelling may preclude guarantees of complete confidentiality—workshop participants record their own stories, in their own voices, which can potentially be recognized by others. The inability to ensure complete confidentiality means that researchers and practitioners must maintain a flexible agenda around publishing stories (either in their entirety or repurposed as text, audio, or images) in print, online, in social media, or via broadcast media, or screening stories in public venues, including within the workshop in which they were created.⁶¹ Although print publications may be a better way to go to ensure confidentiality, as authors can summarize main themes or messages in participants’ stories without breaching confidentiality, this constraint may conflict with the priorities of partner organizations and funding agencies to disseminate the more compelling multimedia material from the project.

At the same time, when safety and respect are clearly not at issue, we urge sponsors to consider an alternative standpoint on the ethics of confidentiality. Rather than bending over backward to protect workshop participants by making sure they cannot be identified, we suggest that digital storytelling offers a utile arena for exploring the terrain between the right to personal privacy and the right to lay claim to knowledge production. Participatory research is predicated on the idea that participants should stand on equal ground with academics. What happens to that ground when

participants are given pseudonyms or their names are deleted in materials produced through a research project that was meant to be empowering? Though often considered common or best practice in the field, researchers might question the knowledge and power dynamic that allows them to attach their names to peer-reviewed publications even though research participants, whose time and efforts are no less intrinsically valuable, must generally remain anonymous.

When digital storytelling workshop participants’ names are made public—allowing them to be positioned as “knowers” with critical standpoints on experience⁶¹—they are positioned to lay claim to the real or perceived social and economic value of the stories they have produced. Hill has found with some Silence Speaks projects that rather than desiring anonymity, storytellers often speak of their participation in a workshop or ability to publicly share their completed stories as opportunities. A public claim, with their names and or faces clearly depicted in their stories, demonstrates that they have acquired specific skills in media production, storytelling, and leadership, and that they, not researchers, are experts on experience.

RELEASE OF MATERIALS

Digital stories may eventually be screened as conversation triggers with diverse audiences, ranging from local community members and health care providers to policymakers and politicians, integrated into provider training curricula and health education materials, posted online and shared through the use of social media tools and mobile devices, broadcast on radio or television, or reproduced in text format for publication—all in the service of health promotion and disease prevention. Storytellers, facilitators, and collaborating partners should be sure to achieve consensus prior to project implementation about where, when, why, and how stories may be potentially distributed, with the storyteller’s authority prioritized. Options may include releasing materials only in the workshop setting; for therapeutic, educational, research, advocacy, or exhibition purposes; or not at all.

Release of materials is a dynamic concept. Participants’ intentions or attitudes toward

sharing their stories may shift over the course of the workshop or even after the workshop has ended. In this regard, consent to release materials is much more a moving target than is commonly recognized in IRB applications. Unlike still images or static transcripts, digital stories are dynamic media in the making. For example, in Flicker's HIV prevention project some youth participants wanted to edit and re-edit their stories, updating and retelling their stories long after the official workshop ended. Consent became an on-going process, making it difficult to publicize and share a final version.

Structural realities must also be taken into account when negotiating release of materials. Alexandra's digital storytelling project, *Living in Direct Provision: Nine Stories* (<http://www.darcyallexandra.com/practice/living-indirect-provision-9-stories>) illustrates the need to negotiate a clear release of materials policy among stakeholders (including storytellers) early on.¹⁴ Alexandra worked with 9 asylum seekers and refugees living in Ireland to construct digital stories about their experiences with the direct provision system. The intended outcome of the digital storytelling workshop was to produce a compilation DVD and conduct public screenings of the stories. The goal was for policymakers and politicians with decision-making power to listen.

However, things did not play out smoothly. Despite the fact that all of the digital stories were placed on a distribution DVD, the DVD was not publicly released because there was concern that 2 of the 9 stories would not be well received and that they could potentially cause problems for the organizations involved in the workshop. One story was about racism and implicated a specific organization, which drew concern from a supporting organization that this could potentially lead to legal troubles. The other story was about the sexualization and objectification of female African asylum seekers, which caused concern among some of the supporting organizations.

In the end, aside from their inaugural showing at a local and international film festival, these 2 storytellers chose to not publicly release their stories. Both were cognizant of organizational concerns and of their own vulnerable positioning. Owing to funding constraints, it was difficult to recreate a DVD

to omit the 2 stories. Thus none of the stories has been widely distributed, despite 7 of the storytellers giving full rights for their distribution. This was an especially disappointing outcome for the other workshop participants, who had hoped to have their stories received by a broader audience.

In the case of digital storytelling work for which there are often expectations about the creation of public stories, the process of obtaining consent to release stories can be challenging to say the least. Most consent forms specify blanket release of materials for all time, failing to take into account the possibility that stories may change for storytellers over time, as the priorities of their lives evolve and change. The researcher or practitioner must carefully balance the wishes of funders and project partners and the concerns of workshop participants. Questions to ask of the release-of-materials process include: What timeframe does the release cover? How can participants be given the option to request an out if they initially agree to publicly release their stories but decide later that they do not want the stories to be circulated? How can funders and community partners be educated about the importance of including such an option? What is the best way of addressing the limitations of such an out, when it comes to the online distribution of stories? What happens if participants simply want to edit or change their story?

