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Crippling the Ethics of Disability Arts Research

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Negotiating artistic research within university strictures reveals a number of tensions: tensions around what we reveal and what we conceal, who we are as researchers and human beings, and tensions related to offering anonymity and confidentiality while giving due credit. As feminist academics committed to social justice, we struggle to negotiate these tensions in a way that prioritises the needs and desires of participants. We also recognise that institutions require researchers to conduct our research in particular ways. Rules and regulations about ethical conduct developed out of a desire to protect participants and researchers (Gray, Cooke, & Tannenbaum, 1978); in practice, however, they often leave us wondering about whose interests they serve and how they shore up boundaries between who is researcher and who is participant in research contexts.

In this chapter, we engage with tensions that arise between following university ethics protocols and co-producing research with participants, in particular, artists with disabilities (including mobility, sensory, psychiatric, cognitive, learning, illness related, and more). We offer two case examples to illustrate complexities of voice, anonymity, and confidentiality. In these examples, we explore: (a) occasions when standard Research Ethics Board (REB)

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protocols regarding anonymity and confidentiality contravene participants' desire for recognition as artists; (b) processes of consent, including the possibility of conceptualising consent as continuous and in flux; and (c) issues of voice, representation, and aesthetics in the production of arts-based research. These case studies emerge from our work at Re•Vision, an art and social justice research centre at the University of Guelph in Canada, in which we conduct multimedia storytelling workshops and have co-created a research-based drama, *Small Acts of Saying*, with non-normatively embodied and enminded research participants.

Our work is necessarily embedded in institutional histories in which disabled body-minds have been put on display or hidden away (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015); we found that in this context, participants may not always desire anonymity and confidentiality and may prefer contingent and continuous processes of consent in which they co-determine the time frame, space, and audience for their art. We do not offer definitive or universal solutions to those ethical conundrums we have encountered, in fact, we hesitate to provide prescriptive instruction for fear of inscribing fixity for necessarily fluid processes. Instead, we discuss how to move beyond 'tick-box' approaches to working ethically with disability communities. We adopt a disability justice perspective which we understand to mean being led by people with disabilities, pushing against ableist practices/representations/systems in our work processes/outputs, and 'cripping' or attending to and embracing the difference that disability makes to ethical decision-making in artistic research (Chandler cited in Reid, 2015, para 7). Crippling ethics, as we understand it, involves orienting to disabilities, not as differences that delimit or confound ethical processes but as complex embodiments, including visible and invisible mind-body attributes, which, through challenging normative standards of the human undergirding conventional ethical frameworks, expand possibilities for ethical conduct by opening the field of decision-making in research. In this way, our discussion provides a jumping-off point for further exploration of the meaning and implementation of 'cripping' ethical principles in and beyond academia.

Re•Vision

Re•Vision, an assemblage of arts-based research projects led by Dr Carla Rice, is an initiative funded by the Canadian Institutes for Health Research (CIHR) and is designed to speak back to dominant representations of disability using arts-based methods, including multimedia storytelling and research-based drama.¹ Throughout the CIHR project, people with disabilities and health-

care providers (not mutually exclusive groups) created over hundred 2–5 minute films about their experiences. Participants made films at workshops in which we worked together to generate stories that centred on the makers' voices. We adapted our workshop structure from StoryCenter's method of bringing people together to tell their stories using a digital format (Lambert, 2013). Additionally, Re•Vision incorporated facilitator trainings, wherein disability-identified individuals were trained in workshop facilitation; these facilitators then led subsequent workshops, including healthcare providers as participants. By making their own self-reflexive films, researchers themselves became research participants; some also identified as members of Disability Arts communities beyond Re•Vision.

As Re•Vision's work progressed, an emphasis on Disability Arts and on incubating the Disability Arts community emerged (Chandler et al., [under review](#); Rice, Chandler, Liddiard, Rinaldi, & Harrison, 2016). Filmmakers and facilitators often came from, went to, or created Disability Arts communities before, during, and/or after their engagement with Re•Vision. Disability Arts communities comprise self-identified D/deaf, Mad,² and disabled people creating art, often but not always about the experience of disability; these communities move beyond a social model of disability, and they advocate primarily for the removal of barriers by advancing the participation of people with disabilities as producers, creators, audience members, and participants in artistic work, and in the creation of a disability culture (Chandler et al., [under review](#)). Project films have been screened for audiences ranging from healthcare providers to film festival attendees at arts festivals and in community theatres, in classrooms, and at conferences.

