

Beyond Compliance Checking: A Situated Approach to Visual Research Ethics

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Abstract Visual research methods like photography and digital storytelling are increasingly used in health and social sciences research as participatory approaches that benefit participants, researchers, and audiences. Visual methods involve a number of additional ethical considerations such as using identifiable content and ownership of creative outputs. As such, ethics

committees should use different assessment frameworks to consider research protocols with visual methods. Here, we outline the limitations of ethics committees in assessing projects with a visual focus and highlight the sparse knowledge on how researchers respond when they encounter ethical challenges in the practice of visual research. We propose a situated approach in relation to visual methodologies that encompasses a negotiated, flexible approach, given that ethical issues usually emerge in relation to the specific contexts of individual research projects. Drawing on available literature and two case studies, we identify and reflect on nuanced ethical implications in visual research, like tensions between aesthetics and research validity. The case studies highlight strategies developed in-situ to address the challenges two researchers encountered when using visual research methods, illustrating that some practice implications are not necessarily addressed using established ethical clearance procedures. A situated approach can ensure that visual research remains ethical, engaging, and rigorous.

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Introduction

Visual methods and artwork such as photography, body mapping, participatory video, murals, filmmaking, and digital storytelling are increasingly used in health and social sciences research (Wiles et al. 2012; Packard

2008; Murray and Nash 2016). These creative contributions are acknowledged as having benefits for participants, researchers, and audiences alike, which include the potential to open up new spaces for conversation and ways of understanding social life (Howell et al. 2015), as well as empowering participants from traditionally stigmatized and marginalized groups to define the narratives and processes of research (Hannes and Parylo 2014). Visual research has facilitated “engagement with alternative modes of knowing and understanding ... to reach beyond the academy” (Nunn 2017, 1) and privileged alternative sources of knowledge. Such research employs tools that involve producing still or moving images, depictions, or creative outputs either as data or to generate meanings in relation to a given research topic and can be collected for both stand-alone and mixed-methods studies (Cox et al. 2014). Most projects are participatory, where individuals are engaged not just as mere “subjects” or participants but as co-creators of new knowledge (Lenette 2017; Nunn 2017). Visual research methods commonly involve a distinct set of continually debated ethical considerations given the audio-visual nature of the data gathered, produced, and disseminated using such tools and the processes involved (Boydell, Solimine, and Jackson 2015; Cox and Boydell 2016; Guta et al. 2014).

Visual methods emerge from the distinctive epistemological “worldview” of arts-based, interpretive, qualitative research (Cox et al. 2014), which are in many ways incommensurable, or at least an uncomfortable fit, with the positivist and quantitative approaches that often dominate health and medical inquiry in particular. As noted by Pitt (2014):

[I]t is common for social and educational researchers to work from a variety of epistemological, methodological and ethical positions, and yet in Australia, as elsewhere, [Human Research Ethics Committees] are required to consider all research proposals—regardless of epistemology and methodology—against the positivist biomedical research model as a gold standard.

While many qualitative research methods like in-depth interviewing and focus-group discussions are more readily deemed as legitimate by ethics committees—often seen as complementary to quantitative methods—other more innovative approaches like visual methodologies are more likely to trigger opposition or lukewarm reactions as they involve different ways of

thinking about what counts as research data and what meets established requirements of ethical and rigorous research. Ethics committees are attempting to navigate cultural dissonance between interpretivist and positivist approaches (as well as critical social and postmodern paradigms) and translating across these “different worlds” in health research contexts in particular (Belgrave, Zablotzky, and Guadagno 2002; Kuper, Reeves, and Levinson 2008). There are often tensions in the way interpretivist research protocols are assessed, which led us to question how ethics committees consider projects using visual methods. Perhaps more concerning is the relatively limited literature on how researchers draw on particular sets of guidelines when faced with unexpected and at times difficult situations in the practice of research (see, for instance, Guillemain and Gillam 2004), particularly in visual research projects. Indeed, Yassi et al. (2016) argue that there are many instances where ethical concerns linked to arts-based research have remained completely unexplored, even when identified as important. This paper aims to address both the limitation of Human Research Ethics Committees (HRECs) in assessing projects with a visual focus and the sparse knowledge on how researchers respond to ethical challenges in visual research practice.

