

# Inspiring Ethics in Social Health Research

This concept note recounts the voyage of our autonomous research group, Inspiring Ethics, towards better university and hospital ethical practices in cross-cultural, survivor, user-led and international social health research. We discuss how we initially came together as a crew to share our research ethics dilemmas and frustrations. We present the ethical map we created, where we charted the troubled waters of university ethics processes. We discovered that depending on our methods and positionalities, we focussed on slightly different issues including the pace and flexibility of the ethics process, its bureaucratisation, the use of vulnerability framings and the imposition of Western values. This note ends with fair weather, describing the different solutions sprouting from our group. This ranges from ethics committee reformation to a full-scale academic revolution. We invite the reader to join our discussions and attempts at change.

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## Introduction

"I run this group and know how to work with them." That is what my Iranian co-researcher said as I sought consent from participants at their migration charity. This was a loaded statement, pronounced after an hour's frustration watching me laboriously go through university ethical requirements to blank, bored faces. The implication of the statement was that I was undermining their knowledge and experience as a community leader, that the imposition of university ethical procedures was paternalistic, and that the values I was communicating were not entirely relevant to the people I was working with.

It was experiences like the above that encouraged my colleagues and I to start thinking about how to make ethical processes around participatory, cross-cultural, survivor, user-led and international research more meaningful. This note describes the voyage of the informal research group we created, Inspiring Ethics. It recounts the discussions and difficulties we had, and the fledgling solutions we proposed. IN this note, ethical processes mean the processes university-based researchers undergo to ensure that their research meets certain ethical standards. These processes usually require approval from a committee.

## Port of embarkation: Collecting people and knowledge

The Inspiring Ethics group started through academic colleagues and grew to include non-university-based members. Our first meetings were trust building exercises, and several members prefaced their comments with the question "Can I just check that our discussions here are confidential?". The legalised language of university and hospital ethics had made researchers reluctant to discuss issues frankly for fear of sanction and allegations of misconduct. We realised that simply creating a trusting confidential space to discuss

ethics was an important step in pushing for change. In this space, without fear of repercussions, we were able to start talking about the disconnect between our experiences satisfying the requirements of ethics committees and the practical realities of conducting a research project in an ethical way that benefits participants. These discussions led to solidarity and support for colleagues through their ethical problems.

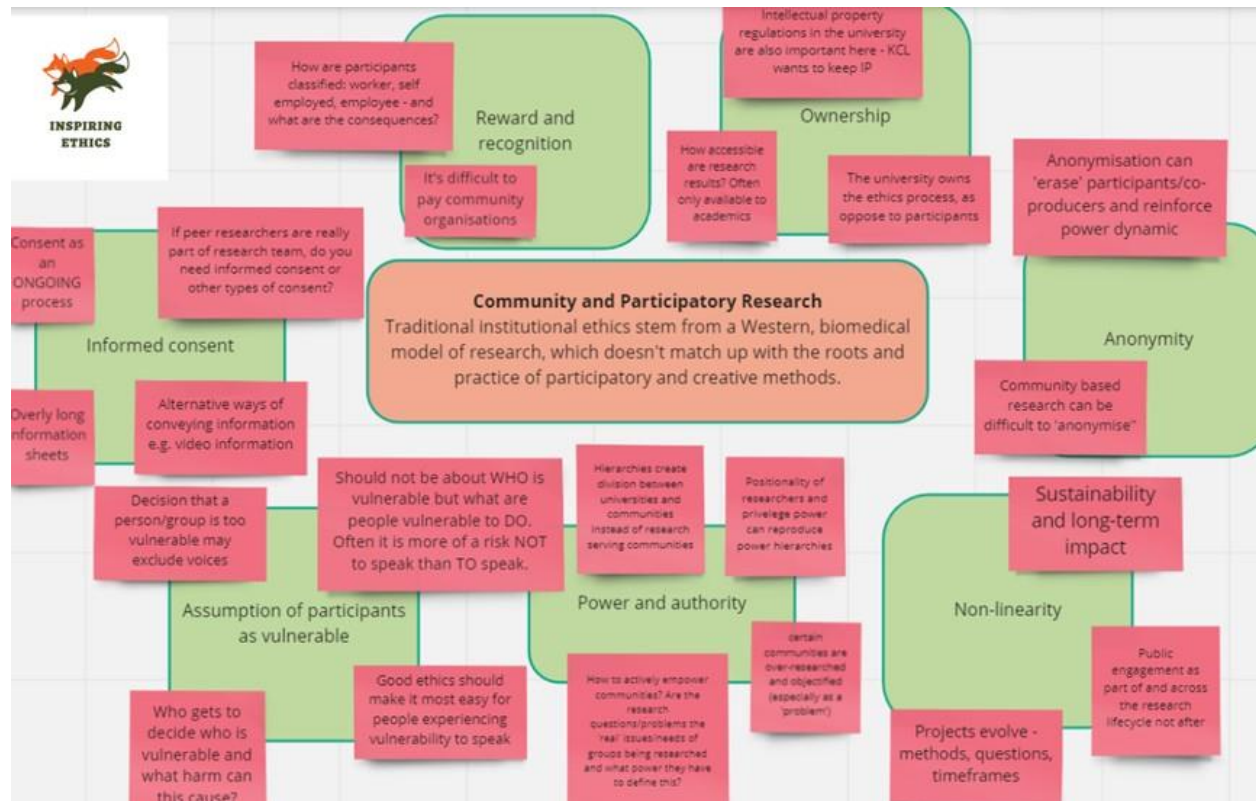
We felt an urgency to our voyage because, counter to the purported aims of ethics processes, they were leading to participant harm and exploitation. Members of the group, for instance, described how the rigidity imposed by university practices around payments could be harmful. The refusal to compensate participants for their time or to only pay in vouchers was often perceived as disrespectful of lived experience, patronising and even exploitative when compared to researcher salaries. Group members felt that the model of 'expert-by-experience' steering committees where members do not get paid, reproduced social inequalities both symbolically and materially. Relatedly, group members discussed how researcher and university control and ownership over data could lead to extractive relationships with participants, where stories and experiences are "stolen" with little benefit. Yet, these issues around payment and ownership were often overlooked by hospital and university ethics committees.