Thematically, the films challenge dominant medical models and representations of body-mind difference, including the troubling legacy of the specialisation of disabled bodies in reference textbooks and as cases for experimentation and medical fascination (Garland-Thomson, 2007). They engage with storytellers' preferred perspectives on and representations of their lives. Healthcare provider stories similarly challenge dominant narratives, due in large part to disabled people's leadership, facilitation, and encouragement of providers to explore the role that mind-body difference plays in their own lives (Rice et al., 2015).

Re•Vision also developed a research-based drama *Small Acts of Saying*. The play was an ensemble performance designed to challenge accepted notions of disability that create healthcare barriers. Based on the devised theatre method (Milling & Heddon, 2005), the play was developed collaboratively by a disability-identified director and disability/difference identifying Re•Vision participant-performers. Performed for several audiences in the Northern

hemisphere during the Fall of 2014, the play treated themes of embodied knowledge and reimagined 'accessibility' in the healthcare context.

Arts-Based Research

Broadly, arts-based research incorporates methods that integrate artistic expression into the building of the understanding of phenomena. Arts-based methods are often conducted in a community-facing, participatory manner, in which artists and participants either train in research processes or otherwise work in close proximity with researchers to enact research (Rice & Mundel, [forthcoming](#)). In our case, we also troubled the boundaries between researchers and researched, inviting researchers to become implicated in the creation of art and engage in self-reflexive artistic practices. Participatory arts-based methods, like other community-based/participatory research methods, have in common a commitment to re-envisioning 'expertise' and challenging researchers to work *with*, rather than *on* or *for*, participants (Israel et al., [2003](#)). They do so by conceptualising research processes as being equally as important as research outcomes; creativity and flexibility are valued in these methods (Boydell, Gladstone, Volpe, Allemang, & Stasiulis, [2012](#)). Arts-based research has the possibility of creating social change in and beyond the groups that conduct this research; the processes and products are commonly emotionally evocative and act as creative explorations of what it means to live in the world and in a body in a particular way (Finley, [2014](#)). Doing research in this way allows us to explore spaces in between how participants have been imagined by others and how they would prefer to imagine themselves (Rice, Chandler, & Changfoot, [2016](#)).

Multimedia storytelling is an arts-based method that has been used in educational contexts and research spaces (LaMarre & Rice, [2016](#); Rinaldi et al., [2016](#)). It invites participants to tell their stories in a flexible multimodal medium; participants give voice to their stories, while simultaneously visually imagining them. The method opens up space for stories without words, stories that operate on multiple sensory registers, and stories that leave us wondering. They invite participants to 'speak from the flesh, to create and represent through the flesh and to construct and interpret their identities in mind and body' (Benmayor, [2008](#), p. 200). Participants do not make stories in a space devoid of social meaning; however, stories are created for an audience in a time and place. Accordingly, just as these stories carry with them individual and social histories, so too do they carry the spaces that surround their creation. Tensions of voice and purpose in storytelling have surfaced in our

prior explorations of the impacts of the method on participants and audiences alike (e.g., Mykitiuk, Chaplick, & Rice, 2015).

Case Study 1: Ethics of Confidentiality, Anonymity, and Acknowledgement

Many, though not all, of the workshops conducted through Re•Vision included participants who self-identified as artists either before or after the workshops. Some participants are self-identified artists and/or curators of disability arts; they bring works of art from where they are created to where they are viewed, moving from the (relatively) private sphere of artistic production to the public sphere of artistic viewing. Curation involves 'bring[ing] different cultural spheres into contact' (Obrist, 2014, p. 24). In so doing, curators disrupt the gaze as it has been traditionally imposed upon people with disabilities who have been seen as spectacles or as examples in medical contexts and elsewhere (Rice et al., 2017).

