

How have researchers navigated ethical tensions with institutional review boards in community research?

A rapid literature review by Inspiring Ethics

Not peer reviewed

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1. What is the purpose of this rapid review?

It is widely recognised that existing ethical review processes at higher education institutions (universities) can find it challenging to accommodate the practice of community¹ research within their frameworks (Jamshidi et al., 2014; Shore, 2007; Wilson et al., 2018). It is apparent that interventions are needed to adjust existing institutional ethical frameworks to accommodate the values and realities of community research. To inform such an intervention, it is necessary to understand what, how, and why conflicts occur, and how institutional and community researchers² and institutions have attempted (successfully or unsuccessfully) to resolve them within existing frameworks.

The purpose of this rapid review is to illuminate case studies of institutional researchers and community researchers working together on projects while navigating ethical conflicts with IRBs, and to explore the underlying mechanisms that have caused these interactions to play out as they have³. Platforming case studies of issues and resolutions provides both precedent and examples for community researchers navigating ethical tensions with institutions, and symmetrically for institutions to understand how they may better engage with researchers and their projects. This rapid literature review (hereafter: 'review') also makes several recommendations concerning potential ways disputes can be resolved in more positive, dialogic, community-centred ways.

The aims of this research were thus:

- To present an overview of case studies of ethical conflicts between community researchers and IRBs
- To provide a coherent narrative of these conflicts in the context of issues university ethical frameworks.

To address these aims, this review sought to provide answers to the following questions:

- What specific conflicts have arisen on community projects between researchers and IRBs?
- How have community and institutional researchers chosen to address these conflicts?
- How successfully (from a community perspective) were these issues resolved?
- What factors contributed to positive or negative resolutions?
- What are the underlying mechanisms that caused the interactions to play out as they did?

- What (if anything) do these case studies suggest researchers can do to improve (from a community perspective) the outcomes of disputes?
- What (if anything) can institutions do to improve the positive outcomes of disputes?

¹ In this review, consistent with the literature found, we are using 'community' to refer to groups of individuals who share something between them, such as identity or belief. We recognise that this may differ from how others use this term, and that 'communities' are not homogenous groups, despite these shared aspects. Where the term 'community' is used, this either is in reference to a **specific** community (consistent with the author's / authors' usage in the case discussed) **or**, in the discussion, in reference to a **hypothetical, specific** community engaging with institutional research.

² 'Institutional researchers' refers to any researcher employed by or affiliated with an institution, which includes researchers employed by or affiliated with institutions who are also members of communities. 'Community researchers' refers to any researcher who is a member of a community and not employed by or affiliated with an institution except for within the context of the institutionally affiliated research.

³ For the avoidance of doubt, our critique of IRBs is not intended to cast blame or judgement on the actions of individuals who work in IRBs, many of whom volunteer their time and expertise. Rather, the purpose is to critique the broader conceptual and institutional mechanisms, practices, and norms that underpin ethical conflicts. Of course, these are facilitated by individual practices, but none of our data specifically identified issues of individual practice. Thus, we hope our work will be read as directed towards IRBs and institutions as structures, not individuals within those structures.

2. How was this review conducted?

This review used strict inclusion criteria to ensure a practical number of papers to screen. As this review was interested in the nuances of ethical clashes and how they played out, literature that was included specifically discussed the nature of disagreements and or disputes between researchers and IRBs, and how they were navigated.

Our inclusion criteria were:

- A community project by design and or practice. In other words, research that used community consultation in project design **or** co-production methodologies to generate data – or both⁴.
- Project approved, at least in part, by an IRB.
- Specific discussion of at least one **ethical** conflict between the researchers and IRB and how this was navigated.
- Found on the first five pages of Google Scholar results (taking advantage of database ranking). Five pages was the number arrived at after checking ten pages with the terms that returned the most hits (“CBPR” AND “Ethical decision making”), and no relevant results appearing after page five.

Finding literature for this review was a significant challenge. Specific discussions of ethical issues in the community literature that were not issues relating to intergroup ethics were relatively scant. Where non-intergroup ethical conflicts were raised, mention of an ethical issue was overwhelmingly **not** in relation to a clash with an ethical review board (of any kind). For example, researchers would mention issues relating to ethical recruitment, or a concern about the ethics of certain inclusion criteria. It took significant testing of terms to find a single relevant paper: A reflective piece on a community project with a disabled dance collective (Acton, 2019). This paper was used to ‘seed’ the review. Extractions were made and classified under themes, and these themes were then used to generate further search terms.

The overall process of searching and extracting was iterative, and used the following steps:

1. Searches made using [Community research term] + [Boolean operator] + [Ethical issue term].
2. Papers meeting inclusion criteria downloaded. Relevant extractions made and key words noted as appropriate.
3. Extractions grouped under existing themes or added to new themes as appropriate.
4. New themes used to replace ethical search term. Steps 1-3 repeated.

The results of all search terms used in this review can be seen below in Table 1. This table has been provided in the interests of transparency, following the recommendations of Haddaway et al. (2015). Papers cited in the review that are not listed under ‘Relevant’ were either found during initial test searching (which was not systematically documented to save time) or provided directly to the research team from Inspiring Ethics members.

⁴ Initially, it was planned to focus on ‘participatory’ projects as this is the term used in the UK. This scope, however, proved problematic in terms of search terms outside of the UK, where ‘community’ was more widely used, and the way research was conducted not necessarily synonymous with participatory approaches and methods. As there was much more literature outside of the UK, it was decided to expand the focus to a community-based, in addition to participatory, projects.

Table 1: Google Scholar search terms and results.

Search terms + operators	Results returned	Relevant
"CBPR" AND "Ethical decision making"	245 (28 March 2025)	(Heard, 2023) (McDonald & Capous-Desyllas, 2021) (Guta et al., 2010)* [references directly relevant (Malone et al., 2006)] (Quigley, 2006)* [references directly relevant (Foster et al., 1998)] (Kia-Keating et al., 2017)
"PAR" AND "Ethical decision making"	20900 (28 March 2025)	None
"Co-production" OR "Coproduction" OR "Co production" AND "ethical decision making"	1660 (28 March 2025)	(Kia-Keating et al., 2017) [Found previously]
"CBPR" AND "Compensation" AND "Coercion"	399 (28 March 2025)	(McDonald & Capous-Desyllas, 2021) (Embleton et al., 2015)
"Participatory research" AND "Compensation" AND "Coercion"	2630 (28 March 2025)	(McDonald & Capous-Desyllas, 2021) [Found previously] (Suarez-Balcazar et al., 2022)
"CBPR" AND "Methodology changes"	4 (15 May 2025)	None
"Participatory research" AND "Methodology changes"	44 (15 May 2025)	None
"CBPR" AND "Ethics amendment"	21 (15 May 2025)	None
"Participatory research" AND "Ethics amendment"	127 (15 May 2025)	(Treffry-Goatley et al., 2021) (Condie et al., 2018) (Famlonga, R., 2023)
"CBPR" AND "Recruitment issues"	86 (30 May 2025)	None
"Participatory research" AND "Recruitment issues"	317 (30 May 2025)	None
"CBPR" AND "Recruitment challenges"	215 (30 May 2025)	None
"Participatory research" AND "Recruitment challenges"	802 (30 May 2025)	None
"Ethics approval" AND "Recruitment issues" AND "CBPR"	9 (30 May 2025)	None
"Ethics approval" AND "Recruitment issues" AND "Participatory research"	37 (30 May 2025)	None
"Participatory research" AND "risk management issues"	87 (30 May 2025)	None
"CBPR" AND "intellectual property"	1217 (30 May 2025)	None
"Participatory research" AND "intellectual property"	9900 (30 May 2025)	(Chad et al. 2010)
"Participatory research" AND "intellectual property issue*"	7 (30 May 2025)	None

3. What did we find in the literature?

Our review found 16 papers discussing 15 different participatory projects⁵. The projects involved a wide range of communities in several different countries – though it should be noted that most gained their institutional approval from an Australian, Canadian, US, or UK (‘Global North’) institutions, a point we will return to in §4. All projects were led by institutional researchers; two projects were led by institutional researchers who were themselves community members (marked with an asterisk in Table 2. Across these papers, we identified nine different types of clashes between researchers and IRBs. Several projects had multiple conflicts with IRBs. In most cases, these were not resolved – instead institutional / community researchers capitulated to the decision of IRB or found workarounds within the IRB’s requirements. Only in two cases was there what we would call ‘genuine negotiation’ between institutions and communities; negotiations where the IRB conceded ground to allow the project to continue as the community desired – highlighted in green in Table 2. Both cases involved indigenous North American community projects backed up by both pre-existing legal frameworks and community advisory / review boards. A summary of these case studies is shown in Table 2.