Ethical Review of Visual Research

Independent ethical review was established as an international norm for clinical research in the 1975 revision of the *Declaration of Helsinki* and subsequently developed for other types of research. The purpose of ethical review is to subject research protocols to examination by an expert group that is independent from researchers (and participants) to approve, reject, or propose amendments. This way, HRECs can ensure that the values underpinning research projects under ethical review align with established guiding principles. In Australia for instance, research involving human participants must comply with the *National Statement on Ethical Conduct in Human Research* (“the National Statement”) (National Health and Medical Research Council [NHMRC], Australian Research Council [ARC], and Australian Vice-Chancellors’ Committee [AVCC] 2007 (Updated May 2015)). Members of HRECs are expected to have read, understood, and be able to apply the principles of the National Statement to research protocols and defend any amendments requested by reference to specific requirements emerging from these principles. The National Statement

is intended to cover human research across all disciplines but recognizes that there are situations where it cannot offer specific guidance or to which its application may be uncertain. In such instances, researchers and ethics committees are directed to seek out other guidelines and codes of practice that are consistent with the National Statement (NHMRC, ARC, and AVCC 2007), which gives researchers the opportunity to refer to guidelines that are directly relevant to their research. However, this is not helpful for formal ethical review and obtaining approval from HRECs, who are required to implement the National Statement rather than apply other sets of guidelines in their assessment of protocols. In practice, many institutional HRECs have developed templates that meet the requirements of the National Statement in relation to consent, participant withdrawal, confidentiality, and disclosure of relevant information, and researchers are required to adopt these templates for individual studies. This “deductive,” positivist determination process using standardized guidelines and templates seems misaligned with the dynamic and iterative nature of ethical issues arising in situ.

Ethical review is then, in part, an exercise in “checking compliance” or risk management with a more or less standard set of guidelines, adapted to the needs of particular studies that fit the scope of work generally reviewed by committees, to ensure there are no obvious breaches to participants’ rights and safety (Guillemin and Gillam 2004). When HRECs function in this way, and where a researcher’s methodology diverges significantly from “standard” projects, there are heightened risks that HREC members may interpret such methodologies as non-compliant with established systems or as “unethical” research (Pitt 2014), rather than recognizing that standard guidelines are not suitable for all forms of research. This is concerning for projects conceptualized outside standard biomedical research models and where consideration of particular methods and contexts is crucial, given, for example, the breadth of approaches in participatory visual research methodologies (see, for instance, Boydell et al. 2012). Given these tensions and challenges, ethics committees often impose constraints on researchers undertaking visual research that are at odds with the methodologies and participatory focus (Allen 2009; Pitt 2014; Gubrium, Hill, and Flicker 2014). Thus, procedural ethics have been externally imposed on (qualitative) projects and “disquiet about the appropriateness of this has periodically been expressed” (Guillemin and Gillam 2004, 264). Some

scholars have described how HREC members may be “unfamiliar with qualitative methods and in some cases, may be antagonistic toward this type of research” (Guillemin and Gillam 2004, 263), compounding the assessment framework even further. This is not to say that there are no new or significant risks with, for instance, widespread dissemination of online information that need to be carefully considered. However, managing such risks should be integrated in current protection frameworks and safeguards, rather than trigger suspicion about the research.

For researchers, ethics procedures are often seen as “a formality, a hurdle to surmount to get on and do the research” and for which they develop “ethics-committee speak” (Guillemin and Gillam 2004, 263). However, the review process also acts as an important reminder of the centrality of research integrity and the need to implement projects soundly without causing harm to participants or researchers. We suggest here that there is more complexity to fully comprehending ethical issues associated with research protocols, particularly when using visual methods. For example, it can be equally important to discuss “when a breach of confidentiality might be ethically required” (Guillemin and Gillam 2004, 264) as it is to know how to maintain confidentiality, given the nature of data collection and dissemination strategies in visual research. There are a number of useful international ethics guidelines for researchers, such as the British Sociological Association’s *Statement of Ethical Practice* (2017), or the *International Visual Sociology Association’s Code of Research Ethics and Guidelines* (2009)¹ that specifically address issues relating to visual research. Such documents, however, are removed from formal institutional processes.

Researchers commonly identify specific ethical issues in their proposed research and introduce strategies to mitigate harms, for example, critically engaging with participants about realistic benefits and potential risks of participation, providing cultural safety and supports, and establishing guidelines for risk management and harm reduction (Gubrium et al. 2014). Despite this, when ethics committees apply less nuanced frameworks in assessing protocols involving visual methods, this can result in requiring amendments (such as de-identifying arts creations) that could compromise the proposed research rather than improve it or reshape the research

¹ See https://www.britisoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf and http://visualsoctology.org/?page_id=405.

design to fit a particular model (Pitt 2014, Allen 2009). Researchers must decide whether to challenge specific requests or recommendations or comply to obtain approval and proceed with their projects (Allen 2009, Pitt 2014). More importantly, there is also a risk that HRECs may overlook or fail to recognize critical ethical issues that could arise for participants, researchers, or audience members, due to lack of familiarity with the intricacies of visual-based research. As the case studies below illustrate, it is not unusual for unforeseen ethical issues to arise once projects are underway (Yassi et al. 2016; Murray and Nash 2016), highlighting the need for reflexive and iterative approaches to minimizing harm that goes beyond the planning stages (Cox et al. 2014). As such, visual researchers may not be well supported by HREC processes when they encounter unforeseen ethical issues, which may compromise research quality in practice.

