


# Sex Work Research, Ethics Review Processes, and Institutional Challenges for “Sensitive” Collaborative Research

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## Abstract

This article examines challenges and barriers seemingly endemic to the research ethics review process. We argue that these challenges and barriers disempower community stakeholders in sex work research and that they put our studies and those who consent to participate in them at risk. To advance this position, we interrogate three of our own encounters with research ethics boards (REBs) in the context of current scholarship on meaningful collaborative research and REB roles and responsibilities in relation to sex work and other sensitive research. As these encounters illustrate, there is an urgent need for established REB processes to be opened up to allow for and respect non-academic expertise. We suggest that such policy and process revisions are particularly important given the growing requirement for meaningful stakeholder involvement in all aspects of studies that engage marginalized groups. In this new anti-oppressive collaborative framework, stakeholder community expertise thus informs study development and design, as well as the collection and analysis of data, and decisions regarding where and how study findings are to be shared. Research ethics review processes must be revised accordingly to acknowledge and give due consideration to community-based expertise. We conclude by proposing institutional and community-based strategies for resisting and revising current research ethics review structures and processes. Applying the lens of where stigma to select REB encounters, this article contributes to existing research about ethical and anti-oppressive sex work research methods and methodologies, arguing that we must account for REB encounters in the growing body of theory that seeks to understand and articulate how best to conduct sex work research in partnership with sex workers.

## Keywords

community-based research, ethical inquiry, feminist research, social justice, Participation Action Research, marginalized communities, sex work, research ethics boards, institutional review boards

A growing body of research and associated policies advocates meaningful involvement of stakeholder (and particularly marginalized) communities in the design, development, and administration of the research that affects them. Despite this reality, and the associated inclusion of non-academic, or “community-based” researchers on research teams, university Research Ethics Boards (REBs)<sup>1</sup> and their protocol review processes continue to prioritize the knowledge and experience of university-based researchers. As such, research ethics review processes create challenges and barriers for effective community-based research, particularly when such research is undertaken with partners from marginalized communities and depends on the knowledge and expertise of those partners to ensure that participant risks in research are minimized, and

that studies are meaningful and non-exploitative for stakeholder communities.

This article examines such challenges and barriers in the research ethics review process that (a) dehumanize and

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threaten to disempower sex workers, even in community-based/collaborative academic research, and (b) fail to support researchers, to promote ethical studies, and to protect study participants. Drawing from three examples of encounters with different REBs at Canadian research universities in the course of two multi-part, multi-year sex work research projects, we examine how REB failure to respect or account for community researcher knowledge and expertise—in these examples a failure refracted through whore stigma and myths about sex work/ers—threatened the stability and hard-won cohesiveness of our research teams, advocated more risky, less ethical protocols than the ones recommended by our community partners, and put our studies themselves at risk of failure. We note that REBs currently do not have policies requiring that they acknowledge and account for the expertise of community researchers. We thus conclude by proposing strategies to resist and change current REB processes and practices to reflect the realities of current community-based collaborative research.

Canadian academic researchers are required to abide by the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*. The most recent version of this policy statement is known as TCPS2 (2018). TCPS2 (2018) is 223 pages long and includes a collection of policies for preparing ethical studies each of which also includes directions for REBs evaluating each of these aspects of study protocols. Significantly, TCPS2 encourages collaboration between researchers and community partners, recommends elaborate consultation with those involved in research (TCPS2, article 4.7, p.53), and provides detailed instructions to REBs for the evaluation of collaborative studies (eg. TCPS2, article 10.1, p.136–137). Feminist anti-oppression, anti-colonial, and anti-racist research guidelines are even clearer on these points: reciprocal relationships, trusting partnerships, and prolonged community collaboration are integral to conducting this kind of research (Beckman, 2014; Bromley et al., 2015; Brown & Strega, 2015; Gaventa & Cornwall, 2006; High, 2009; OCAP, 2007; Smith, 1999; Wilson, 2008).

What we have discovered, however, is that REBs, the applications we submit to them, and the exchanges we engage in with them continue to prioritize academic knowledge and expertise. In the cases we discuss here, such structures resulted in exchanges with REBs wherein our non-academic community researcher, an integral member of our project management team, was not only ignored in REB communications, but also quite clearly imagined as a study participant, not study co-director. We argue that research review processes must be brought into alignment with both TCPS2 (2018) and established international anti-oppressive collaborative research methods and methodologies.

## The Importance of Community Partnerships

Over the past two decades, an increasing number of researchers have collaborated meaningfully with sex workers in sex work research. Here in Canada, established sex work