Table 2: Alphabetical (by first author) summary of case studies of clashes between researchers and university ethics boards. Projects led by institutional researchers who were also community members marked with an asterisk. Cases of ‘genuine negotiations’ between IRBs and communities are highlighted in green.

Paper and overview	Location	Conflicts	Summary of resolutions
(Acton, 2019)* CBPR of timing in integrated (inclusive) dance with a disabled dance collective	Alberta, Canada	3	Conflicts resolved by capitulation to IRB. Community unhappy about their lack of agency and control over the project.
(Condie et al., 2017)* Reflections on research of social discovery apps (ex. Tinder) using participatory methods	Sydney, Australia	3	Incompatibility of IRB framework with realities of a digital research environment. Researchers conceded and devised workarounds to IRB pushback against issues of authorship. Researchers reflected that their justifications of ‘public domain data’ to gain ethical approval were ultimately not ethical – despite acceptance by the IRB.
(Cowan et al., 2021) Participatory project of the effects of the pandemic on young people’s wellbeing in south London	London, UK	1	Protracted ethical approval process was not compatible with the community need for urgency, resulting in the project achieving a lower impact than it would otherwise have.
(Distefano et al., 2013) Participatory research of HIV and HPV vulnerabilities in Mariana Islands and Tonga	Mariana Islands and Tonga	1	IRB practices did not align with community ways of working built on rapport and mutual trust, initially preventing effective collaboration of researchers with community advisory board (CAB). Dialogue eventually established by creating traditionally adherent meetings between CAB and IRB.
(Embleton et al., 2015) Participatory project involving street-connected children and youth (SCCY)	Western Kenya	1	IRB requirement of parental consent for children’s involvement in research was impossible to realise safely or meaningfully due to potential inability of parents to provide informed consent. Researchers granted a waiver for this requirement.
(Famlonga, 2023)	Beagle Bay, WA, Australia	1	Objections from community navigators were resolved within the IRB framework via ethics amendments. Clinical nature of project prevented full ownership of project in full. Within this

⁵ One of the cases was discussed twice, once from the researchers’ perspective, one from a member of the overseeing IRB. The researchers’ paper explicated the nature of the conflict while the IRB member provided insight into the legal underpinnings of the IRB’s decision. Both perspectives were valuable, hence two sets of extractions.

Participatory project of skin health with remote Aboriginal communities in Beagle Bay			framework, data sovereignty procedures developed with community navigators to the best standards available.
(Foster et al., 1998) Community-informed project gathering genetic data on factors in diabetes mellitus and prostate cancer Apache Tribe of Oklahoma	Oklahoma, USA	1	Extensive negotiations between university and community partners to establish a community-centred agreement for fair compensation to the Apache Tribe for setting up a CAB to facilitate the project, and 50-50 intellectual property rights over samples (usually solely owned by the institution).
(Heard, 2023) Art-based CBPR of intimate relationships and IPV in in Samoan community	Samoa	1	Risks of power dynamics inherent in IRB frameworks impacting informed consent in cultural context where deference and obedience towards power. Issues mitigated within IRB framework using ongoing informed consent and establishing meaningful dialogic partnerships with community members.
(Johnson, 2010) Participatory project of health needs among urban indigenous populations in Tulsa	Tulsa, OK, USA	1	Following initial concerns, the university and the Indian Health Care Resource Centre (IHCRC) legal counsels negotiated and reached an agreement to give full intellectual property rights over the research to the community, contrary to standard practices.
(Kia-Keating et al., 2017) Participatory photography project with LatinX youth	Santa Barbara, CA, USA	2	Significant concerns from IRB about risks which researchers conceded, ultimately choosing not to compensate participants to minimise coercion and requiring additional levels of agreement and agreed conduct by young researchers.
(Malone et al., 2006) CBPR of single-cigarette sales in community neighbourhood	San Francisco, USA	2	Despite considerable and protracted negotiation, researchers ultimately capitulated to the IRB. Researchers felt community values and safety were not respected.
(McDonald & Capous-Desyllas, 2021) CBPR of child caregiving by grandparents; CBPR of LGBTQ+ former foster youth	USA	3	Clashes stemmed from different community norms and expectations. Some issues like compensation could be navigated within IRB framework due to permitted researcher autonomy. Some issues like authorship could only be resolved democratically outside of IRB jurisdiction.
(Saleh et al., 2020) CBPR of air pollution in southern Malawi	Malawi	1	High risk of ethics dumping ⁶ due to IRB policies around compensation. Risks mitigated within the university's framework via a community fieldworker.
(Suarez-Balcazar et al., 2022) Two case studies of participatory projects with immigrant communities Note: (Kia-Keating et al., 2017) case repeated and not extracted	Santa Barbara, CA, USA	1	IRB and university policies prevented compensation without endangering a coresearcher. IRB safeguards were (while well-intentioned) inappropriate / counterproductive to participatory approaches and working methods. Researchers were able to work around this to compensate and build productive relationships with the community.
(Treffry-Goatley et al., 2021)	South Africa	2	CAB made multiple recommendations to researchers and approved changes, which required multiple rounds of re-approval with IRB. Protracted approval IRB processes made

⁶ 'Ethics dumping' here refers to the imposition of ethical norms and practices from a higher income context on a lower income context without due consideration by researchers of the potentially harmful sociocultural impacts, under the belief that such ethical practices are beneficial (Saleh et al., 2020).

Reflections on visual research project exploring HIV treatment adherence in rural South Africa			researchers reluctant to seek further amendment for their surveying, resulting in a less effective evaluation of the intervention.
(Wolf, 2010) IRB perspective of Malone et al.'s (2016) issues.	San Francisco, USA	3	Highlighted legal knowledge disparities between researchers and IRB, resulting in 'talking past each other', compounded by differences in terminological conceptualisation and communication issues.

Themes of ethical conflicts

As mentioned, eight themes of ethical conflict between community researchers and IRBs were identified. Ordered by frequency of occurrence, these are:

1. **IRB issues with financial compensation** [5 cases]
2. **Community ownership of intellectual property** [3 cases]
3. **Inability or difficulty making methodology changes** [3 cases]
4. **Incompatible risk governance / safeguarding concerns** [3 cases]
5. **IRBs rejecting co-designed recruitment protocols** [2 cases]
6. **Communication differences / barriers between IRBs and communities** [2 cases]
7. **Protracted ethical approval timelines** [2 cases]
8. **IRBs rejecting authorship in favour of confidentiality** [1 cases]

Below, we provide the relevant extractions for each theme, with associated analysis.

1. IRB issues with financial compensation

In the cases below, institutional researchers were unable or chose not to financially compensate community researchers / participants due to IRB concerns.

- **(Acton, 2019, p. 202):** "Not paying dancers for their labour was not considered ethical within CRIPSiE [Collaborative Radically Integrated Performers Society in Edmonton] [...] Unfortunately, concerns about the Research Ethics Office's objection to paying participants and the timing of arts granting cycles meant that I was unable to pay the dancers/researchers."
- **(Kia-Keating et al., 2017, p. 379):** "[...] the university internal review board (IRB) held concerns about the potential for coercion if we included a provision of \$25 gift cards to youth participants as an incentive for participating in the research interviews. [...]"