In response to the specificities of visual-based research, Cox et al. (2014) developed guidelines to assist researchers and ethics committees to effectively consider and address the range of ethical issues linked to visual methods—both in design and implementation. These include issues of authorship and ownership, anonymity, and confidentiality, “dangerous emotional terrain,” and interpretation (see also Yassi et al. 2016). However, there remain a number of knowledge gaps regarding how ethical guidelines such as these can be effectively translated across research contexts and supported in practice, including when unforeseen ethical issues arise. For instance, we know little about whether and how such guidelines are used by researchers using different forms of audio or visual research in different contexts or by HRECs in decision-making. It is also unclear how guidelines on ethical visual research are adapted to the sensitivities specific to different fields and whether currently available guidelines retain relevance over time, given the continuing transformation of visual data sets and art forms, and the rapid development of apps and technology that yield new research methods. This lack of robust discussion warrants a deeper exploration of approaches to ethical visual research to understand the nuances and practicalities specific to visual methodologies.

Of particular interest to our team researching ethics across diverse contexts are the tensions inherent to health and social science research and visual research in particular. The gap our paper seeks to address is not in the development of ethical guidelines for visual research, as thoughtful guidance is already available

(see, for instance, Cox et al. 2014; Guta et al. 2014; Yassi et al. 2016). Our concern is primarily a procedural one: How can HRECs ensure they are adequately skilled to interpret and apply ethical guidelines thoughtfully and appropriately to projects using visual research methods? How could researchers draw on such resources when they encounter unexpected situations requiring careful consideration of tensions in the field? We draw on available literature and two case studies in which two researchers who co-authored this paper, CL and KB, identify and reflect on nuanced ethical implications. The case studies highlight a discrete set of issues and challenges encountered in situ and strategies developed prior to and throughout projects using visual methods. This way, we illustrate a number of practice implications that are not always adequately addressed using established ethical clearance procedures.

Method: Case Studies

We present two brief case studies as a method of capturing contemporary perspectives on the topic, in the context of our short-term funded project aiming to explore the ethics of visual-based research in health and social sciences research. CL and KB were asked to answer the same set of open-ended questions as part of a reflexive approach to ethics in practice (see Guillemin and Gillam 2004; Yassi et al. 2016) without any specific definition of ethical issues, allowing their own interpretations to emerge. CL and KB designed the questions based on the literature review. KB (respondent 1) is a professor from Canada now working in Australia with extensive experience in visual research who has published widely on the topic. CL (respondent 2) is a mid-career researcher in Australia with growing experience with and publications on visual methodologies.

Case Study 1

Briefly explain the extent of your experience using visual research methods I have been using visual methods in my research (knowledge creation and knowledge dissemination) for the past two decades—the first was in the context of a study on access to mental health services for children and youth in rural communities. We had a budget for knowledge translation at the end of the research and thought that we would host a policy forum—our advisory committee queried the efficacy of doing

that and we decided instead to partner with the film department at the local rural university (Laurentian University, Sudbury, Ontario) to create a fifty-two minute documentary film (*Lost in the Woods*) featuring the narratives of two of our family member research participants. This film was used in rural communities in a “town hall” type forum to share research results with service providers, families, and other stakeholders. It was also picked up by a number of community colleges for teaching in social work. Since then, I have drawn on research-based dance, digital storytelling, found poetry, mural art, body mapping, and other arts-based genres in the research process as a knowledge translation strategy.

What do you particularly value about using visual research methods? I believe that the visual is of critical significance—humans actually process visual information 60,000 times faster than textual information—so, for me, as a knowledge translation/research translation strategy, that is of utmost importance! Visual methods have the power to illuminate the human dimensions of health and illness (in my research area) in ways that lower interdisciplinary boundaries and improve our understanding of health and social care. Visual methods offer a unique way of engaging diverse stakeholders on important issues—they enhance our understanding through their focus on experiential and interactive aspects of the phenomenon under study. Visual methods can produce key embodied and affective responses for both participants and audiences over and above only cognitive understanding of any given topic.

What do you find particularly challenging or constraining? The funding landscape is always a challenge—the “legitimacy” of engaging in this work and what “counts” in academia—particularly as a researcher in a department of psychiatry/in medical research. The time-consuming nature of the work is also often challenging for both researchers and participants. For example, in creating a research-based dance performance depicting the results of a qualitative study on pathways to care (described below), the process of co-creation took six months and involved many meetings between the creative and research teams to discuss the findings of the study and to create the choreography and musical score to accompany the performance.