Requesting consent to air a story in a public forum (such as on a website or in a public exhibition) raises different issues than does requesting consent to show a story solely within the closed environment of a workshop setting or to use the story as a source of data for analysis in a peer-reviewed publication. We suggest that the request for consent to release stories should never be viewed as a one-time process but rather should be woven throughout a project. For example, researchers and practitioners can first raise the implications of publicly sharing personal information or images in a digital story when they are recruiting workshop participants; again when participants agree to make stories; yet again when narratives are being shared in a story circle and crafted in scripts; and still again when participants are making decisions about what images to include or not include.

Story release decisions can then be more appropriately reached at the end of a project. At this time, researchers and practitioners must review with participants all possible options for story distribution, verbally and in writing.

CONCLUSIONS

Recognizing digital storytelling workshop participants as "knowers" offers public health researchers and practitioners the potential to disrupt commonly accepted hierarchies between experts and members of local communities. When stories are produced and distributed in local settings, digital storytelling also subverts the economics and power relationships of traditional mass media creation and circulation. The method affords special opportunities for building more ethical relationships between research institutions, community organizations, and the communities they study and engage, by creating forums where workshop participants learn about, interrogate, and ground research and media ethics in their own experience.

Just as using digital technologies can make research more accessible to a wider range of audiences, it can also add new dimensions to the social and ethical relationships between researchers, their interlocutors, and other key stakeholders. Gready's call for a responsibility to story⁵⁷ evokes a core tension of participatory digital research and practice methods like digital storytelling. Digital storytellers are often told that the research or media-making process can potentially benefit them because it encourages reflective conversation, catharsis, and empowerment. Although this may be so, public health researchers are also clearly conducting the work for data collection and analysis purposes, and public health practitioners are engaged with an eye toward the impact that the process can have on participants and the stories can have on viewers. The tension lies in negotiating means and ends. How can researchers make use of a digital storytelling workshop as a forum for conducting ethnographic research, incorporating participant observation and field notes, individual and group interviews, without getting in the way of the participants' experience of the workshop? And how can public

health researchers and practitioners involved in social change work bring a critical eye to the ways in which participatory media strategies like digital storytelling and its end products may or may not be useful elements of this work?

A specific approach is for workshop organizers or researchers to articulate clear goals for supporting the production and sharing of stories in ways that aim to improve the lives of workshop participants and their communities, at the same time acknowledging ethical complexities of the process and outcomes. Useful examples can be found in Wallack et al.'s media advocacy work in public health,⁶² which employs media as a tool for advancing progressive policy agendas, and in the work of Gregory et al. at WITNESS,⁶³ which intentionally links video creation and distribution to specific goals for human rights promotion. Even though a discussion of the ethics of sharing digital stories with viewing audiences is beyond the scope of this article, we believe that researchers and practitioners have a responsibility to disclose content information to viewers prior to a screening, prepare them to watch highly sensitive content by offering information about self-care, and debrief story screenings so that viewers who may have been unsettled or deeply affected by difficult content have a chance to share their feelings and achieve closure before leaving an event. We suggest that this responsibility applies to both electronic and in-person methods of story distribution.

Clearly, when it comes to ethically using participatory visual and digital methods like digital storytelling in public health research or practice, both process and end products must be considered. Examples from our own digital storytelling work highlight the need to focus especially on the means—the process—to ensure a safe, enjoyable and meaningful workshop experience for participants, rather than solely on the ends—the digital videos—that are so often enunciated as measures of success.

Ethical engagement in public health research and practice is an ongoing, iterative, and complex process. Rather than positioning ethics as an introductory component to a project—a one-off occasion of gaining consent—ethics must be understood as a process that involves ongoing dialogue among all stakeholders

about how best to design and implement an ethically responsible project. Although we do not claim to have covered every possible scenario, we do hope that the issues raised and examples provided will stimulate discussion and debate within the field, as it is important to continually explore who benefits and how from public health interventions.⁶⁴ At the very least, and particularly in the context of research, we need to grapple with what Menzies terms the “situated practice of ethics” for conducting respectful research:

Mastering this form of respect—proper consent forms, arranging informed consent, filling forms and completing ethics applications—is only the first step. Putting our words into action, this is the real content of respect.⁶⁵

We offer these considerations for ethical practice in the spirit of encouraging other public health researchers and practitioners undertaking this work to do so in ways that make this action possible. ■

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A. C. Gubrium wrote the initial draft of the article. A. L. Hill contributed to the second draft of the article and added case study examples from her own work to elaborate on key points. S. Flicker worked with the 2 authors to reframe the article around the 6 ethical issues and added case study examples from her own work to elaborate on key points.

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