Some researchers have previously used incentives with youth participants in photovoice projects. [...] Despite these precedents, we ultimately chose not to have any financial incentive for participation in our project to reduce the possibility of coercion. Notably, our photovoice program was already embedded in the context of a high school class within which participants were getting graded and receiving course credit. Since these aspects could also be considered coercive, we assured all students in the class that their decision to continue or cease participation in the project once it began would have no consequence or impact on their grade in the class." (p. 379)

- **(Suarez-Balcazar et al., 2022, p. 323)** "[...] our university policies, following state and federal rules, limit the amount of payment that a research participant can receive without proper documentation, and in the case of someone who is undocumented, restrict pay for work altogether. Compensating the mother would also require her to disclose personal information that she was uncomfortable or not ready to provide. [...] We openly talked to Maria about our inability to compensate her for her time and

we also involved her in the discussion on how to address this issue. She continued to enthusiastically be the Zumba instructor while we underscored that she had no obligation to attend or lead all the sessions. Yet, she enjoyed her role tremendously, as well as the opportunity to take on a leadership role within the agency. She never missed a session. Collectively, we identified benefits she valued and made intentional efforts to provide those things. For instance, we were able to pay the maximum allowed by our institution without having to declare income, in the form of gift certificates. We listed her contributions to the project deliverables and provided her with a certificate upon completion of the program. Our efforts were not sufficient to compensate her for the actual amount of work she contributed, yet she appreciated such efforts." (p. 323)

Across these cases, the variation in reasons for non-payment of community researchers / participants is notable. In Acton's (2019) case, it is somewhat ambiguous whether the IRB did formally object to paying participants, or whether it was simply a concern among Acton and the other members of CRIPSiE that the IRB *might* object. Reading further however, we interpret their subsequent remark: "This was not the only time that the expectations of CRIPSiE and the university research clashed." (p. 202) as indicating that paying community members was formally rejected by the institution – though the question of **why** remains. It is possible that "coercion" (mentioned in the following paragraph concerning recruitment protocols (p. 202)) was a factor, but this is speculation. In any case, it is apparent that Acton's not compensating the dancers involved in their research was a decision made **for them** by the institution – despite it being antithetical to the values of those involved in the research.

Kia-Keating et al. (2017), meanwhile, chose not to compensate the students involved in their research. This seems to have been backgrounded by initial IRB objections to the proposal of gift card payments. While this is not explicated, it seems that coercion became a particularly active concern of the researchers following this objection, ultimately leading them to identify several other potential sources of coercion and thus choosing to not create another with remuneration. This could be seen as an IRB satisfactorily fulfilling its role – bringing ethical concerns to the attention of researchers to enable reflection that leads to more ethical research. As we will discuss in §4, however, this also speaks to an overarching question of whose ethics researchers, particularly institutional ones, choose to defer to.

Suarez-Balcazar et al.'s (2022) case is particularly interesting as it evidences the incompatibility of university legal obligations and policies (grounded in legal frameworks) with community research with certain communities – in this case, those who are not legally recognised or at risk of legal action should they come under scrutiny. Nonetheless, they were able to find a workaround with Maria that allowed her to receive what she saw as fair compensation while also being recognised for her work. This workaround, however, further invites the question of the potential risks of exploitation of community researchers when compensation occurs outside of institutional oversight. It appears that Maria was exceptionally generous with providing her time and labour to the research and would have been willing to do so regardless of the compensation she received. The institutional researchers themselves recognised that the compensation was insufficient for the value of her labour. While this does not appear to have been contextualised as problematic in this instance, it is easy to imagine how, having been pushed into alternative, non-financial means of remuneration by an IRB, and operating in a grey area outside of institutional oversight, less ethical institutional researchers **could** exploit the goodwill of community researchers and members.

Two further cases were also extracted under this theme, highlighting different issues:

- **(McDonald & Capous-Desyllas, 2021, pp. 367–369):** "We were conflicted with regards to wanting to support the youth in need while following the IRB protocol. It is not uncommon for vulnerable populations to view research as a transactional process to be negotiated. [...] Perhaps if CBPR principles had been incorporated into our institution's IRB practices it would have allowed for a flexible, on-the-spot collaborative consultation about how to proceed and tailor the originally approved

protocol.[...] We decided that in order to maintain the researcher–participant relationship it was best to provide the most marginalized youth with monetary reimbursement prior to collecting their photovoice data. This proved to be the right approach because it cultivated a sense of trust between the researcher and the participants." (p.367)

"Although CBPR promotes collaboration throughout the research process, neither of our studies was designed and approved by the IRB in a way that would allow for discussions about how funding would be spent. As researchers it was up to us to determine where the money would go from the beginning stages of both evaluations." (pp. 367-368)

- **(Saleh et al., 2020, pp. 524–527):** “[...] ethics dumping [is] described as ‘the export of unethical research practices from a high-income to a resource-poor setting’. Ethics dumping may take the form of export of research for the purposes of eluding strict ethical regulations or may be more subtle. Such cases include researchers applying lower standards of ethical scrutiny in the belief that their work is beneficial to vulnerable populations, particularly in low-income settings, or a lack of attention to sociocultural values in their research settings.” (p. 524)

“In settings of widespread economic vulnerability, decisions around provision of financial payments or goods and/or services can be complex. Ethics dumping here could represent researchers failing to fully value participants’ research contributions and thus providing inadequate compensation or by allowing monetary payments or other influences to increase participation among communities who would otherwise be opposed to involvement—so-called undue influence. Additional concerns around participant compensation, again rooted in wider contextual inequities, include risks of comparatively large payments disrupting household or local dynamics or adversely affecting local researchers through systemic inflation. These concerns reflect a contested field with decisions of what constitutes best practice unclear.” (p. 525)

“On application for in-country ethical approval, we learned that Malawian ethics committee guidance required monetary participant compensation amounting to US\$10 [...]” (p. 528)

“[...]US\$10 is a comparatively large amount of money, carrying the potential to cause disruption within and between households and, as some have proposed, ‘undue inducement’ to research participation. In our study, deep and honest engagement with residents and regular discussions with the resident fieldworker afforded an extra level of community feedback, and we saw no evidence of disruption or undue inducement in the study, although the possibility of undetected low-level disruption within the community remains. [...] In the current situation, however, where power imbalances left decision makers (usually senior researchers) able to make judgements, leaving a relatively disempowered population to respond by agreeing to participate or not, ethics dumping was a real risk. Our study design allowed us to solicit community views and alter protocols accordingly [...]” (p. 528)

The McDonald & Caspous-Desyllas (2021) case highlights how, even in cases where IRBs have no objections to financial compensation, there can still be barriers to this being done compatibly with other values of community research, such as collaboration and power sharing (Brown & Reitsma-Street, 2003; Burduladze et al., 2024). As, in this case, financial compensation and community consultation had to be approved simultaneously, it was not possible for the former to influence the latter, leading to the researchers holding all decision-making power. While this seemingly did not prevent fair compensation in this instance, it is easy to imagine a situation arising under this IRB’s framework which this would result in a community being unhappy with a remunerative decision.

The Saleh et al. (2020) case is striking for drawing attention to the phenomenon of ‘ethics dumping’. They helpfully illuminate several mechanisms of ethics dumping. In their case, the mechanisms of concern

seems to have been twofold: First, the project involved researchers from outside Malawi, with norms of research among UK-based researchers being shaped by the relatively higher income context. Second, the mandate of the Malawian ethics board to compensate participants originated in the relatively higher income context of a university compared to the community context. Despite this policy being a contrast to those of previously discussed IRBs – perhaps even seeming desirable in other contexts – the potential for inappropriate and unethical imposition of research norms persists, as described extensively by Saleh et al. Furthermore, we note that Saleh et al.'s consideration of these issues was something they took upon themselves to recognise and consider – it does not appear the IRB considered the issues they identified. Moreover, the institutional researchers were only able to monitor the situation through their community researcher, rather than implement any type of workaround.