The importance of the curatorial tradition within the disability context cannot be overstated, in terms of both the ability to select and to portray certain aspects of self and to choose which aspects of bodily self to display (and to whom). Even, or particularly, when disabilities are not visible, the display/portrayal of complex embodiments and enmindments is an act of curation and is often socially governed by someone other than the person with the disability. A biomedical brush paints disabilities as: abnormalities, conditions requiring intervention and cure, and aberrances caused by defective biology. In medical textbooks, people with disabilities have been used as examples of 'rare' or 'abnormal' conditions; as 'befores' on the way to 'fixed' or 'cured' body-minds; or as examples of the incurable, the tragic, or the diseased (Garland-Thomson, 2012). Disabled bodies were (and still are) displayed in parts: faces covered with black boxes, identities concealed under the auspice of ethical conduct. This dehumanised representation of disability in which people are reduced to the parts of their body-minds deemed defective, resembles the spectacularisation of disability beyond the clinic or medical text, in historical 'freak shows' and contemporary mass media alike (Sandell, Dodd, & Garland-Thomson, 2010), a representation that people with disabilities, including artists, have actively challenged. As Gay, with Fraser (2008), writes: 'Disabled people throughout the world are engaged with a long and complicated struggle with the way we are portrayed and the meanings attached to these portrayals that include disability as stigma, as a sign of a damaged soul, as being less than human, as dependent, weak, sexless, valueless' (p. 21).

Many participants were troubled by the idea that to be included in Re•Vision's work they needed to adopt a pseudonym or have their identities concealed. This is not surprising, given the entwined legacies of being put on display or hidden away in institutions and homes with which disabled people have had to contend (Rice, 2014). Often, creators preferred to use their real names and to own the artwork produced. Particularly when films were screened at film festivals or art shows, participating artists asserted their unquestionable right to be recognised for their work and some took up leadership roles in curation in more than a conceptual sense.

Revealing storyteller identity is 'a central aspect of making a political statement about a group', an especially salient task when those making the art are from misrepresented communities (Mykitiuk et al., 2015, p. 379). This is also an important part of reconfiguring roles in research encounters or at least attenuating asymmetrical power relations between researcher and researched. The job of defining boundaries between researcher and researched and establishing the overall direction and meaning of the project traditionally falls to the researcher (Scantlebury, 2005). Researchers working from feminist/critical perspectives commonly attend to power dynamics in research relationships by working to facilitate participant comfort with data collection protocols and by working relationally (Blodgett, Boyer, & Turk, 2005). Researchers oriented towards community-based methods often work actively to share power, inviting participants to help decide on research directions, questions, and analysis (Banks et al., 2013). In Re•Vision, participants and researchers were not mutually exclusive categories: researchers became participants and participants became researchers at various stages of the research processes. Still, we were conscious of the multiple roles we brought into the space; power distribution remained unequal despite our 'cripping' of the roles of researcher and researched.

Arts-based research carries its own set of ethics considerations, including authorship, ownership, interpretation, and aesthetics, as well as more standard ethical considerations like informed consent, anonymity, and confidentiality, and the emotion that might emerge from the conduct of research (Boydell et al., 2012). The issue of artistic ownership and acknowledgement is particularly relevant to Re•Vision artist-participants and has surfaced in and after our workshops. Lafrenière, Cox, Belliveau, and Lea (2013) question the ultimate ownership of artistic research: is a piece produced by an artist in the cadre of a research project an artistic product or a research output, or both? Who might be credited, and whose CV and career does the production enable? Boydell, Volpe, et al. (2012) offer a solution wherein the artist owns creative research pieces once they have engaged with it; however, this is not an

easy stance for all researchers to adopt as some argue that ‘protecting’ research participants entails minimising artist ‘ownership’ of ‘products’ (Lafrenière et al., 2013). These examples, however, apply to arts-based research projects wherein artists engage in knowledge translation/dissemination of previously conducted research, or when the artist is not himself or herself a participant in the research process. In our multimedia storytelling workshops and in the research-based drama, participants were themselves the artists, though the identity of artist itself carries particular complexities, and not all participants conceptualised themselves in that way.

Playing an active role in framing their work was particularly important to those who identified as artists beyond the storytelling space. Filmmakers were eager to add the films to their CVs and to share their work in order to contribute to the growing Disability Arts movement in Canada (Chandler et al., [under review](#)). A major part of being seen as more than a spectacle but as a human being with desires, preferences, and occupation, involves being more than a research participant. Given the problematic legacy of conducting research *on* people with disabilities, some artists agreed to participate in the research only because of its artistic components; many brought critical awareness of the ableism typically embedded in research practices and the need to ‘crip’ decision-making processes. It makes sense, then, that creators, as a condition of participation, would seek to control not only the content of the representations (and the conditions under which they were made) but also their screening and wider dissemination.