researchers Benoit & Shaver emphasized fifteen years ago the need to “go beyond the standard moral and criminal views of ‘prostitution’ that have been topics of Canadian and media fascination for decades” (Benoit & Shaver, 2006, p.243). Many Canadian researchers have come to recognize and support politicized sex workers’ “struggle to be understood as knowledge producers, not simply as objects of research or study” (Van der Meulen et al., 2013, p.3; see also Durisin et al., 2018; Hunt, 2010, 2013, POWER, 2012). In addition, scholarly discussions here in Canada (Benoit et al., 2020; Lebovitch & Ferris, 2018; Parent et al., 2013; POWER, 2012; Shaver, 2005; Van der Meulen, 2011) and internationally (Agustin, 2007, 2004; Argento et al., 2011; Baratosy & Wendt, 2017; Hardy et al., 2010; International Committee on the Rights of Sex Workers in Europe [ICRSE], 2015; Kim & Jeffries, 2013; Global Network of Sex Work Projects [NSWP], 2021, 2004; Wahab & Sloan, 2004) have emphasized the importance of collaborative participant-centered harm reduction research wherein academic researchers partner with sex workers in all stages of research, including study design, methodologies, data analysis, and dissemination of results. Collaborative studies with sex workers and other hard-to-reach communities significantly facilitate the recruitment of larger, more diverse and representative participants (Benoit et al., 2020) and produce more valid and reliable data (Agustin, 2004; Baratosy & Wendt, 2017; Benoit et al., 2020; Longo, 2004). More broadly, community-based and participatory research is described as highly valued by research institutions across Canada. For example, this is clearly expressed by the institutional strategic plans of many Canadian universities (Simon Fraser University, n.d.; University of Alberta, 2016; University of Toronto, 2018) as well as by the federal research granting body the Social Sciences and Humanities Research Council of Canada and the Canadian Institutes of Health Research.

## Research Ethics Review Boards and “Sensitive” Research

Recent scholarship examines issues encountered in ethics review by qualitative researchers doing sensitive research (Bowen & O’Doherty, 2014; Bromley et al., 2015; McCracken, 2020). Discussing the positivist frameworks through which research ethics review practices in the West have developed, ethnographer McCracken (2020) notes that REBs evaluating collaborative studies “can potentially harm participants and co-researchers—most especially when they solidify the power differential that exists between “researcher” and “subject” (p.4). In other words, REBs put studies and researchers at risk when they fail to account for variation on research teams, including the study leadership and expertise that community researchers contribute on collaborative participatory projects.

We set out to consider in more detail how already complicated, even fraught, processes for research ethics review can

disproportionately affect sex work researchers, regardless of the membership of their/our research teams. This is a particular concern for student and early career researchers, of course, but has wider reaching effects for all qualitative researchers working on “sensitive” projects. The descriptor “sensitive” applied to certain areas of research comes from US-based shield laws that protect confidentiality for sensitive issues studies, including but not limited to as follows:

- Research on HIV, AIDS, and other STDs [*sic*];
- Studies that collect information on sexual attitudes, preferences, or practices;
- Studies on the use of alcohol, drugs, or other addictive products;
- Studies that collect information on illegal conduct;
- Studies that gather information that if released could be damaging to a participant’s financial standing, employability, or reputation within the community; and
- Research involving information that might lead to social stigmatization or discrimination if it were disclosed (qtd in Palys & Lowman, p.267).

Indeed, considering the high stakes of sensitive research projects, a greater consideration of the impact of REBs on research practices and participants is necessary.

Work that has been done to date is instructive in informing our own perspectives about both the complexity and potentially negative consequences of sex work research and REBs. For example, ethnographer Sanders (2006) notes, “one of the first stumbling blocks for the researcher (especially students) is gaining approval for the project from the internal institution’s ethics committee” (p.451). Ethnographers Pérez-y-Pérez & Stanley (2011) attribute similar barriers to “strong stereotypes and potential dangers” connected to the sex industry. Like Sanders, they note that protocols for sex work studies are “over scrutinised and charged with queries that expect more insight from the novice researcher” than might reasonably be expected (Sanders, 2006, p.453). Dewey and Zheng (2013), also ethnographers, note that sex work studies are often rejected outright by REBs because of the risks assumed to be attendant to sex work. Sanders and Pérez-y-Pérez & Stanley credit such processes with encouraging deeper researcher reflexivity. Dewey and Zheng (2013) advise us to scrutinize and engage more deeply in methodological justifications of the risks and benefits of our research when preparing our research protocols. McCracken (2020), also an ethnographer, advises researchers on sensitive studies to spend time educating REBs.

While we do not dispute the benefit to junior researchers of reflecting on research protocols to ensure their ethical application, the seemingly ubiquitous extended exchanges between sex work researchers and REBs require further interrogation, particularly in terms of how they can compromise or discourage sensitive research. Criminologists Palys and Lowman (2010)<sup>2</sup> argue REB’s policy

interpretations can stymie sensitive research, influencing especially junior or early-career researchers to “water down their research objectives” (p.265) or “conduct ‘vanilla’ research because they are unwilling to spend the time it takes to negotiate with REBs in order to be able to conduct research on sensitive topics” (p.266). Palys & Lowman point to the ways such practices result in REBs functioning as an unwitting “state-sponsored instrument for sanitizing potentially controversial research” (p.266). One solution to the troubling patterns we analyze in this article is the formal revision of REB protocols and practices to reflect the contemporary realities of collaborative research, especially for studies undertaken with marginalized communities.