2. Community ownership of intellectual property

In the case below, IRB regulations on intellectual property in clinical trials prevented an Aboriginal community from obtaining full ownership of their data, though they were provided the maximum level possible under Indigenous Data Sovereignty (IDS) guidance.

- **(Famlonga, 2023, pp. 51–56):** "During the consultation process with the community navigators, they also raised concerns for community members over the sharing of this knowledge as intellectual property and who owns the data they are sharing" (p. 51)

"Indigenous data sovereignty (IDS) principles recognise that Indigenous peoples and communities should own the data they provide to researchers. Due to this project being embedded in a pre-existing clinical trial (the SToP Trial), it was not possible for participants to retain digital copies of their data. This level of data ownership was based on the best standards of IDS guidance 56 that was available at the time the SToP Trial received ethical approval which meant that the host institution for the SToP Trial research (TKI) retained legal ownership. The AIATSIS Code for Aboriginal and Torres Strait Islander research highlights that "ownership, management and communication of research data results should be negotiated between Indigenous people and the researcher" (AIATSIS, 2020) and I have therefore engaged in continual consultation with the Beagle Bay community to ensure that the data is used and held in a way that is acceptable to the participants and the broader community. TKI and the SToP Trial recognise that this process is not equivalent to full Indigenous data sovereignty, which would be represented by the community having legal and physical ownership of the digital copies of the data. However, to operate within the current SToP Trial protocol and legal limitations of clinical trials, this is the greatest level of ownership and control that could be provided to the community at this time. This control which has been created in consultation with community includes the addition of several data sovereignty procedures to the project, including asking community navigators about where and by whom data should be stored, including study participants in data analysis sessions, and asking community members how the findings from this study should be translated to the wider community." (pp. 55-56)

Though the community involved in Famongla's research appeared not dissatisfied with the level of data sovereignty they were ultimately granted, this case speaks again to a non-resolution of conflict between an IRB and community interests. Only by finding workarounds within existing regulatory frameworks was it possible for the community to own most of, but not all, the data they shared with the project. This speaks to two key issues. First, there is a problematic power dynamic, incompatible with the norms of community research, whereby participants lose ownership of the data they share and can only reacquire ownership should it be granted by the institution. This likely speaks to deeper issues of intellectual property law embedded in IRB frameworks. The loss of ownership when data is shared with institutional researchers seems to appeal implicitly to the notion that the data shared by communities is a gift to institutional

researchers, which thus forfeits ownership – unless it is re-conferred by the giftee. This runs entirely contrary to the values and norms of shared knowledge and power in community research.

Second, it is apparent that this re-conferring of ownership was only possible because a clear legal framework to safeguard the intellectual property rights of Aboriginal and Torres Strait Islander people and communities. It seems plausible that, if another community, without similar legal safeguards, had raised similar concerns, they would not have been granted the same levels of ownership of the data they shared – if at all. This speaks to IRBs being less concerned with listening to and accommodating community interests than they are in ensuring **compliance** with legal obligations. While this had a positive outcome in this case, this general approach again runs contrary to the value of due regard for communities and their interests that is central to community research.

While Famlonga's case seems to be another instance of an institution seeking to merely comply with existing regulations, the following two cases illustrate frankly remarkable instances of communities, institutions, and institutional researchers working together to reach mutually beneficial solutions to intellectual property concerns:

- **(Foster et al., 1998, p. 698):** "The Apache CRB (community research board) functioned as the public arena for a dialogue in which investigators provided information and answered questions in eight formal meetings over the course of 6 mo. Members of the CRB, in turn, related specific features of the proposed agreement to their extended families. Questions or concerns that arose out of those discourses in private social units were brought up by the CRB when we met. Apaches discussed implications for the community as issues separate from those for individuals. They recognized that risks of stigmatization and discrimination would apply to all tribal members, not just to those who might volunteer as study participants. They asserted a communal interest even for biological specimens that would be individually anonymous, because of the use of the collective name "Apache." This communal interest was no less for stored materials subject to studies in the future. [...] A tentative agreement was reached, and a written draft prepared by the university counsel. The tribal CRB approved it unanimously. However, final approval by the Apache Business Committee was not given for several months, while private discourses continued in the extended families. Only after a consensus in these private social units became apparent did the Apache Business Committee approve the contract. The agreement includes funds to compensate the tribe for expenses of maintaining a CRB and helping to recruit volunteers. It does not obligate members to participate in the research. Nor does it supplant standard informed consent by individual participants. [...]"

According to long-established practice, as well as limited legal precedent, individuals who donate biological materials do not have legal claim on the intellectual property derived from them (Knoppers et al. 1996). In our agreement, the owner of any intellectual property is the university, the sponsoring institution. The subcontract, however, recognizes the unique contribution of the participating community in the creation of that intellectual property."

- **(Johnson et al., 2010, pp. 66–67):** "[...] the university legal counsel had some concern regarding intellectual property rights. As is standard practice, when the university research partners entered into a contractual agreement with IHCRC, the university legal counsel drafted a memorandum of understanding. This initial document awarded all intellectual property rights to the university and its principal investigator (a non-Native researcher). Although universities often use this practice to protect data and publication rights, it directly contradicts the core principles of CBPR (Israel, Schulz, Parker, & Becker, 1998; Viswanathan et al., 2004), which state that the research and its data belong to the community and its members. The university research partners and IHCRC staff agreed that the community and its representatives should have full intellectual property rights and discussed the situation with legal representatives for both parties for 2-3 months, educating the university about

CBPR and research with Indigenous populations. It helped that they presented a consolidated front; in the end, the university legal counsel made provisions in the contract so that the researcher could publish material from the project, in partnership (and with the approval of) IHCR and the community."

What is striking in both Foster et al.'s (1996) and Johnson et al.'s (2010) cases is the genuine negotiation between IRBs and communities. Unlike every other case discussed in this review, the IRBs in these cases were willing to amend their own position to better align with community interests and demands. The final agreements seemed to represent something of a middle ground between the two parties, rather than being communities ceding completely to the IRB position. It is notable that, in both cases, reaching an agreement that was sensitive to community demands was driven by individuals within an institution who were both cognizant of potential issues relating to intellectual property, and willing to act to mitigate those issues. This seems to have been a key ingredient in the remarkably democratic outcomes reached. It is clear in both cases that it **is** possible for IRBs to compromise their position and genuinely negotiate with communities, but that such willpower is found very rarely in the literature.

What is notable about all three cases here, which all, to varying extents, had positive outcomes for communities and community researchers, is that they all involved indigenous groups. It seems the presence of legal frameworks to protect the interests of indigenous communities; genuine regard for the authority and voices of community approval boards; and sensitivity to indigenous communities within institutions all played a role in these positive outcomes. The fact that positive outcomes or conflict resolutions were experienced far less frequently with other community groups is indicative of the importance of these factors in improving conflict navigation.

3. Inability or difficulty making methodology changes

In the cases cited below, institutional / community researchers experienced difficulty or were unable to make methodology changes that were co-designed and approved by a community. The Malone et al. (2006) and Wolf (2010) extractions have been grouped together as they discuss the same case.