Despite our embrace of the disability justice principal that artist-participants have the right to self-identify as artists/creators, research ethics protocols frequently made enacting this commitment challenging. At the beginning of the project, this kind of research was novel for the REB with whom we were working. We went through many rounds of revisions with the REB in finalising our ethics protocols. We were initially asked to do things that were in conflict with our commitments to enact truly criped ways of doing research. For instance, we were asked to obscure the identities of all people in the multimedia stories, pixelating faces and rendering voices unrecognisable. This REB was using standard ethical guidelines to justify their need to maintain participant anonymity in order to protect against disclosures of participants’ experiences to those who might be in a position to impact on their lives in negative ways. Here, the expectation that anonymity would be preserved eerily echoed the legacy that would reduce people with disabilities to ‘abnormal’ or pathologised body-minds.

Another request that reproduced ableist logics, or re-inscribed the power of the non-disabled researcher and conflicted with disabled participants’ control

of their representations, was the expectation that researchers would not get to know or develop friendships with participants beyond the workshop space and would not re-contact participants after the project's end. These expectations foreclose the research relationship to the research encounter, conflicting with a deeply held disability justice-grounded commitment to a continual, processual, and dynamic perspective on ethics that is based on relationships, reciprocity, and trust. Because of the problematic legacy of using the stories and bodies of people with disabilities to prop up the careers of researchers and uphold deeply ableist notions of normative humanity, there is a particular need to build reciprocity and trust in research relationships with disability communities. Being unable to re-contact participants subsequently minimises the possibility for building the Disability Arts community and puts the power of decision-making around screening the stories and framing the art into the hands of researchers.

Terminating contact with participants further presumes that participants' stories are fixed and static rather than fluctuating and changing with subjectivities. It minimises the possibility of envisioning consent as an ongoing dynamic process that may change as participants change. While informed consent has been a cornerstone of research ethics, its adoption in conventional research protocols positions the process of obtaining consent as something that is done prior to research contact and closed after a signature has been obtained. When consent is described as a process, this generally extends only to the length of the study; in projects such as ours in which outputs may be screened or performed long after the research has 'closed', we question the need to close consent with study closure. After all, the stories participants tell at one moment may not fit in the future. When this individual is a disability-identified artist practising on ableist terrain, they may assert the need for greater control over which versions of their selves they present through art into the future.

We learnt the rubs between procedural and processual ethics through experimentation and failure. Even with our knowledge of the harms done to those with disabilities in research and our commitment to crippling the process, we did not fully account for the inaccessibility of the ways in which research ethics can be inscribed onto research process. We think it is important to acknowledge how our awareness of the limitations of procedural ethics came partly through our inability to anticipate all possible ethical conundrums that arise in this kind of research. Standard ethics procedures have their place, especially in preventing the more overt or generally acknowledged violations of participants (such as in the now infamous Tuskegee Syphilis Experiment, when researchers withheld critical life-threatening/-saving information from

participants). These procedures were designed to avoid *repeating* ethical misconduct and are updated to reflect the ever-changing nature of ethical conduct. Acknowledging the dynamic, ever-changing nature of ethics would be a helpful step towards envisioning a more accommodating ethics process.

Every time participants alerted us to the discomfort they felt with participating in research as prescribed, we learnt new ways of approaching the ethics process that would be open to disability and enable a radical processual ethics. For instance, through failing to account for the need to be able to re-contact participants before screening their work, we learnt that we needed to state explicitly in our ethics protocols that we would offer participants the opportunity to revisit their consent throughout and beyond the project. Through the REB request for pixilation, we discovered that we needed to introduce some critical theory into our research ethics requests, highlighting the history of the representation of disability as an assembly of abnormalised parts rather than a self-represented whole. We continue to grapple with tensions that emerge between participants' preferred self-identification as artists and curators of their experiences rather than as research participants. This unresolved tension leads us to wonder, each time we distribute consent forms to participants, about the process of agreeing to participate in research and what that means for creators in terms of personal risk and perceived safety in research.

Case Study 2: Voice and Staging in *Small Acts of Saying*

Our research-based drama, *Small Acts of Saying*, similarly brought up ethical tensions with which we continue to grapple. Mykitiuk et al. (2015) detail how disabled artists reclaim the stare through talking back to the spectacularisation of disabled bodies and minds in *Small Acts of Saying*; the play explores audience reactions to arts-based research in which artists intentionally put disability on display. In this case study, we reflect on curation in the process of choosing which stories to tell in the context of the play, noting again the performer awareness of audiences and possible readings of their performances. A review by Boydell, Volpe, et al. (2012) offers us a starting point for interrogating the ethical tensions of voice and representation but largely assumes that the creator(s) of the artistic piece and the research participants are different people. Both dynamics operated for us because we had research participants who were performers, as well as a disability-identified director who had directorial discretion in determining the overall aesthetic presentation of the play.