Some scholars have highlighted the tensions evident in REB decision-making between management of risks in sensitive research and of risks sensitive research can represent for institutions. Analyzing two case studies, one of which involves an REB overtly discouraging a junior researcher from doing sex work research, social scientist Hedgecoe (2016) points to the disturbing ways that REBs operate as reputation managers for research institutions. McCracken (2020) reminds us that REBs “protect human subjects, and they also serve to protect academic institutions from potential lawsuits that could emerge as a result of research” (p.4). McCracken nonetheless notes that REBs evaluating sensitive research, including her own with incarcerated participants, too often privilege risks to the institution over participant protection. Both Hedgecoe (2016) and McCracken (2020) argue that without specific policies directing otherwise, REBs can (and do) operate to discourage sensitive studies that may bring “bad press” to institutions, rather than to protect study participants against the real risks they may encounter in research. Palys and Lowman (2010) similarly advocate for a re-orienting of research ethics review to prioritize participant and researcher protection. Such a (re)orientation would, we agree, both facilitate the diverse research foundational to social justice aims and further resist the marketization/neoliberalization of universities and research (Breeze & Taylor, 2019; Canaan & Shumar, 2008; Giroux, 2019; Maisuria & Helmes, 2020; Taylor & Lahad, 2018).

### REB Whore Stigma and Disregard for Community Expertise

While some of our team are early career researchers, none at this point are novice researchers. We nonetheless continue to encounter challenges in the ethics review process that at best slow down our work and at worst threaten the integrity of the studies we collaborate to design and develop. We wish to interrogate, then, the power dynamics between REBs and experienced sex work researchers. While we acknowledge that research ethics review processes can slow down and/or impede any study, we are concerned with the ways such dynamics result in more extreme delays and impediments to research as review committees disregard community

researcher expertise and over-scrutinize protocols through stigma-laden lenses. It is alarming that such disrespectful communication continues despite the ways that the protocols we submit for review both state and demonstrate the meaningful integration of sex working and non-sex working members on our research management teams.

Whore stigma—a term coined by social psychologist Pheterson (1996) to describe the particular repugnance reserved in Judeo-Christian societies for those who participate (or who are perceived to participate), willingly or no, in sex industries (p.11)—is evident at all levels of Western societies. Sex workers and their allies in and outside of the academy identify whore stigma as “one of the central issues, and major burdens, for people working in the sex trade” (Jeffrey & MacDonald, 2006, p.136). On the one hand, we are not surprised to encounter whore stigma in the research ethics review process. On the other hand, we strongly oppose the ways that stigma reinforces outdated positivist research paradigms that (1) fail to account for community research knowledge and expertise; (2) perpetuate symbolic violence against sex workers, including project research partners; and (3) threaten to strip away necessary protections for our study participants. Interrogating three of these stigma-laden exchanges on our studies, in concert with ongoing scholarship on REBs and collaborative research, leads us to consider how sex work researchers might begin to push back against REB structures that perpetuate such inequity, symbolic violence, and risk. In order to contextualize these exchanges, we first provide a brief overview of the projects for which the REBs referenced have reviewed protocols. Participants in each of the studies discussed provided informed verbal consent.

## The Sex Work Activist Histories Project

SWAHP is an interdisciplinary initiative to record and disseminate the radical knowledges, activist expertise, and alternative histories created by sex work activists here in Canada and then—we hope—around the world. Marrying the expertise of activists and researchers, SWAHP is collaborating to create, analyze, and disseminate through a variety of platforms the rich knowledges of sex work activists regarding community building and support; engagement in anti-violence, anti-colonial, and social justice activism generally; and engagement in sex work activism particularly.

SWAHP developed out of three intersecting realities, the first of which is ongoing extreme violence against persons who are or who are perceived to be sex workers, and sex work activists’ ongoing struggle to make themselves safer—a struggle that involves efforts to humanize themselves to hostile journalists, politicians, police, courts, academics, and a wider public.<sup>3</sup> The second reality is the recent pursuit by Canadian sex work activists and their allies of two successful internationally celebrated (ICRSE, 2010; Scarlet alliance, 2013) constitutional challenges to prostitution-related laws: one originating in the western province of British Columbia

(Canada [Attorney General] v. Downtown Eastside Sex Workers United Against Violence Society, 2012) and one originating in the central province of Ontario (Canada [Attorney General] v. Bedford, 2013). The BC challenge established the right for a marginalized group to bring a charter challenge as a group, not as individuals. The Ontario challenge<sup>4</sup> resulted in a unanimous Supreme Court decision to strike down three laws because they violated sex workers’ rights to safety and security under the *Canadian Charter of Rights and Freedoms*.

The response of the former federal Conservative government to the Supreme Court’s ruling in Bedford brought about the third reality that led to SWAHP: the 2014 *Protection of Communities and Exploited Persons Act (PCEPA)*, a controversial set of laws that essentially expanded and reinvigorated the laws struck down in the Bedford case. While the Supreme Court rulings offered hope and established legal precedents, sex work activists have much work still to do in the struggle to foreground and protect the concerns—including human rights and rights of citizenship—of sex workers.

In this fraught political terrain, SWAHP seeks to record and remember the efforts as well as the hard wins and losses by sex work activists. Relationships with individuals and groups of sex work activists are critical to the development, establishment, and perpetuation of the initiatives that make up the Sex Work Activist Histories Project. *Sex Work Activism in Canada* (ARP, 2019) and the Sex Work Database are the most developed of SWAHP initiatives to date. They are the research projects from which we draw the examples discussed in this article.