- **(Acton, 2019, p. 203):** "[...] the dancers/researchers decided on the second to last rehearsal that they did not want to hold a focus group to reflect on the overall research process. [...] The dancer/researchers [...] proposed that I send them my focus group questions to answer, individually, over email. Changing from a focus group to an email interview, however, required me to submit an amendment to the REO. [...] this brief gap was baffling to a few of the dancers/ researchers [...]. There was confusion about why I would need to ask permission—after all they had unanimously told me to make this change to the research plan. In retrospect, I should have anticipated possible changes to the research plan and taken more time at the start of the process to educate the dancers/researchers on the role of the REO and why it exists."
- **(Condie et al., 2017):** "However, another set of ethical issues rise up when research participation moves into a more public online sphere. When we requested an ethics amendment to ask our online questionnaire participants if we could publish their stories on our website, our university ethics committee questioned this move. Our ethics panel queried the link between an individual's data and communicating the projects focus to participants to facilitate participant recruitment. In relation to the digital storytelling map, issues around anonymity are particularly important as participants may choose to forgo their rights to anonymity or they may inadvertently compromise their anonymity and that of others in the telling of their relational and spatial stories. As such, we have designed in a moderation system to anonymize any information that may identify other people within participants' stories. [...] While moderation shifts ownership of stories from participants to researchers, this design feature balances the needs to ensure rights to anonymity and confidentiality and extend those rights to others mentioned within participants' stories." (p. 152)

- **(Malone et al., 2006, pp. 1916–1917):** “IRB approval for an observational study was obtained [...] After the protocol was approved, however, the community research partners (all adults) discussed it further with the academic partners and decided that observation alone was inadequate. [...] The IRB refused to approve our modification for several reasons. First, they did not seem to appreciate the status of our community research partners, who were initially seen as subjects rather than as researchers. This misunderstanding led the IRB to believe that academic researchers were using money to solicit community partners to “commit an illegal act” rather than paying them as research partners. [...] The IRB also argued that trying to buy a single cigarette would constitute “entrapment” of store personnel. In our response, we pointed out that store owners and managers were already responsible for observing state laws as a condition of retail licensure and that store owners would be free to decline and explain that such sales were prohibited.” (p. 1916)

“Furthermore, the IRB did not believe that the anticipated benefits of the study justified what they still saw as a risk to store personnel however, the precise nature of that remaining risk, given our protection measures, was never specified. [...] Community research partners felt betrayed by the IRB’s rejection. In their view, the IRB chose to protect “community predators” over the health of the community itself. This seemed a bitter irony.” (p. 1917)

(Wolf, 2010, p. 78): “Controversy arose when the researchers sought to modify the study from a simple observational study to one in which the community researchers would seek to purchase a single cigarette in the local stores (Report on Research Compliance, 2006; Malone et al., 2006). There were several reasons for seeking this change. The researchers felt that it was not safe to loiter around some of the stores, and occasionally there was a lot of time between sales. Thus, it would be quicker—and safer—to try to buy a single cigarette and document whether the store would sell it. The REC did not approve this modification, even after the researchers, including community members, attended an REC meeting to address the REC’s concerns.” (p. 78)

The Acton (2019) and Malone et al. (2006) cases both exemplify a key issue under this theme: The need for institutional and community researchers to seek ultimate approval from an IRB, regardless of whether the research team / community have themselves reached a positive consensus. In both cases, this was felt by community researchers to undermine their autonomy and authority.

A less obvious, related issue in Acton’s (2019) case is the issue of institutional researchers – even when they are members of communities, as in Acton’s case – **automatically** deferring final authority to an institution. They would most likely have had to seek approval for modifications to their data generation protocol regardless of this reflex, and issues would have arisen regardless. It is notable, however, that Acton seems to regret this automatic deference.

Both the Condie et al. (2017) and Malone et al. (2006) cases exemplify, in slightly different ways, the issue of researchers being forced to work around IRB mandates. In Condie et al.’s case, to satisfy IRB objections, they were forced to develop a protocol that ran contrary to values of power sharing and co-ownership in participatory research (Brown & Reitsma-Street, 2003; Burduladze et al., 2024) In Malone et al.’s case, it is apparent that capitulating to the IRB rejection was felt to be itself and act antithetical to the research being community-centred, prioritising legal obligations and concerns over community ones.

4. Incompatible risk governance / safeguarding concerns

In the cases below, IRB regulations and concerns relating to risk management and safeguarding resulted in conflict between IRBs and communities and institutional researchers. The Malone et al. (2006) and Wolf (2006) papers have again been grouped together as they discuss the same case.

- (Embleton et al., 2015, p. 6):** "For most types of research, guidelines recommend parental permission for a minor's research participation [...] In certain situations ethics committees can grant waivers to the requirement for parental permission. [...] For SCCY [street connected children and youth] it is generally not possible to safely obtain parental/guardian consent. Firstly, many of the children who live full-time on the streets have either no identified parent/ guardian, or have no contact with parents/guardians [...] Children who are on the street during the day and return at night are frequently in neglectful and abusive situations, raising issues of safety. Secondly, for research on sensitive topics such as substance use and sexual reproductive health, parental permission may actually represent a risk, rather than a protection, and it introduces a risk of loss of confidentiality. Thirdly, while many SCCY may have adequate cognitive capacity to make autonomous decisions about their participation in research without a parent/guardian, in others, cognitive capacity is uncertain for a variety of reasons including: illiteracy, lack of formal education, substance use resulting in cognitive impairment, and very young age (<12 years). [...] *Mabaraza* [a traditional Kenyan community assembly] identified the community's perception of street children's capacity to provide informed consent and many felt street children could consent for themselves [...] Ensuring the community is informed and accepts that the research is going to be carried out was considered to be the first step in seeking informed consent for children to participate in research. Children older than 10 years were considered competent to make a decision regarding their participation in research. Study 1 and 2 sought a waiver of individual guardian consent because as per human subjects regulations, the studies were minimal risk, the studies could not have been practicably carried out without the waiver, and because the waiver did not adversely alter the risk-benefit ratio for participants." (p. 6)
- (Kia-Keating et al., 2017, pp. 377–378):** "[...] the university's internal review board (IRB) raised concerns about risks related to providing youth with cameras, such as potentially encouraging them to take photographs with risky content [...] However, if we were to fulfill our goals of equity and empowerment, it was also vital to allow youth to depict the reality of the challenges that they or their community faced without unnecessary constraint. [...] Given that the youth in our study all had personal cell phones with cameras, it is important to acknowledge that they already had constant access to a form of digital picture-taking and, as such, had the freedom to be taking photographs of any content, regardless of our study. Nonetheless, we wanted to encourage safe choices [...] First, we addressed this issue by providing participants with training on ethical practices in participatory photography. [...] Prior to receiving their cameras, participants signed a written agreement that they would obtain consent of all individuals represented in their photographs and would not intrude on an individual's personal space, disclose embarrassing facts without permission, or place individuals in false light with photographs."
- (Malone et al., 2006, p. 1916):** "Upon learning that we wished to appeal, the IRB referred us to the university's risk management department, which seemed uncertain about its role in the matter and referred us to the university's legal department. After considerable delay, the legal department informed us that it could not approve any university "involvement in illegal activity," but it noted that it could find no relevant legal authority or policy that prohibited the research activity we had proposed, because asking to buy a single cigarette was not illegal. After extensive research, the legal department determined that the IRB was the final authority and suggested in its written response to the IRB that the potential danger of violence to our community research partners might be a risk management issue for the university if the researchers were harmed while in the stores. The IRB again denied approval."
- (Wolf, 2010, p. 79):** "First, the researchers argued that the REC was confused about what role the community partners were playing—that the REC mistakenly understood that they were subjects when they were actually members of the research team. The researchers may be right; while I honestly do not remember whether there was confusion in this particular study, this is a common challenge for CBPR and REC oversight because CBPR community partners often perform dual roles—both collecting and providing data (Khanlou & Peter, 2005; Minkler, 2005; Shore, 2007). However, if data is collected about

community partners, as well as by community partners, then they may be human subjects under the federal regulations. If so, the REC has both a legal and ethical obligation to protect the rights and welfare of those human subjects."(p. 78)

- "Returning to the issue of the community vs. individual focus, some of the problems between the UCSF REC and the PHAT [Protecting the 'Hood Against Tobacco) researchers may have stemmed from confusion regarding the definition of "community." For those involved in the PHAT study, the community comprised those residents of Bayview–Hunters Point who had participated in the research collaboration through their engagement in deciding on a research question, and developing and carrying out the research protocol. The REC, on the other hand, had a broader view of what constituted the community. In addition to the Bayview Hunters Point residents who had collaborated with the academic researchers, the REC felt it had to consider the interests and well-being of those who owned, operated, and worked for the stores from whom data were obtained (Report on Research Compliance, 2006). Even if they were not human subjects as defined by the federal regulations, they were members of the Bayview–Hunters Point community whose interests and trust in research could be jeopardized if the REC approved the researchers' amendment."