In *Small Acts of Saying*, we wondered about the selection of the stories to be told which were, necessarily, a fraction of the sum total of participants' lives and embodied realities, as well as about potential conflicts between the aesthetic and representational visions of the director and between various storytellers. The play was grounded in the expectation that all people involved would have a role in determining its devising and direction, following the tradition of devised theatre (Milling & Heddon, 2005). And yet, within the tradition of theatre, where the director's job is to lead, some voices are inevitably more dominant than others and aesthetic decisions sometimes conflicted with political positions and research aims.

Here, we see how accessibility requirements might conflict when negotiating voice/vision in the context of research-based drama as well as how aesthetics, research purposes, and researcher/performer politics can arouse tension. For example, the director conceptualised large boxes to signify performers' medical files as a major part of the denouement of the dramatic action. Storytellers moved through space to engage with these boxes. Though the director envisioned the file box as an important part of the play's action, the devise paradoxically imposed normative ways of moving onto some cast members who struggled to carry their boxes. One cast member tripped and fell during a rehearsal. Despite this challenge to normative ways of moving, the director felt strongly about the presence of the boxes for the play's aesthetic integrity and elected not to alter the aesthetic.

We do not present this tension as either a breach of ethics or as a power struggle but as an illustration of how multiple visions and accessibility requirements simultaneously operate in disability arts research. Using the framework of accountability in emancipatory disability research, Barnes argues that 'to be accountable to the entire disabled population would be impossible' (2003, p. 7). Access needs will necessarily come into conflict as we navigate artistic and research spaces in collectivity. Participants came into the space as people who had lived experience of being pathologised, controlled, and monitored in many contexts, as did the director, a disability artist who took up a position not previously open to individuals with disabilities. Boydell (2011) comments on how performers may experience the emotional ramifications of engaging with challenging subject matter; in this case, however, rather than those without lived experience, performers with situated realities and lived experiences were re-exploring their own experiences and emotions. Reconciling various accessibility requirements is complicated by conflicting research, aesthetic, and political aims. At times, the commitment to present an aesthetically sophisticated piece contravened the bodily realities of performers. These tensions also take shape through constraints imposed by the (neoliberalised) research apparatus itself,

which necessitates the production of a polished art piece within the prescribed period, thereby imposing pressures on performers to attend all rehearsals, to be on (normative) time, and to tell stories in a certain amount of time, and so on. (Rice & Mundel, [forthcoming](#)). From a disability justice perspective, these constraints emerge as ethically problematic and reveal the limits of attempting to crip the arts through arts-based research.

For performers, telling stories is not necessarily enough to ensure that all voices are heard in the way that they all want them to be heard. As with multimedia stories, the play is delivered to audiences who have their own preconceived notions of performers' lived realities, perceptions that necessarily impact on their listening (Dion, 2009). The words are not delivered into an empty space of understanding but are filtered through ideas about what performers might be saying. For example, one of the performers crafted a narrative designed to be humorous commentary rather than responding to the humour in the piece; however, audiences read the story as inspirational. This response was possibly tethered to a preconceived understanding of people with disabilities as tragic victims or heroic survivors. Audiences, particularly medical audiences, are largely unused to hearing stories directly from people with disabilities that may actually have little to do with their pathologised 'condition', stories that may just be funny. Particularly in a play like *Small Acts of Saying* in which stories ranged from funny to angry to sad, audiences may not have been prepared to shift their reading beyond the conventionally told stories of disability.

Elsewhere, we have considered the 'problematic of audiences', in terms of both how vulnerable stories might do harm to audiences and how audience responses may do harm to storytellers (Mykitiuk et al., 2015). Storytellers might fear that their stories will become 'psychologised' or be misunderstood; this is particularly true for individuals whose stories have been repeatedly psychologised. An REB response to this concern might be to encourage anonymisation of performers, or else have those without lived experience represent or dramatise the work. From a disability justice perspective, this re-inscribes ableist logics underpinning most disability representations (which position disabled people as research participants or allow for disability's humanisation only when portrayed by non-disabled actors) rather than embracing crip logics which work to ensure that people who embody difference are recognised as performers, artists, and researchers. Audiences may not be ready to hear stories just as performers with disabilities wish, however. The performer whose funny story was misread described how in the past they made what they now consider 'bad art' in order to get people to listen; they told a story that would make audiences feel included. In *Small Acts of Saying*, they delivered a different kind of

story and that was mis-read. This leaves the disability-identified artist in the uncomfortable position of being, as they put it, a pedagogical commodity for the telling of disability in a capitalist, artistic twenty-first century, rather than an artist.