## *Sex Work Activism in Canada: Standing Out, Speaking Up* (ARP Books, 2019)

Co-edited by SWAHP members Amy Lebovitch and Shawna Ferris, *Sex Work Activism in Canada* was developed in collaboration with its 23 contributors over the course of 5 years. Prior to creating the first call for contributions, the editors met with a group of current and former outdoor largely Indigenous sex workers and sex work activists to develop both the political vision for the collection and an array of supports for any group or individual that indicated they might require them to complete their chapter. Notwithstanding the growing number of sex worker-authored books to date, many of the records we have of sex work activists continue to be found in the digital realm, on the vast array of websites and social media spaces that make up the World Wide Web. The Sex Work Activist Histories Project thus also includes the Sex Work Database.

## The Sex Work Database

The Sex Work Database is a digital activist archive that currently includes thousands of digitized and “born digital” activist records (pamphlets, posters, and photographs; websites, blogs, digital press releases, etc.) created and circulated

by sex work activists. SWAHP's research team is working with sex work activists from across the country to scan, organize, and create accompanying descriptive "metadata" and then to upload these archival records to the Sex Work Database. Relationships and partnerships between academic and non-academic community members are similarly critical to SWD. The ongoing preparatory work would be impossible without the support and paid work of the sex work activists with whom we collaborate.

## REB Encounters: Facilitating Community Exclusion and Participant Risk

The enactment of equity on our collaborative, participatory and feminist anti-oppressive research projects is a challenge in the context of the positivist paradigms still evident in the systems through which research is administered. Research ethics review is a particularly challenging system in this regard. This is the case even as we develop studies together, including all project management team names, academic and non-academic, on REB protocol forms. This process adheres to both the literal and the intended outcomes of collaborative, participatory feminist anti-oppressive research methods—that is, the building of capacity for non-academic stakeholders to engage meaningfully in research (Beckman, 2014; Bromley et al., 2015; McCracken, 2020). Such collaboration deepens all research management team members' understandings of ethical research practices and protocols; it also accurately reflects the reality that none of us has the expertise, on our own, to conduct these studies.

The following three examples of REB encounters outline problematic interactions with Canadian REBs to which we have submitted study protocols in the service of *Sex Work Activism in Canada* and the Sex Work Database. While we argue that these exchanges are indicative of systemic, not individual expressions of whore stigma, individual expressions of whore stigma cannot be discounted entirely, given the influence individual review committee members can wield in these contexts. Indeed, both individual and systemic stigma were evident in these exchanges—with effects that threatened to compromise the research and that put additional emotional and intellectual stresses on the research partnerships on which our project management teams depend. Although paraphrased to protect the anonymity of the REBs in question, we describe our encounters in great detail below. We do so as a form of consciousness raising in this under-explored area, both to demonstrate and closely analyze the REB reviewer comments as well as to be very clear about their consequences.

### Encounter 1: Framing Sex Workers as Risky Populations for Academics to Manage

We first encountered whore stigma from a research ethics board that evaluated the second stage of a project that we were

undertaking at the request of a group of adult sex work activists. This REB required that we inform both the REB and the adult activists we proposed to interview that we would report any child abuse learned about during the interview. This was not a problem in and of itself, given our duties in this regard under Canadian law and under TCPS2. However, the REB further requested that we state clearly in the information and consent form provided to interviewees that we have a legal responsibility to report child abuse, if we see or hear about it.

We had already interviewed the group in question once and had worked with them to develop the framework and interview questions associated with this next interview. We had also stated explicitly in our ethics application that we would be meeting with an established, respected group of adult experiential sex work activists and that we planned to interview them specifically about their activism. We had made equally clear that we planned to meet in a private room at a secure community facility accessed by adults.

*The Tri-Council Policy Statement on Ethical Research with Humans* (TCPS2, 2018) is clear that researchers must be aware of instances we might encounter where our duty to report may compromise our ability to protect the anonymity of those who do research with us. TCPS2 (2018) is similarly clear in its directive that researchers remind study participants of such duties on the part of the researcher—to report law breaking, for example, or abuse of children—so that participants are able to weigh the risks and benefits of participating in the research and thus to give their informed consent.

However, the REB in question did not appear concerned with participants' informed consent. Their directives to us in the exchanges that followed on that first communication indicated instead their preoccupation with a stigma-laden understanding of sex workers as a criminal and "high risk" population. In our first response to this REB, we noted academic members of our research team had not been required to insert such direct and detailed language about duties to report into protocols or consent forms for studies we had done with non-sex working populations. In fact, on these other studies, REBs had not reminded us of this duty to report at all. We argued that such explicit wording was equally irrelevant for this study.

More than this, we explained, we could not insert any such detailed statements about reporting child abuse into our information and consent packages for this study without threatening the relationships necessary for the study to proceed. We explained that both we and those we were interviewing are well aware of the ways that stigma and the moral panic associated with prostitution inform how non-allies and non-sex workers view sex working individuals: as formerly molested children, for example, who are neglectful or abusive parents themselves.<sup>5</sup> To put a statement about child abuse in our study materials would, we argued, be stigmatizing; as such, it would destroy the trust between interviewers and interviewees that is necessary to do the work we had been invited to do.