Across these cases, the inflexibility and incompatibilities of existing IRB risk management and safeguarding approaches and regulation with participatory research are strongly apparent. The cases also exemplify the non-resolution of incompatibility, with researchers required to either capitulate or work around IRB requirements. In Embleton et al.'s (2015) case, the IRB framework provided the option of a waiver of normal safeguarding obligations, which resulted in the project being able to continue appropriate to the community context. It is, however, notable that the waiver was **not** granted because the IRB recognised the requirement of parental consent as inappropriate in the research context. Rather, the waiver was granted because the way SCCYs would be involved did not meet the threshold of risk to warrant a parental waiver. Thus, the **reason** for which the waiver was granted did not, in fact, reflect the community understanding that SCCYs needed and were able to consent without the agreement of a guardian / parent. Thus, while the institutional researchers were able to successfully (in terms of outcome for the community) navigate the IRB safeguarding requirements, this was only possible because they could reframe the competence justification in a risk-framework. It is easy to imagine an alternative scenario in which this would not have been possible.

For Kia-Keating et al. (2017), such reframing was not necessary; the potential hazard was risk-centred in both community and IRB understanding, and thus the institutional researchers could directly address the IRB's concerns – naïve as they may have been. Arguably, in their case, the protocols Kia-Keating et al. ended up implementing are a positive case of an IRB ensuring institutional researchers carefully consider **how** they are meaningfully ensuring the safety of their community researchers. It seems implied that, until the IRB flagged the risk, the institutional researchers did not have these protocols and training for their community researchers in place. Misplaced as the IRB's understanding of relevant risk may have been, the outcome was nonetheless positive.

The Malone et al. (2006) case, supplemented by Wolf's (2010) commentary, provides a stark, though usefully explicit exemplification of how risk management is approached by IRBs through embedded legal frameworks. It is clear that it was the federal laws, to which the IRB was bound, were at odds with the desires and interests of community researchers, more so than the IRB itself. The total inflexibility (insofar as the IRB was able to change them) of federal laws thus led to a situation in which both the IRB and researchers were able to genuinely negotiate: the IRB had a completely fixed position it could not shift, and the community researchers could only concede their values and beliefs or change them fundamentally.

5. IRB rejection of co-designed recruitment protocols

In the cases cited below, IRBs reject recruitment protocols that had been co-designed between institutional researchers and communities, and already approved by those communities.

- **(Acton, 2019, pp. 202–203)** “[...] the REO suggested that I change my recruitment procedure to navigate my position of power [...] and avoid coercion. Initially I had suggested that I would email potential dancers/researchers directly to inform them of the study. The reviewer suggested that instead, I should provide my supervisors with contact information and one of my supervisors would email potential dancers/researchers. When I took this change to CRIPSiE’s research review process it was roundly rejected. The artistic associates were not comfortable with someone outside of the community, who artists had never met, emailing them to recruit them for a study. They suggested instead that my Co-Artistic Director email potential dancers/researchers. This change was accepted by the REO, but reveals different assumptions about where the moral authority of the project was located.”
- **(Treffry-Goatley et al., 2021, p. 6):** "When we first presented our proposal to the CAB [community approval board], we were planning to run the workshops at our Institute, which employs hundreds of people from the local community. Yet CAB members immediately identified the risk of HIV disclosure as an ethical concern. They were concerned that if community members heard that the workshops were about ART and HIV, they might assume that all of the participants were HIV positive, and this could lead to stigmatization. Consequently, they suggested we hold the workshops away from the Institute at a private venue. Once we had adjusted our proposal, and received official approval from the CAB to proceed, we sent it to the REC for review. Although the REC saw the value of applying PVM [participatory visual methodology] to learn more about HIV drug adherence and to stimulate community engagement with this pertinent health topic, they argued that sharing personal stories about HIV in a context where stigma and discrimination prevailed was too risky for the participants involved. [...] Consequently, we revised the proposal over three rounds of review [...] before proceeding with project activities."

Both the Acton (209) and Treffry-Goatley et al. (2021) cases reveal a core issue of decision-making power ultimately not residing within the communities generating the research. In both cases, the communities co-designed recruitment protocols with institutional researchers and had this approved by the community. We can likely infer that the respective communities each felt that this the research, *in that form*, was something that they were willing to be involved with, and that risks had been satisfactorily mitigated. Despite this, IRBs still determined that the project contained impermissible levels of risk to the community. Such overruling makes plain that IRBs see themselves as being in the best position to judge risk – something which Acton noted was deeply undermining of community authority and agency. This is even more stark in Treffry-Goatley et al.’s case, where the IRB overruled a decision by a community approval board, a community body with designated authority over research involving their community.

6. Communication differences / barriers between IRBs and communities

In the cases below, communication differences and barriers between IRBs and communities resulted in or contributed to conflicts or working difficulties.

- **(Distefano et al., 2013, p. 71):** “[...] the CAB was initially reserved in its demeanor, which limited its critical input, and was both reflective of and antecedent to persistent mutual trust issues among the CAB, the CBOs, and the university. [...] This lack of personal and reputational rapport presented a barrier to open participation among Tongan and Chamorro community leaders, who culturally gauge relationships based on reputation in the community more than any other measure [...] Our solution evolved to engage the CBO partners in bridging the cultural gaps between the CAB and CSUF. [...] We achieved this mainly by conducting PI-style CAB meetings, attendant to Tongan and Chamorro cultural traditions.”

- **(Wolf, 2010, pp. 80–81):** "I think part of the problem may lie with its procedures, which are not unique among RECs. The REC relies primarily on written correspondence. As anyone who has written an e-mail that has been misinterpreted can testify, tone and nuance can be tricky in electronic correspondence. Moreover, the correspondence summarizes the REC's decisions and may not capture the full extent of the REC's considerations. The UCSF REC encourages researchers to contact staff (there is an REC staff member assigned daily for that purpose) at any stage, and individual REC members may and do contact researchers with questions. Nevertheless, these communications may not reflect the views of the full board, and indeed, they may not even be shared with the full board." (pp. 80-81)

"Some RECs invite researchers to present their protocols at a convened meeting when their protocols are being reviewed. The UCSF REC relies on its members to present the protocols they review which, as described above, may be based on communications with the researcher. Researchers are invited to a convened meeting only if issues have not been resolved after multiple requests for revisions. This stage of the review is the last chance for approval. This is what occurred with the PHAT study. Thus, the stakes were high, and the meeting was formal. It took place at the normally convened REC meeting in a UCSF conference room. The UCSF researchers and community partners attended and were seated at the end of the conference table. Looking around, the community partners would have seen few REC members that looked like them, which would be true for other RECs (Ball & Janyst, 2008; Catania et al., 2008). I know that the REC was supportive, in principle, of the PHAT project, but the UCSF researchers and community partners entered that room distrustful of the committee and of its commitment to its mission. The situation placed the researchers and community partners at a disadvantage. I am not at liberty to disclose what occurred during the meeting, but anyone who has read the Malone et al. article can surmise it did not go well." (p. 81)

Both the Distefano et al. (2013) case and Wolf (2010) commentary on the conflicts in the Malone et al. (2006) case illuminate how the working, and particularly communicative practices of IRBs can be both incompatible with or contrary to community ways of working. The dimension of cultural sensitivity (and initial lack thereof) is particularly apparent in Distefano et al.'s case, and highlights how the heterogeneous meanings of 'dialogue' between different communities are not reflected in the frameworks or practices of IRBs and their homogenous understanding. It was fortunate in this instance that the institutional researchers exhibited sufficient awareness and sensitivity to bridge these differences. It is easy to imagine such differences could easily have escalated into greater conflict or simply been insoluble due to lack of dialogue, were it not for this facilitation.