Conclusion

Research ethics protocols were built out of necessity to help researchers avoid doing harm to those with reduced power in the research encounter. Without being open to difference, however, REBs lack, at times, the improvisational stance required when working differently with body-mind difference. Particularly in arts-based research, we have engaged in continual negotiations with REBs in order to do our work in a way that cripps ethics. In enacting disability justice-oriented arts research, we have attempted to invite new ways of conceptualising the researcher-participant relationship and the role itself of the 'participant'. We entered into this work with our own ideas about what might be involved in conducting ethical disability arts research. As we have moved in these spaces, we have inevitably failed. Through failure, we have reimagined how to do this work in a way that corresponds with a crippled ethic, welcoming a plurality of experiences and ways of being.

Negotiating issues of voice, anonymity, and confidentiality is made complex by research 'as usual'. Particularly when participants have a history of being slotted into boxes or dis-assembled into component parts, further imposing checkboxes, black boxes, and aesthetic boxes can have negative impacts on experiences of research. Through the cases of multimedia storytelling and research-based drama, we have offered critical examples of times during which participants challenged the given standard ethics protocols. In both cases, we grappled with issues of anonymity and confidentiality against a burgeoning Disability Arts community in Canada. Many participant-artists engaged with the project under the condition of being identified as artist. Pixelating faces, assigning pseudonyms, and showing multimedia stories in the contexts of researchers' choosing contravene the expectation that artist-participants actively collaborate in the research from start to finish, and as such has the potential to recolonise disabled people's stories as research products.

In the context of research-based drama, the development, staging, and performance of *Small Acts of Saying* raised issues of voice and audience interpretation. It also alerted us to the impossibility, under ablest neoliberal logics, of completely resolving conflicting accessibility requirements and conflicts

between aesthetic, research, and political aims when ensemble casts, researchers, and directors work together to speak to audiences. This is held in tension against participant-performer desires for representation on their own terms in ways that acknowledge their unique artistic contributions to the ensemble. Here, we witness how rehearsed responses to ethical conundrums cannot acknowledge the complexity of disability and other arts research. A 'quick fix' for the potential for emotional harm on the part of the performer would be to have others perform their words, thereby abstracting them from the audience and protecting their identities. Doing so, however, would require us not to acknowledge artists' contributions.

Finally, arts-based research means creating a product that is more fixed and final than subjectivities and experiences. The stories that participants tell are not representative of the entirety of their experience which are in continual flux. In presuming that one-time consent can stand for the duration of the screening or performing of stories neglects to acknowledge the contextual, process-based nature of consent. Offering the opportunity to revisit consent and opening multiple options for levels of consent have acted as provisional ways of engaging with artist-participants to work towards a fuller acknowledgement of how circumstances and orientation to creative pieces can and do change and shift as time goes on.

We consider a process-based orientation to ethical engagement with participants to be preferable to one that fixes ethics to a set of forms and procedures set out at the beginning and closed at the 'end' of a research project. This has meant, for us, ongoing negotiations with both REBs and participant communities. It has meant a contextualised consideration of ethics including the ethical harms done to groups in the past in the name of 'protection'. We underscore the imperfection of this work and the unfinished nature of the engagement with ethics itself. As we continue to conduct this research, we will inevitably stumble upon ways in which we could more closely attend to the ever-changing needs, conditions, and understanding of participant communities.

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Notes

1. This project received ethics approval from the Research Ethics Board at the University of Guelph in 2012 (certificate number 12AP010).
2. We use the terminology ‘Mad’ to refer to art produced by and related to the experiences of users or former users of mental health services and other people with non-normative ways of thinking and feeling. An evolving interdisciplinary field, Mad Studies offers critical inquiry into mental health and madness in ways that foreground the oppression, agency, and perspectives of Mad people, past and present, as well as in diverse cultural contexts, to challenge dominant understandings of ‘mental illness’.

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