The REB Chair responded that they understood these points and acknowledged that we were not legally required to put such a statement into participant materials. The Chair then proceeded to quote Canadian legal policies regarding our duty to report child abuse and directed that we put in writing to the board, if not to our participants, what steps academic research team members would take if child abuse was uncovered in the course of our research. The funding we had secured to do the proposed project was about to run out. We thus felt we had no choice but to comply with this last request as we had no time for further discussion and debate. We needed the ethics certificate issued by this REB in order to proceed, however troubling (and ironic) the ethics of this exchange. We understood, however, that our arguments about avoiding whore stigma had not actually been taken into consideration at all. Equally disturbing, these exchanges suggested that this REB had disregarded entirely that their comments were coming to a project management team that included a sex worker. If they had considered that sex working team member, would they have implied that sex workers have a disposition to abuse children? Indeed, our sex working team member experienced this interaction—their first after reading TCPS2 and co-authoring this study protocol for REB review—as horribly stigmatizing and symbolically violent.

This interaction resonated in our research partnership and plans in two important ways. First, as a result of this interaction, our sex working team member came to understand REBs as empowered to treat the sections in TCPS2 (2018) about partnering with and protecting marginalized communities for anti-oppressive research as just “words on a page”—that is, having no actual intent to promote or protect marginalized communities. It became painfully clear that when faced with the choice between involving sex workers in research in equitable and respectful ways and treating them as “risky” research populations to be managed by paternalistic academics, REBs could and would most likely choose the latter because, as [McCracken \(2020\)](#) and others persuasively argue, REBs protect universities first. That our sex working team member chooses to continue partnering for academic research despite this reality speaks to her strength of character, to the strength of our working relationships, and to the pressing need for research to inform and support sex work activism.

The second way in which this REB interaction resonated for us was in an almost 6-month delay in the project timeline. While REB-related time delays are a reality with which many researchers regularly deal, community-based researchers experience additional pressures in this regard as non-academic communities cannot always accommodate, tolerate, or understand the delays associated with REB protocol applications and review. In this case, the delays were demonstrably predicated on whore stigma as well as a failure on the part of the REB to account for the presence of community researchers. Such delays can threaten the good relationships required to do any kind of community-based research, and

they can push project timelines past the deadlines imposed by the various funders on the grants that facilitate our projects. Given the long history of academic exploitation in sex work research,<sup>6</sup> such delays pose a particular risk for sex work studies.

Indeed, in this case, REB-related delays had both a logistical and a relationship-oriented effect on the research to be done. We had assumed—naively, as it turns out—that it would not be difficult to attain REB approval for a second interview that we had been invited to undertake by a group we had already been approved to interview before. We had thus set a prospective meeting date prior to submitting our protocol to the REB. As the REB process stretched over months, we checked in regularly with our community partners, reporting each time that we could not yet establish a new meeting date. Repeatedly putting off plans for a mutually agreed upon interview put us at risk of losing the trust of study participants.

Equally important were the financial and administrative challenges created by this timeline delay. First, the timeline pushed us past the deadline by which the particular funds earmarked for this project had to be spent.<sup>7</sup> We were left to choose, then, between abandoning the interview, or paying out of pocket to make it happen. We decided that both we and our interviewees needed the work to proceed; we therefore covered the not insubstantial research costs—flights, hotels, taxis, food, and participant honoraria—with our personal funds. In addition, the receipt of our research ethics certificate in mid-August and the requirement that we travel right away to complete the study resulted in our traveling during the more expensive summer months.

## *Encounter 2: Prioritizing Academic Communities*

Our second stigma-inflected exchange with an REB occurred after we applied for approval of an interview that we had, once again, been invited to undertake. We were to interview members of a sex work activist group for a collaborative project examining the history and goals of their organization. The REB recommended that our principle investigator analyze and publish more from the interview in question. This REB noted that wider dissemination would serve both the PI and the academic community more appropriately than the original dissemination plan. This despite our clear indication in the protocols submitted that the dissemination plan had been collaboratively developed with the people we planned to interview, per anti-oppressive participatory research protocols ([Beckman, 2014](#); [Bromley et al., 2015](#); [Brydon-Miller et al., 2003](#); [OCAP, 2007](#); [Van der Meulen, 2015](#)).

In our response to this REB, we emphasized that, in keeping with anti-oppressive collaborative research methods, the group we would be interviewing could do what they wanted to disseminate the information produced through the interview because it belonged to them and was theirs to manage and share as they saw fit.<sup>8</sup> We explained that as

interviewers and outsiders to the group interviewed, we had agreed to produce only one type of publication. In addition to the research methods governing these agreements and associated protocols for research with marginalized groups, we explained that we were working against a long history of exploitative research with sex workers in particular. There is, we explained, a long history of researchers parachuting into sex working communities, taking the information we need to further our research agendas and our careers, and offering no benefit whatsoever to study participants (Craig, 2011; Pivot Legal Society, 2006, POWER, 2012; Rekart, 2005; Shaver, 2005; Van der Meulen, 2011; Van der Muelen et al., 2013). Over the past decade and a half, some sex work researchers have begun to counteract the community distrust created through these exploitative histories. But memories of such injustices are long, and some of this bad research continues. Going back to ask for more after having already agreed on the dissemination plans we submitted to the REB would both contravene anti-oppressive research methodologies and damage the trusting relationships we had worked hard to build so that the project could happen at all.

The encouragement to violate the trust of the interview group and publish more than the agreed-upon materials in service of the PI's career and the academic community's knowledge base—a piece of advice that was framed as helpful professional mentoring for the PI—could have been a disruptive point in our working relationships, if our PI had experienced it as pressure (which she did not), and if she did not have other means of publication and thus retention of her job (which she did). This advice and the requirement that the PI explain and reinforce to the REB the ethics governing our decision seemed to all research team members to treat the needs and concerns of study participants as secondary to the interests of academic communities. Such advice betrays a lack of understanding of how community research proceeds where trust between parties must remain central at all costs. We wondered why, given the centrality of community researchers in contemporary collaborative research, REBs did not appear to have either the requisite expertise or any appropriate guiding policies for evaluating of and advising on community-based research protocols.