What are some of the ethical issues or dilemmas you have encountered in your research and how have you

managed or overcome those? I was involved in a project that led to the co-creation of a mural by young people with psychosis, which raised ethical issues in relation to confidentiality, anonymity, and potential harm. The project was used as an opportunity to visually depict help-seeking experiences of young people with psychosis. We were required by the ethics committee to maintain the anonymity of the young people involved, which led to some debate by members of the team. Some felt that promoting anonymity was perpetuating the stigma of mental illness, especially when several participants were not averse to having their names included in the public domain. However, other members had concerns about identifying individuals and the possibility of causing harm, including into the future. Because we had already promised anonymity to our ethics review board, we took a photograph that depicted the entire group of participants holding the mural up and having just their faces showing from the eyes up, not identifying them but still providing a sense of ownership. The young people who were keen to continue involvement participated in the dissemination events and accompanied the research team to schools where the mural project was installed and were key to our presentation panel and talkback sessions. Another project that comes to mind is a research-based dance project, which raised concerns regarding the potential for audience misinterpretation and potential harm, as well as tensions between aesthetic qualities versus research validity. The project involved in-depth examination of pathways to mental healthcare for young people experiencing psychosis and the creation of a dance performance as part of this. Issues arose when deciding between the aesthetic qualities of the performance and its content, though a decision was made by mutual agreement to maintain the integrity of the performance. However, when performed at an international symposium, alternative audience interpretations that were at odds with our initial intentions were evident. Whilst the team had concerns about this and felt that the dance had the potential to perpetuate stigma, we also recognized that an important aspect of the dance was to encourage dialogue and open discussions about the topic with the audience.

What are some of the key principles that guide your approach using visual research methods? Our team recognizes the big “E” and little “e” ethics—procedural ethics and everyday ethics encountered in the field (and

often unanticipated at the outset of any study)—from the work of Guillemin and colleagues at the University of Melbourne. Principles that guide the approach of my colleagues and me are linked to the ethical issues encountered in past research: (i) the ethics of authorship and ownership of arts-based intervention processes and products, (ii) the right of acknowledgement versus protection of anonymity, (iii) the ethics of “dangerous emotional terrain,” and (iv) the ethics of representation. Overcoming some of these ethical dilemmas has been the topic of many of my co-authored publications, where we have outlined our own specific strategies for dealing with these issues. Examples include: (i) creating working agreements about ownership within the research team and with participants to reflect the needs and sensibilities of all. This is approached as a procedural ethical issue, with flexibility to reflect and adapt as conditions require; (ii) if future consequences are properly explained in a manner that is understood by participants, they should be allowed to make the choice regarding whether or not they want to be identified—and have the right to change their mind during the research process (this is often something that has to be negotiated with the HREC); (iii) artists/researchers should have permission to explore emotionally-charged topics as long as they are trained to deal with potential problems and have informed support available for everyone involved including the artists/researchers themselves; training is key; we have written about this issue in particular and reflected on our experience of the dancers who took on the experiences of youth with psychosis—what were the potential negative/upsetting consequences for the dancers? We ensured lots of safe space to encourage reflection and well-being of all members of the team; and (iv) take preliminary “results” back to participants for feedback. Another strategy is to establish a monitoring process for the group during the interpretation process.

Case Study 2

Briefly explain the extent of your experience using visual research methods I started using visual research methods in fieldwork for my PhD ten years ago, and focused on photo-elicitation, photovoice, and digital storytelling. My topic was resilience and well-being of refugee women from a sociocultural perspective. I wanted to do more than merely interview participants about their perspectives on these concepts. I hoped that

the process would be as interesting and engaging for them as it was for me, and it turned out to be a great first research experience. Digital storytelling in particular was fascinating to me and I have since used the method in other projects with newly resettled refugee women who raise children alone. I have also focussed on analysing visual representations of refugees and asylum seekers and their influence on public opinion and policy. Delving into the world of visual research methods has led me to consider other research approaches in refugee health and well-being, such as engagement in community music, body mapping, and filmmaking.

What do you particularly value about using visual research methods? There are two important aspects that I appreciate the most about using such methods. First, it is much more engaging for participants (and researchers) to be offered the opportunity of having a creative element in a research project. For so long, researchers had a “dip in, dip out” approach, where participants were expected to answer a series of (at times very personal) questions in terms of what was needed *for the research*. With visual methods, there is a much more dialogical, reflexive process involved in the creation of stories, and there is broader potential to promote participant agency and respect their wishes about the meaning of the research. Participants can also retain ownership of what is “produced” (i.e., the short film or body map). The very process of engaging with visual means to talk about concepts that are often abstract or sensitive can have beneficial aspects for participants, which is even more important when English is not a first language. Second, in this day and age, we need to come up with more creative and impactful ways of conveying research findings to broader or more diverse audiences. Visual methods offer different angles on topics that have often been studied at length without achieving the desired impact or effecting meaningful policy change. Researchers with a concern for genuinely participatory research are increasingly turning to new ways of telling narratives collaboratively to challenge traditional ideas about knowledge creation.