The commentary by Wolf provides a particularly intriguing insight into the communicative practices of IRBs and the associated potential limitations, particularly a lack of transparency around IRB member viewpoints. A lack of transparency itself runs contrary to the norms of community research, where many key values such as power-sharing and democratic decision making depend on there being trust, which depends on transparency. The impacts of a lack of trust on the outcome of conflicts is plain in Wolf's commentary. It is apparent that at least some members of IRBs are aware of the limitations of their communication practices. For as long as communication practices remain unchanged, however, it seems unlikely that this awareness can meaningfully translate into better outcomes in ethical disputes in community research.

7. Protracted ethical approval timeframes

In the cases below, institutional and community researchers experienced (to varying extents) compromised research outcomes due to the length of time it took for ethical approval to be granted.

- **(Cowan et al., 2021, p. 150):** "It also turned out that rapid research isn't always so very rapid, and sometimes it really isn't rapid enough. We started applying for Dystopia Now! in April, but funding wasn't secured until July, and then we only received ethical approval in August. By the time we had coordinated and started putting on workshops with young people it was October. The first lockdown was long past and, as we found out, many young people were tired of speaking about how COVID-19 had affected their lives. While Bella and Destiny, along with their advisory group members, agreed that it was good to keep talking about it, and far better to do so through a fun, creative process, our questions no longer seemed so urgent."
- **(McDonald & Capous-Desyllas, 2021, p. 367):** " If we were fully able to apply CBPR principles in the design phase of the study it would likely have enhanced our understanding of the context and provided participants with an equitable role in designing the study."

Researchers of course have the option to address issues that emerge during the research process by modifying and resubmitting protocols. There were two factors that contributed to our decision not to pursue a modification of the protocols in both studies. The first was that our IRB was undergoing an extensive audit during the time that caused 5–8 month delays for both new submissions and modifications. [...] The second reason stemmed from [...] We had spent significant time building trust with participants. We were concerned that modifying the protocols would indefinitely delay the photovoice portion of the project, while other aspects of the evaluation moved forward. We ultimately made a judgment call to deliver what mattered most to participants, the photovoice portion of the evaluations." (p. 367)

In the Cowan et al. (2021) case, it is apparent that the research outcome was compromised by the urgency of community interests not being met with corresponding urgency in IRB timescales. This seems to have led to reduced relevance and impact compared to if approval had been more expedient. It seems there was no way for the researchers to express this urgency to IRBs – not that this is likely to have made any difference, but it nonetheless underscores a lack of dialogic engagement between IRBs and communities and researchers.

The McDonald & Capous-Desyllas (2021) case highlights how ethical approval timelines can be a deterrent to doing what would be ideal or most beneficial for a project. It is clear the institutional researchers were cognizant of the limitations of their study design due to a lack of ability to consult the community they were working with. This is itself an issue, but remaining on theme, the researchers were then forced to choose between rectifying limitations of the project and potentially compromising the quality of the research and community researcher relationships by further delaying the project; or preserving relationships within a somewhat compromised research design. The fact that approval timelines factored so heavily into their decision is a significant issue, as it seems to have come at the expense of other values in community research such as co-construction. Furthermore, it appears this choice was one McDonald & Capous-Desyllas, as institutional researchers, made unilaterally without consultation with their community researchers. The reasons for this are unclear, but it highlights a further issue of power-sharing in decision making that likely would not have arisen had there been a more expedient approval timeframe, and thus a genuine choice for the institutional researchers to present to their community researchers.

8. IRBs rejecting authorship in favour of confidentiality

In the case below, McDonald & Capous-Desyllas encountered issues with their IRB refusing to allow participants claim authorship as this would make them identifiable.

- **(McDonald & Capous-Desyllas, 2021, pp. 368–370):** "We struggled with wanting to honor confidentiality while not being paternalistic. Rather than taking power away from participants, we

affirmed their decision to use their real names [...] Our ability to have participants use their real names in the exhibit phase of the process was enabled by the fact that it did not fall under IRB oversight. While the IRB does approve protocols where participants consent to being identified by name, it usually occurs in studies that involve nonvulnerable populations." (pp. 368-369)

"Given that the community art exhibits were not under the guidance of the IRB, we were in a position to engage in a dialog with community members and negotiate culturally appropriate standards for the representation of photos. [...]

One of the ethical dilemmas that the research team most successfully navigated fell outside of consultation with, or guidance from, the IRB. The art exhibits were a phase in both projects where the process was most collaborative and democratic." (p.370)

It is clear that conflict was not resolved – instead, the institutional researchers found a workaround by using a community art exhibition, outside the IRB’s jurisdiction, to identifiably platform some of the work of their community researchers. Two key issues are apparent here. First, and consonant with previous points under Theme 5, despite community researchers choosing to accept or take on certain risks, the IRB still saw fit to overrule their decision, clearly placing the locus of power as outside the community. Second and relatedly, the interactions between institutional and community researchers were most democratic outside of IRB oversight. Within IRB oversight, it is apparent the institutional researchers felt particularly bound to the regulations of their institution and held a much greater share of power than their community researchers, pointing to IRB regulations reaching further than their direct manifestation in approval schemas into pervading the practice of researchers themselves. This recalls previous points raised under Theme 3, discussing Acton’s (2019) reflections. While this is arguably not an inherent negative, and did not seem to be strongly so in the McDonald & Capous-Desyllas (2021) case, it is nonetheless another important exemplification of this phenomena.

4. How can we understand these findings?

Even at first glance, it is apparent that the thematic groupings of issues discussed are related to each other to varying degrees. We contend that this is owing to them all being encompassed by a single, superordinate theme that explains the fundamental source of these issues – namely, conceptual and cultural differences between community researchers (and community representatives in some cases) and IRBs. As indicated in our analysis, community researchers often had very different conceptualisations of their role, ownership, and stakes of the research to those of IRBs. The literature indicates conceptual understandings among community researchers are often centred in the norms, practices, and (particularly in the case of aboriginal indigenous communities) traditional customs of their specific communities. Differences arose with these being unaccounted for or incompatible with IRB definitions, frameworks, and or legal obligations. These differences often led directly to conflicts with IRBs and further secondary conflicts.

A key conceptual and cultural difference that underpinned numerous conflicts is norms of decision-making – specifically, **who** community members feel is allowed to have a say in decisions concerning the interests of their community. The reviewed literature makes apparent that, for many community members, the right to have a say in decisions is dependent on earned trust through relationship building. Most often, trust is built through someone being a member of a community or, in the case of community outsiders like non-member institutional researchers, through perceiving ways of working that show due regard for the community’s values and agency. IRBs are, most often, due to lack of direct engagement with communities, perceived as outside this relationship of trust and are thus not entitled to a say on community interest. Despite this, de jure and de facto, the IRB **is** the final authority on all community research with institutional affiliation. This ability and entitlement to have a say in decisions, while circumventing the trust-building process has, evidently and understandably, been, at best, a source of confusion – at worst, a cause of outrage and offence. In addition to being contrary to established norms of community practice, the fact communities did not hold final authority

was felt to diminish and undermine their agency and autonomy, while implicitly calling into question their capacity to make reasoned decisions in their best interests. This infantilisation / paternalism became explicit reality when, in many of the cases above, IRBs either challenged or overruled community decisions.