### *Encounter 3: Obfuscating Community Researcher Expertise*

Our final examples are taken from exchanges with an REB to which we submitted protocols for multi-day meetings with a number of sex worker groups across the country. The feedback we received from this REB about participants' economic and legal risk on the project was particularly concerning. In each of the comments we discuss below, we consider how or if whore stigma resulted in the REB's disagreement with our assessment of risks associated with the study and with the protocols we proposed to mitigate against these risks. Had we agreed to modify our protocols as the REB suggested, we consider that

our study would not have adequately protected study participants.

This REB responded positively to our protocol submission but required responses to their remarkable provisos about the risks to study participants that we had identified. While they approved, generally, our cautious approach to the research, they suggested that we had been unnecessarily cautious in defining potential loss of income for participants as a risk. The REB suggested that loss of income due to participation in study activities was something participants would/should expect, given the breadth of the activities. There are a number of potentially problematic repercussions to such downplaying/elision of economic risk.

Perhaps the most important of these potential repercussions was our intent to pay participants for the considerable amount of time we were asking them to spend on our project. If we agreed to downgrade the loss of income from a risk to a natural consequence of study participation, would we then have to change or even eliminate our remuneration protocols? We were asking for multiple hours—days, in some cases—of participants' time. How could the loss of income not be considered “risky” in these contexts?

More than this, we considered ourselves better situated to determine risk in this context than the REB. Why did this REB not perceive us as the experts on this matter? Our protocol made clear that our study management team included a sex worker and activist who had extensive relationships with sex workers across the country and was thus well-positioned to assess risk in this context. We knew the actual costs of participating in the kinds of consultations we were proposing could be quite high, financially speaking. Why should not sex working participants expect us to acknowledge and mitigate against these risks in our study design?

For several reasons, we did not feel that we could take up the point about the perceived impugning of our expertise as researchers. We knew, however, that we had to affirm that loss of income constitutes a real risk to study participants. Admittedly, we do not think this is a clear example of whore stigma, but perhaps more a misunderstanding of what it means to be precariously employed.

Later in this exchange, the REB suggested that our study involved no real risks, economic or otherwise to participants. They advised, therefore, that our response to a question in their protocol submission form about whether there are risks associated with our study should be changed to “no.” The argument in this case hinged on the assumption that sex workers' lives are rife with risk of many kinds and that meeting with our research team would, in comparison, seem not-at-all risky such seasoned risk-takers.

This commentary clearly expressed whore stigma. Downplaying real risks to study participants because of assumed risk-taking in their everyday lives clearly stigmatizes and fails to protect potential study participants. Equally problematic is the way such commentary frames research participation as a break from risk-taking and ignores the well-documented damage that

bad research can actually do to sex workers (Bromley et al., 2015; Craig, 2011; Gaventa & Cornwall, 2006; POWER, 2012; Pivot Legal Society, 2006; Rekart, 2005; Shaver, 2005; Downtown Eastside Sex Workers Against Violence Society [SWUAV] et al., 2019; Van der Meulen, 2011, 2013).

Also significant in this instance, the REB did not appear to imagine community researchers as receivers for their messaging about research protocols, despite our including a community researcher—identified as project management team member—in the study protocols the REB was reviewing. Would the members of this REB have written about the risks sex workers are accustomed to if the sex working community researcher on our research team was front of mind? Despite our sex working team member's position on the research management team and her delineation as such in the protocols submitted for review, if they thought of her at all, this REB appeared to imagine her as operating outside of study protocol design and review process. They appear, at best, to imagine her as part of the population to be researched (i.e., as a study participant), not as a community researcher with attendant knowledge and expertise.

Our team was alarmed and frustrated by this REB commentary. But we had learned already that engaging on the larger issue of whore stigma could easily result in a prolonged exchange that could delay our start date. We opted, therefore, not to engage whore stigma directly in our response to this REB's risk-related commentary. Instead, we pushed back by highlighting concerns relevant across marginalized, or sensitive, groups who participate in research. We wrote, "Respectfully, we do not feel that this should be changed. The risk here is not specific to sex work; rather, it is an economic risk for all of those—including the sex workers with whom we do research—who are precariously employed. Even a few hours not spent working when one could be making money can indeed put precariously employed people at risk of not making the money for rent, food, childcare, etc."

As noted previously, REB-researcher exchanges can facilitate productive and rigorous discussion and debate (Sanders, 2006; Pérez-y-Pérez & Stanley, 2011). Such discussions can indeed bring about the development and implementation of more protective, respectful, and thus more ethical research protocols. However, our interaction with this REB did not lead to these kinds of satisfying ends. Furthermore, while we successfully negotiated this exchange and thus avoided compromising our study, we wonder whether such exchanges experienced by students and other junior scholars doing sex work research tend more toward the effects Palys and Lowman document: the scrapping of sensitive research entirely. More broadly, these kinds of REB-researcher encounters have very real consequences for community-oriented researchers, our projects, and the communities with whom we work. Acknowledging the extent to which REB policies are responsible for negative outcomes is the first step in bringing

these policies more into alignment with the current realities of community-based collaborative research.