What do you find particularly challenging or constraining? By far the biggest challenge for me is to have the legitimacy of this approach questioned, even among social sciences audiences. This makes it very difficult to apply for competitive funding when the effectiveness and beneficial dimensions of the approach

are not recognized, particularly for projects that rely entirely on visual methods for data collection. As a more immediate effect, my applications for ethics clearance for projects involving visual methods always require further information from HRECs, even when I have been meticulous and detailed in my outline of ethical concerns, strategies to mitigate impact, and my rationale for using identifiable methods. Second, despite the benefits, the use of such research methods requires more time, which can become too demanding for participants and researchers alike. The emergence of new visual data sets such as social media posts or large media platforms means that we contend with new challenges and do not always have strategies in place to comprehensively understand the implications of using these data sources. Finally, the question of whether and how visual research methods and outputs can influence policy directions is still opaque—in some fields more than others. In my field of refugee studies, there is still a long way to go in terms of knowledge translation and concrete policy changes.

What are some of the ethical issues or dilemmas you have encountered in your research and how have you managed or overcome those? Two examples come to mind. Both are drawn from the process of undertaking a digital storytelling project with newly arrived refugee women, for which ethical approval was granted. As the project was part of a larger, three-year research project, casual assistants were employed to undertake the practical aspects: a research assistant (RA) prepared the ethics application and variation prior to implementing the digital storytelling project (which I reviewed and approved) and a facilitator with prior experience with the method was engaged to oversee the development of the digital stories. One issue regarding participants maintaining ownership of the movies emerged towards the end of the process. The facilitator wanted to work with a smaller group of women than planned and spent many more hours than anticipated with each woman to develop the digital movies. While some great stories were produced, the allocated budget was expended quickly, and the facilitator concluded her involvement. A few months later, the RA discovered that one of the participants never saw the end product or received a copy and as such had declined to participate in follow-up stages. We immediately arranged for her to be given a copy of her movie, and we apologized for the oversight. We checked with other participants whether

they had had the opportunity of providing feedback on the finalized version and received copies of their movies (which they did). We also debriefed as a team about the implications of this oversight. A second issue arose because of the process employed to generate ideas for participants' digital narratives. Because of her prior experience, the facilitator wanted to meet each participant one-on-one; however, the research team had also committed to hosting a workshop involving all participants. The workshop became very difficult to organize. A university campus was chosen as the venue because it was cost-neutral and had IT facilities; however, two participants declined to attend when they realized the workshop would be held on a Saturday. Even though costs of travel were covered, it still involved too much time for these participants to attend. Another issue arose when interpreters were cancelled at the last minute when participants declined to attend. We were therefore unable to ensure equity in participation at the workshop; in the end, only the participants who did not have children to care for, did not work, or lived relatively close, were able to attend. Additionally, the one-on-one meetings were dependent on participants' availability (and rightly so) and represented another time commitment that became hard to negotiate over time. This remains a tension that is difficult to resolve without compromising the digital storytelling process itself.

What are some of the key principles that guide your approach using visual research methods? It is important not to fall into the trap of seeing visuals as accurate representations of participants' lived experiences. While "closer" representations of realities may be possible compared to other methods like, for instance, surveys or even interviewing, it is still a "preferred story" that is used to convey specific messages at the time the narrative is created, and it is up to participants-as-protagonists to decide on the structure and content. How the methods are used should be centred on participants' wishes, and the research agenda should not overpower that. We already set parameters at some level because of accountability to funders and institutions, but if participants do not guide the research and it does not have a clear purpose to them, the research outputs may become hollow. The "aesthetics" (while important to engage with audiences) should not be the focus; rather, it is about participants' narratives and particular aspects

of their lived experiences. Sometimes, the only audience that matters is the participant her/himself. Participants own the “outputs,” and concerns for how others may perceive the “product” may not be relevant. Researchers act as facilitators to achieving desired outcomes, which are negotiated with participants. It can be tempting at times to showcase the outputs that participants produce to wider audiences; however, it is up to participants to decide who should be their audiences. In past experiences, where academics, research students, or community-based practitioners have asked to view participants’ digital stories, they have been somewhat surprised by the idea that the stories belonged to the refugee women I collaborated with and were not for public broadcast. However, this element of ownership is a critical aspect as it is based on relationships of trust. Conversely, researchers also have the responsibility of ensuring participants are fully aware of some of the more opaque ethical implications of wide dissemination over time and beyond national boundaries. Finally, the soundness of identifying participants in visual outputs can be questioned at times, but being guided by participants’ input means that I always respond to how they want to represent themselves. Very often, this means that they want to be identified, as it is their story, and they want to own it fully. Anonymity would be inappropriate in those cases where being identified is actually a way of exercising agency.