It was apparent in most cases, people were not (or not adequately) informed by institutional researchers about the fact that agreeing to involvement in institutionally affiliated research would, necessarily, involve surrendering their ability to be a final authority on decisions. It seems this transfer of power was not discussed because institutional researchers assumed (without reflecting on their own immersion with institutions and their practices) that this was obvious, or because they failed to appreciate how contrary decision-making that circumvents of trust and relationship building would be to the values of the communities they were working with. This failure to fully inform and manage expectations thus resulted in surprise when the full nature of the IRB's control was revealed, and likely exacerbated the ill-feelings previously outlined. Moreover, in several cases, it appears that this, in conjunction with the discovery of (unintended) non-transparency did some damage to the relationships between institutional researchers and their community partners. This underscores the importance of reflexivity in the practice of institutional researchers to ensure communities, as institutional outsiders, are fully informed of what their involvement in institutionally affiliated research entails, particularly with regards to how conceptual and cultural norms differ, and how they will be required to surrender power.

Of course, identifying the weakness in practices of institutional researchers, while not quite 'missing the forest for the trees', is to overlook the central issue of **why** institutions are able to circumvent or disregard community norms in decision-making and have the power to reject or challenge decisions communities have already determined are in their best interests.

As public bodies, higher education institutions are expected and obligated to comply with and uphold what is legally in the broader public interest (Higher Education Better Regulation Group (HEBRG), 2011). Failure to meet these obligations places the wider institution at risk of legal action and corresponding financial and reputational penalties. As bodies within universities, IRBs also hold this responsibility. Further to this, IRBs are legally expected to safeguard the rights and safety of researchers and participants, in accordance with (as illuminated by Wolf's (2010) commentary) definitions set by public bodies – such as government regulators. IRBs are only able to approve individual community decisions if as they are consistent with or not a risk to compliance with these legal obligations. Here, definitions community's members may have of, for example, 'safety', and 'vulnerability' may compete with the definitions an IRB **must** use. As such, disregard for alternative definitions is unavoidable during the decision-making process of IRBs.

Furthermore, IRBs are not directly accountable to the interests and values of specific communities. While, as mentioned, IRBs are accountable to the public interest as defined by legal and regulatory scope, this accountability does not extend to the norms and values of specific communities. This lack of accountability licenses them to act outside of community norms and to overrule community decisions. Community members can either give up on their desired outcome and accept the IRB's decision, or they can hold onto their desired outcome and cease involvement in the research. Clearly, neither outcome is desirable with regards to upholding values of community agency and autonomy. Communities should have agency in decision making. They should be co-drivers, not mere passengers. Ethical processes should involve working together to safely and effectively reach a mutually agreed destination, that is itself constantly reviewed for suitability.

Unsurprisingly, the legal license for defiance of community norms and overruling of community decisions is most often not explicated to communities and researchers – both community and institutional. As was starkly apparent in the Malone et al. (2006) case and Wolf's (2010) commentary, for as long as IRBs continue to be non-transparent in their legally centred reasoning for challenging or rejecting community decisions, communities will continue to perceive these decisions as baseless and autocratic. A reality in which IRBs and communities 'agree to disagree', but understand each other's reasoning, is preferable to one in which they

simply disagree. This being said, as much as this review underscores the importance of IRBs and institutional researchers being transparent with communities, improving transparency ultimately amounts to little more than improved expectation management. Disclosing obligations to and justifying decisions in terms of immovable legal definitions does not absolve or erase the fundamental issue of IRBs and communities working and conceptualising things in different, sometimes incompatible ways.

How, though, do we account for the Foster et al. (1998) and Johnson et al. (2010) cases (and, to a lesser extent the Famlonga (2023) case) where IRBs **did** engage in genuine negotiation with communities regarding intellectual property interests? As previously discussed, these cases all involved indigenous communities, with established legal rights and protections. These legal frameworks grounded a formal accountability to the interests of the involved communities. Thus, it seems the involved IRBs were legally obliged to make adjustments to their standard agreements that reflect the interests of the involved communities. These cases thus do not transcend our central contention that IRB accountability to community norms or interest extends only so far as the law requires – rather, they seem to exemplify it.

We should, however, not be too cynical in interpreting these cases as ‘mere compliance with the law’. It is apparent there was a genuine desire and interest from members of IRBs in the Foster et al. and Johnson et al. cases to work with the involved indigenous communities and to find ways to reach agreeable solutions to the issues their members raised. The authors’ presentations of these interactions suggest that legal frameworks provided a **mechanism** for these desires to be enacted – compliance was necessary, but not the principal motivator. Nonetheless, without legal mechanisms, it seems likely these desires would have amounted to little more; the involved IRBs (as collective entities) would not have had any legally obliging reason to consider the concerns of the involved communities, let alone find a mutually agreeable solution. These cases importantly illustrate how legal frameworks can, to an extent, transcend being merely apathetic compliance to being that which enables meaningful implementation of individual desires to uphold the values of ethical research.

Identifying conceptual and cultural differences and legal license for IRBs to impose their conceptual and cultural norms, practices, and understandings on specific communities does make addressing the question of what is to be done to improve things very difficult. Changing culture and ameliorating differences, particularly where existing laws are not conducive to such (and arguably even encourage non-resolution), is far from straightforward. It is apparent that whatever solution is found should oblige IRBs to specific community values and ways of working as much as to their public-sector responsibilities. What actions, however, this requires, particularly from a legal standpoint, is beyond the scope of this review to propose, and further research is required to understand what may be viable.

5. Limitations

This was conducted over a relatively short (15 working day) period, resulting in numerous pragmatic compromises being made. This included use of only one database; very strict inclusion criteria; and not exhaustively reviewing every search result. This, in conjunction with the inconsistent and interchangeable use of terminology to describe community research (e.g. Participatory research, participatory action research, community action research, CBPR) means it is highly likely some case studies that would have met our inclusion criteria were missed. This would likely have contributed some extra themes of issues and or made the case for existing themes even more robust.

The decision to use Google Scholar was primarily driven by the research team’s familiarity with the database from a previous project (which eliminated the need to spend time gaining database familiarity). Of course, Google Scholar is known to have issues and limitations such as replicability of results; citation metrics contrary to academic norms; platforming of unethical journals; non-transparency of algorithmic rankings; values and

practices contrary to those of open research; and susceptibility to fake research due to databasing by web-scraping (Coiffait, 2019; Elliot, 2024; Goldenfein & Griffin, 2022). These issues, however, are not unique to Google Scholar, and some of these disadvantages are also arguably strengths. For example, databasing by web-scraping increases the breadth of literature captured (Coiffait, 2019; Elliot, 2024) – Scholar is highly effective at pulling ‘grey’ (non-peer reviewed) literature in addition to peer-reviewed literature (Haddaway et al., 2015). Haddaway et al. have cautioned that Scholar should not be used in isolation to perform a systematic review. However, as stated in §1, this review is not a systematic review. Considering the pragmatic, ethical, and conceptual factors together, it was decided that for the purposes of this research, there was no decisive reason against using Scholar as a database, and strong reasons in favour of pragmatism and efficiency.

6. Conclusion

This review sought to explore how community and institutional researchers navigated ethical conflicts with IRBs when undertaking community research. We found eight themes of conflicts across 15 case studies. Most of these conflicts were not resolved, with researchers capitulating to IRB decisions. Only in two cases did IRBs engage in genuine negotiations with communities to reach a mutually agreeable decision. We argue that at root cause of all these conflicts are conceptual and cultural differences between institutions and communities, most notably in the way decisions are expected to be made. Greater transparency from institutional researchers and IRBs about what involvement with institutionally-affiliated research entails will lead to better informed involvement – though this is ultimately expectation management, rather than a genuine solution to this conceptual and cultural gap. Further research is required to investigate how ethical processes can be altered to obligate IRBs to communities as much as to their public-sector responsibilities.

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