We are also motivated, as sex work researchers, to consider whether or how improving REB policies to better account for and respect the roles of community researchers might also begin to address the whore stigma that stymies our research ethics review processes. Audience responses to a version of this article presented at the Law and Society Association conference in 2020 (Ferris et al., 2020) suggest that sex work researchers around the world are making difficult decisions about when and how to engage with REBs. We agree that training researchers to scrutinize sex work and other sensitive studies with exceptional care and precision prior to REB submission is important (Dewey & Zheng, 2013; Pérez-y-Pérez & Stanley, 2011; Sanders, 2006). We are also interested to engage at both the community- and institutional policy levels to ensure that this fraught labor does not disempower our community research partners, or discourage new research in our field.

## Where do We Go from Here?

There are, now, a critical mass of sex work researchers, a growing number of whom have experience in sex work themselves. Some of us are also quite senior in academic hierarchies and are working within, or are affiliated through projects with the university system. Now is thus a very good time (a) to coalition build with researchers working on other collaborative and/or sensitive studies and (b) to further develop work to value community researcher roles in research ethics review processes. Palys and Lowman (2010) identify four stakeholders in the protection of the quality of research, especially research on "sensitive" topics, and those who participate in it: "(1) researchers; (2) research ethics boards; (3) university administrations; and (4) the federal granting agency Presidents and their advisors" (p.274).

We follow McCracken (2020) in adding another key stakeholder to this list: community groups. Indeed, the lack of formal recognition for community researchers and the absence of related REB policies has led to responses by individuals representing REB committees that are stigmatizing, harmful, and betray the spirit of our commitments to community-based research. In our experience, REB reviewers assume they are only and always speaking to researchers who are not members of "researched" or participant communities. Community researchers, their voices, needs, and considerable expertise must become visible; from a policy perspective, they must be both "seen" and taken into account in REB-researcher exchanges. What follows is a discussion, or the beginning of one, at least, of ways we might further develop our engagement at each of these levels. We plan to augment this early discussion with further future research that will build on the findings offered in this article.

We suggest, first of all, that we need to contribute to ongoing interrogations of research ethics frameworks in general.



With [McCracken \(2020\)](#), [Palys and Lowman \(2010\)](#), [Hedgecoe \(2016\)](#) and others, we need to consider, from the perspective of community researchers more generally, and of sex work researchers in particular, who is actually protected by current ethics regulations and research systems. In our experience, REBs privilege and protect universities and university-based researchers above all others. In addition, hierarchies of researcher and researched continue to be upheld through REB processes such that even when community researchers such as sex workers operate on research management teams, they continue to be referenced as research subjects, or those to be “researched,” not as experts and/or researchers themselves.

We must find ways, then, for community assessment of their own levels of risk to be prioritized, especially when/if community researchers are speaking for themselves in research protocols submitted for REB review. We appear already to be sharing some preparatory training, particularly for junior researchers, through more traditional academic means ([Dewey & Zheng, 2013](#); [McCracken, 2020](#); [Pérez-y-Pérez & Stanley, 2011](#); [Sanders, 2006](#)). There is room, however, to further develop this training, perhaps through informal but less public networks such as “old school” national or transnational listservs for sex work researchers. If we operate outside public and institutional settings, we might facilitate the sharing of “pushback” responses to REBs, responses that we might not want shared in more public forums such as academic venues, social media, or even community web platforms. In this way, we can move from the more general directives we already share, such as checking in/working with REBs prior to protocol submission ([McCracken, 2020](#)) and carefully scrutinizing our studies ([Dewey & Zheng, 2013](#); [Pérez-y-Pérez & Stanley, 2011](#); [Sanders, 2006](#)), to developing more sex work-specific language and communication strategies. This would ensure that junior researchers get trained in REB communication specific to sex work-related research.

More formally, we could work to ensure folks with sex work experience, perhaps especially those who are also well-versed in academic research, gain seats at the tables where policies are being established and research protocol-related decisions are being made. In other words, “our” people need to be represented on—even chairing—as many research policy-making and REBs as possible. We need representatives in administrative roles such as Associate Deans or VPs of research. As well, in Canada, TCPS2 ([2018](#)) has made room for community assessments of study protocols (section 6.4–6.5 of TCPS2, [2018](#)).<sup>9</sup> Have other nations and contexts begun similarly to make space? How might we be involved in such space-making in meaningful ways?

As the many collaborative projects referenced in the literature review above make clear, many researchers around the world have been working with local organizations to build community knowledge and capacity for participation in and direction of sex work research. Inspired

by work others have done in this regard, members of our research team have been working with a local sex worker rights group in our city and with some US-based groups to develop processes for sex workers/groups to screen researchers, to screen the studies to which researchers regularly attempt to recruit them, and to instruct researchers in ways to strengthen their sex work data by collaborating meaningfully with sex workers in research.<sup>10</sup> As both the [Meharry-Vanderbilt Community Engaged Research Core \(2013\)](#) and [McCracken \(2020\)](#) make clear, key efforts in this regard have led to the establishment of Community Review Boards (CRBs) that are “instrumental in their review of research plans to determine risks for the community members’ and organizations’ perspectives” (p.8). Such efforts indeed can and are effective in improving studies, particularly when REBs are educated to value community review in their assessments ([McCracken, 2020](#)).