Discussion

Ethical considerations relating to practices and processes involved in visual research are increasingly documented in the literature (Boydell et al. 2012; Pitt 2014; Gubrium et al. 2014) and highlighted in the examples above. Both case studies point to similar challenges, including having the legitimacy of the approach questioned, encountering difficulties in obtaining funding and receiving ethics approval, and the approach’s time-consuming nature. While there is certainly a place for rigorous assessment of research protocols deploying visual methods, there is still much scope to strengthen ethics procedures to ensure that projects with a visual focus are regarded as having value and a legitimate source of knowledge,

while also recognizing the specific protections that ought to be in place.

However, there is a growing trend to expand and intensify the activities that HRECs regulate,² and this climate of conservatism in ethics processes may in fact be particularly detrimental to projects using visual research methods or other creative means. One of the consequences of increasingly formalizing research ethics processes is that the contours of the realms of “following the rules” (i.e., “compliance-check”) and “acting ethically” can become blurred, leading to growing tensions between rigorous assessments of projects using visual methods (and appropriate resources to do so) versus researchers’ ethical responsibilities and research integrity. This is not unlike concerns in other fields where adopting an overly risk-averse approach can deny opportunities to examine insights from the perspectives of those affected and to adopt more participatory and equitable approaches. Some have described this gap as “quite a gulf between procedural ethics and ‘ethics in practice’” (Guillemin and Gillam 2004, 269). Importantly, “following the rules” and “acting ethically” are not mutually exclusive; there is more continuity between “procedural” and “ethics in practice” than one might think, given that the latter is actually an extension of the former (Guillemin and Gillam 2004). This common ground between the two is useful when considering how guidelines for ethical visual-based research can be implemented effectively, although explicit discussions on the topic remain rare.

A key issue arising in the practice of research is that ethical concerns can become evident at different stages of the process, depending on whether it is related to generating data, gathering and interpreting evidence, evaluating outcomes, or disseminating findings. Ethics approval as an institutional requirement—usually in the form of a one-off, pre-recruitment review of research plans and documents, along with minor modifications along the way that are typically submitted for noting and refinement—is deemed sufficient irrespective of project duration (regular reports and variations are important to signal and address emerging issues but may also fall into the category of “compliance-check”). However, as some of the examples discussed above suggest, it may be that researchers are not prepared or well-equipped to respond to at times complicated concerns by different stakeholders at different points in the process, well after

² Haggerty (2004) coined the term “ethics creep” to describe this trend.

ethics approval is granted. Some researchers have taken the initiative to draw on their own expertise to address this gap and have come up with their own recommendations (like Cox et al. 2014; Yassi et al. 2016). For example, in response to the growing use of arts-based health research and the lack of ethical guidelines in this space, a workshop was held in Canada in September 2011 to bring together an international group of scientists to identify and submit examples of ethical concerns they encountered in their research. These were collated and summarized: authorship/ownership of the work; “truth,” interpretation and representation; informed consent/anonymity/confidentiality; dangerous emotional terrain; and issues of aesthetics (Boydell et al. 2012). Similar examples are now well documented in the literature and include resolving conflicting priorities or approaches among research team members, maintaining participant confidentiality and anonymity when appropriate, finding a balance between aesthetic quality and content of end products, ensuring equity in participation, ensuring participant ownership and seeking approval for end products, and avoiding potential harm throughout and beyond. What remains striking is the gap in alignment between these key issues in visual research and the more “compliance-check” approach of HRECs. For example, in Yassi et al.’s (2016) account of key ethical issues in arts-based research, it was observed that some Indigenous participants in digital storytelling projects were hesitant to sign written consent forms because they felt that these were tools of colonialism, and so, in practice, witnessed spoken consent would be deemed more respectful.

Additionally, entrenched issues of power dynamics, where research/er agendas can overpower the processes despite best intentions, can limit participants’ meaningful engagement, especially if researchers fail to engage in reflexive processes to consider the more nuanced ethical issues that may emerge in their research practice (see Yassi et al. 2016). The blurring of roles and purpose, particularly on what constitutes “research” and what is the creative practice (while there are overlaps) can also become problematic, as can the issue of raising false expectations about potential project outcomes. Yassi et al. (2016, 201) argue that, in addition to the lack of knowledge on how various ethical issues in the literature (such as informed consent and anonymity) interrelate, many issues in arts-based research more broadly “have not yet been fully unpacked let alone critically theorized.” Consequently, researchers

deploying visual methods can often find themselves in situations where they are caught off-guard and with limited resources to draw on.

Based on our combined research expertise in health and social sciences, case study reflections, and review of the literature on ethical visual research in these disciplines, we have identified two immediate procedural issues that deserve prompt attention. First, while researchers may be conversant with the specific ethical issues raised by their proposed research and introduce strategies to mitigate harm to participants, HREC members commonly apply a less nuanced ethical framework to evaluate such projects. As noted previously, this may result in HRECs requiring amendments that could compromise the research rather than enhance its value and sensitivity to participants. Second, HRECs, particularly those without any training in the specific ethical issues raised by visual research methods, may overlook or fail to recognize critical ethical issues that could arise for participants, researchers, or audiences, due to unfamiliarity with their methodologies. The standardized approaches that most HRECs (have to) adopt can in fact do little to assist researchers when they encounter the subtle, and at times emotionally taxing, ethical situations that they may not be well equipped to address (Guillemin and Gillam 2004). This may leave researchers uncertain as to where to seek further advice to tackle the issues encountered promptly, and depending on the context, they may have to make independent decisions on how to manage such issues as they occur, as “[u]ltimately, responsibility falls back to the researchers themselves—they are the ones on whom the conduct of ethical research depends. Arguably, procedural ethics has little or no impact on the actual ethical conduct of research” (Guillemin and Gillam 2004, 269). The kinds of ethical issues of concern here are *situated* and emerge in relation to the specific contexts of individual research projects and as such, may be difficult to pre-empt. Since HRECs cannot possibly cover absolutely every ethical aspect of visual research projects, we suggest that they may require a different approach to the usual one-off, pre-recruitment review of a research protocol and associated documents that is currently the norm.

A Situated Approach

The two key issues identified above highlight the compliance focus of ethics committees compared to the approach of researchers who work outside the standard

biomedical research model and need and seek flexibility, such as visual researchers. Pitt (2014) has argued that HREC codes in Australia for instance should be rewritten to not only accommodate but also enable and support researchers to develop a research ethic appropriate to the epistemological approach, design, and context of their research. This certainly has implications for HREC members, who are the “implementers” of such codes, particularly those who may be largely unfamiliar with visual research methods. Thus, further guidelines and training for HREC members to manage the protocols that incorporate visual methods would be essential to acquire the appropriate skills to assess such proposals. There are additional options to consider so that the responsibility for rigorous assessment of visual research projects does not fall entirely on institutional HRECs. These include:

1. National ethics organizations could establish a specific, carefully trained, nationally based HREC to review applications for research projects that use visual methods. Any institutional HREC could then refer protocols to this committee and be assured of an appropriate standard of review within reasonable timeframes.
2. National ethics organizations could train a selected group of researchers with an interest in visual methodologies from different regions, and these researchers could be used as “resource people” or consultants to be co-opted by institutional HRECs on a case-by-case basis to assist their review of such protocols (perhaps for a small fee and without overburdening them). Researchers planning projects using visual methods or encountering ethical issues with the implementation of visual methodologies could consult with these trained personnel in their locality.
3. Individual researchers using visual methodologies could be trained on the specific issues arising in visual research and placed on a national database. Institutional HRECs could, as required, request a specialized pre-review of a specific protocol (similar to the scientific advisory model that some HRECs use). This could be recognized as part of their professional contribution to the field and to the academy or as a form of professional semi-accreditation in their respective disciplines.
4. Chief investigators leading projects using visual methodologies should be strongly advised to set up advisory committees with representative

memberships, for instance, community leaders from the participant group as expert advisers, as well as non-government and government practitioners and research officers; such committees could address “micro” ethical tensions that arise on the ground for quick resolution, rather than relying entirely on institutionalized HREC processes, particularly for time sensitive issues. There are existing models (such as the Family Planning New South Wales advisory committees, and Human Research Ethics Advisory panels at University of New South Wales that review low-risk ethics applications focusing on particular research areas) that could be replicated for this purpose.

More generally, HRECs and visual researchers have joint responsibility in addressing the issues raised in this paper. More open and honest communication between HRECs and researchers can serve as a form of knowledge exchange to avoid ongoing adversarial positioning.

Conclusion

The overarching issue identified is a concern for whether HRECs are equipped to deal routinely with research projects using visual methods and to support researchers and participants in such endeavours. Our review of the literature on this topic identified that ethical challenges differ according to the research stages of generating data, gathering and interpreting evidence, evaluating outcomes, or disseminating findings. The absence of specific guidance on the ethical evaluation of research using visual methodologies in formal guidelines, the increased reliance in institutional standardization in ethical review processes, and the significant qualitative differences between research projects that adhere to normative researcher–participant paradigms and those where participants are co-producers both of art, creative outputs, and of research-generated knowledge adds up to a system that may fail to provide optimal ethical review, evaluation, and guidance. We propose a situated approach in relation to visual methodologies that encompasses a negotiated, flexible approach to informed consent, anonymity, and confidentiality to ensure that such research remains ethical, engaging, and rigorous. We echo the call from Guillemin and Gillam (2004) for more reflexivity when considering ethics in practice.