But what if we took community review a step further and established sex worker-majority REBs? In this action, we might take lessons from existing CRBs, including those developed by Indigenous nations across Canada, the United States, New Zealand, and Australia.<sup>11</sup> To date, however, separate REBs do not in and of themselves solve or avoid many of the institutional challenges and barriers discussed above. For example, requiring two ethics review processes will necessarily create further delays in research projects. This is primarily because most current institutional policies require that projects must be reviewed by both institutional and community-based review boards.<sup>12</sup> Perhaps such discouraging and time-consuming realities can be changed via cross-community cooperation and associated advocacy for institutional policy changes. Thus, this is an important area for careful future exploration, to determine how, if at all, such systems might be applied in the context of sex work community research.

Further to, or even in lieu of separate REBs, we could draft guidelines that interpret the policies governing research from the perspective of highly researched sensitive communities such as sex workers. We could then do the work [McCracken \(2020\)](#) suggests to re-orient the REB role to one of a “partner that helps researchers conduct more ethical and inclusive research” (5). Given the breadth of experience among sex work researchers globally, this work could be shared and proceed relatively quickly among us. It could also, we imagine, be disseminated effectively to granting agencies, universities, professional associations, REBs, community groups, and individual researchers. Determining the solutions to these issues also requires community input and consultation. Next steps will thus involve extensive consultation with sex work researchers with the goal of proposing key changes in both community and institutional policies and procedures for sex work and other sensitive research. In these and other ways we are sure you can envision, researchers on sensitive projects may, in the end, make ethics review processes and encounters both less fraught and more ethical.

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## Notes

1. Ethics review boards are most often referred to as REBs at our Canadian institutions. We employ this terminology and associated acronym throughout to delineate any appointed committee of university-based researchers that reviews study protocols submitted to them by peers at their institutions in order to determine their ethical acceptability according to established research ethics policies and protocols. Other titles for such review boards include Institutional Review Boards (IRBs), independent ethics committees (IECs), and ethical review boards (ERBs) (Wiki, 2021).
2. Lowman, now Emeritus, is a long-time researcher in prostitution laws. Lowman appeared as an expert witness in hearings for the Bedford case (see section below entitled “Sex Work Activist Histories Project,” incl. note 4) and many others.
3. Of course, this struggle is not unique to the Canadian context. Sex work activists around the world routinely call for a recognition of their basic humanity, arguing that a recognition of their humanity must be accompanied by the dismantling of policies and laws that construct violence against sex workers as normal, unremarkable, and even largely the fault of sex workers themselves. Sex work activists thus agitate for, among other things, the removal of laws that criminalize sex workers and their clients. They argue that these laws marginalize and further stigmatize already marginalized and stigmatized populations, leaving them especially vulnerable to extreme violence. For more information, see websites of [Durbar Mahila Samanwaya Committee \(DMSC, 2021\)](#); this is an Indian activist organization that is 65000 members strong), the [Global Network of Sex Work Projects \(NSWP, 2021\)](#), and the [International Committee on the Rights of Sex Workers in Europe \(ICRSE, 2021\)](#).
4. This challenge was brought by Amy Lebovitch, Valerie Scott, and Terri Jean Bedford. The case is often referred to in

community parlance as “the Bedford case,” or simply “Bedford,” because Bedford’s name is listed first alphabetically in court documents.

5. One of the most widely cited researchers disseminating this kind of messaging, Melissa Farley, has been discredited (Ontario, 2010, para 353; Sanders et al., 2008). Moreover, it has long been known that victims of childhood sexual abuse are not over-represented among sex workers (McCarthy et al., 2014; Shaver, 1994, 2005).
6. Academic researchers have been criticized in community and academic venues for “parachuting in” to sex worker communities, extracting information required to further our careers, and never giving back to or doing research that meets community needs (Craig, 2011; Metzenrath, 1998; Pivot Legal Society, 2006; POWER, 2012; Rekart, 2005; Shaver, 1998 & 2005; Van der Meulen, 2011, 2013). As a sex work researcher, one risks losing community buy-in for a given study if the community perceives that researchers are, once again, putting academic timelines and requirements ahead of community ones.
7. Many reading this article will be familiar with these kinds of finicky administrative policies attached to research funds. It is helpful to have institutional support when applying for and managing research funds. Such supports often come with bureaucratic strings attached.
8. Such negotiations are key to feminist and other collaborative anti-oppressive research methods. See, for example, Beckman’s (2014) article, *Training in feminist research methodology: Doing research on the margins*; or the *First Nations Principles of OCAP, or Ownership, Control, Access, and Possession* (<https://fnigc.ca/ocap-training/>).
9. We are in the process of researching where, how, and if such room has actually been “taken up” by sex workers or their allies and how we might get more sex work research-oriented folk represented in these spaces.
10. Many researchers have worked with groups and individuals to create guidelines/review/screening processes for sex workers to use when approached by researchers, as well as checklists for junior researchers who want to do research with sex workers.
11. Two members of our research team have recently submitted a research funding proposal that, if successful, will enable us to investigate interest in and potential for such endeavors in Canada.
12. See, for example, Article 9.9 of TCPS2 (2018), entitled “Institutional research ethics review required” (p.120).

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