Further research is warranted on gathering the perspectives of HREC members about the approaches used when assessing research using visual methods and the mitigating strategies. Researchers who are proficient in managing projects with visual-based elements and those who have been reticent to incorporate such methods in their research thus far should engage in further interdisciplinary dialogue to continually share and pre-empt some of the issues linked to “everyday” ethics or “microethics” (Yassi et al. 2016) that can at times be brushed under the carpet. It would also be useful to explore some of the emotional challenges researchers may experience (Dickson-Swift et al. 2009) when faced with particularly complex ethical dilemmas when using visual research methods and how they maintain research integrity in such situations. More importantly, participants who have experienced meaningful involvement in visual-based research should be invited to reflect—to be shared with decision-makers—on positive as well as more problematic aspects (such as issues of anonymity) to identify what works particularly well in projects with a visual focus. Collating and sharing the range of strategies employed in different settings would add to the potential approaches to be considered by researchers, HRECs, and specialized committees. This would help inform future endeavours and provide another platform for participants to express their views about what matters in knowledge creation through visual research.

References

- Allen, L. 2009. “Caught in the act”: Ethics committee review and researching the sexual culture of schools. *Qualitative Research* 9(4): 395–410.
- Belgrave, L.L., D. Zablotzky, and M.A. Guadagno. 2002. How do we talk to each other? Writing qualitative research for quantitative readers. *Qualitative Health Research* 12(10): 1427–1439.
- Boydell, K.M., C. Solimine, and S. Jackson. 2015. Visual embodiment of psychosis: Ethical concerns when performing difficult experiences. *Visual Methodologies* 3(2): 43–52.
- Boydell, K.M., T. Volpe, S. Cox, et al. 2012. Ethical challenges in arts-based health research. *International Journal of the Creative Arts in Interprofessional Practice* Spring Supplement (11): 1–17.
- Cox, S., and K.M. Boydell. 2016. Ethical issues in arts-based health research. In *Creative arts in public health: International perspectives*, edited by P. Camic and L. Wilson, 83–91. London: Oxford University Press.
- Cox, S., S. Drew, M. Guillemin, C. Howell, D. Warr, and J. Waycott. 2014. *Guidelines for ethical visual research methods*. Melbourne: University of Melbourne.
- Dickson-Swift, V., E.L. James, S. Kippen, and P. Liamputtong. 2009. Researching sensitive topics: Qualitative research as emotion work. *Qualitative Research* 9(1): 61–79.
- Gubrium, A., A.L. Hill, and S. Flicker. 2014. A situated practice of ethics for participatory visual and digital methods in public health research and practice: A focus on digital storytelling. *American Journal of Public Health* 104(9): 1606–1614.
- Guillemin, M., and L. Gillam. 2004. Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry* 10(2): 261–280.
- Guta, A., S. Flicker, R. Travers, et al. 2014. *HIV CBR Ethics fact sheet #4: Ethical issues in visual image-based research*. Toronto, Ontario.
- Haggerty, K.D. 2004. Ethics creep: Governing social science research in the name of ethics. *Qualitative Sociology* 27(4): 391–414.
- Hannes, K., and O. Parylo. 2014. Let’s play it safe: Ethical considerations from participants in a photovoice research project. *International Journal of Qualitative Methods* 13(1): 255–274.
- Howell, C., S. Cox, S. Drew, M. Guillemin, D. Warr, and J. Waycott. 2015. Exploring ethical frontiers of visual methods. *Research Ethics* 10(4): 208–213.
- Kuper, A., S. Reeves, and W. Levinson. 2008. An introduction to reading and appraising qualitative research. *BMJ* 337: 404–409.
- Lenette, C. 2017. Using digital storytelling in participatory research with refugee women. *Research Methods Cases* (SAGE online).
- Murray, L., and M. Nash. 2016. The challenges of participant photography: A critical reflection on methodology and ethics in two cultural contexts. *Qualitative Health Research* 27(6): 1–15.
- National Health and Medical Research Council, Australian Research Council, and Australian Vice-Chancellors’ Committee. 2007 (updated May 2015). *National statement on ethical conduct in human research 2007 (updated May 2015)*. Canberra: Commonwealth of Australia.
- Nunn, C. 2017. Translations—generations: Representing and producing migration generations through arts based research. *Journal of Intercultural Studies* 38(1): 1–17.
- Packard, J. 2008. “I’m gonna show you what it’s really like out here”: The power and limitation of participatory visual methods. *Visual Studies* 23(1): 63–77.
- Pitt, P. 2014. “The project cannot be approved in its current form”: Feminist visual research meets the human research ethics committee. *Australian Educational Researcher* 41(3): 311–325.
- Wiles, R., A. Coffey, J. Robison, and J. Prosser. 2012. Ethical regulation and visual methods: Making visual research impossible or developing good practice? *Sociological Research Online* 17: 1.
- Yassi, A., K. Lockhart, L. Fels, and K.M. Boydell. 2016. Ethics in community—university—artist partnered research: Tensions, contradictions and gaps identified mid-way in a 5-year multi-institutional “arts for social change” project. *Journal of Academic Ethics* 14(3): 199–220.