In the first few meetings we decided that, like any good researchers, we needed to begin our project with a literature review. Having identified key areas of concern around conceptualisations of vulnerability and risk, sensitive topics, power, community-based participatory research and cross-cultural settings, we undertook a collaborative rapid scoping review of published literature. This included academic articles and guides produced by community organisations. We explored how the bioethical values often promoted by universities, the technical and mystifying language used in consent and information forms, and the lack of representation on institutional ethics boards risks reproducing exploitative power dynamics that harm research participants. We felt that addressing ethical processes was a matter of social justice, and an integral part of being an academic.

Navigating stormy seas: Mapping out the problems we face

Through our literature review, discussions and presentations, we amassed a treasure chest of ethical quandaries. Given that many people in our group specialised in creative and/or arts-based methods, we decided to sort and map the ethical challenges we encountered visually. We created mind maps for ethical challenges around informed consent, reward and recognition, the practical difficulty and potential harm of anonymity, ownership of research, research values (e.g., around bioethics and power), funder requirements, bureaucratisation and more. **Figure 1** demonstrates our thinking around how these issues intersect with community-based and participatory research.

**Figure 1 – A Visual Summary of Ethical Challenges around Community and Participatory Research**



The process of mapping our ethical issues was complicated due to our different backgrounds, methodologies and subject areas. We managed this process through honest conversation and openness. It was important to acknowledge that there were different perspectives on our ship and to build a map that included everyone’s concerns. The following subsections describe each of those perspectives. Please note that many of the below perspectives are overlapping and members of our group occupied multiple positionalities. Even methodologically, many group members used several approaches.

*The community-based participatory research crew*

There was a strong current of thought coming from community-based participatory research (CBPR) in our group. CBPR researchers saw fundamental issues with the pace and flexibility of ethics processes. They felt that ethical approval took too long, often at the cost of building lasting relationships with communities, recruiting enough participants and project momentum. They disagreed with the expectation from ethics committee that projects complete the ethical process before they start the research, arguing that ethics needed to be based on trusting relationships developed over time and an ongoing, iterative process of negotiation throughout the project.

CBPR researchers also felt that ethics process inefficiencies affected the flexibility and collaborative evolution of projects, as each methodological adjustment or addition to the research plans must be passed by ethics again. Moreover, in CBPR, the direction or narrative of the inquiry and the methods used to explore the chosen topic might shift throughout the research process. Flexibility is the strength of these

methodologies, however, the current process of gaining ethical clearance does not allow this flexibility and consequently compromise the core of truly collaborative research practices.

#### *The Practiced Hands*

There were some in our group using more "traditional" methods, but who still saw problems with incomprehensible ethics documentation. These members did not necessarily want to see an ethics revolution, but they felt that there were elements of the university ethics process that could be usefully changed at relatively little cost. They felt that university and hospital research ethics processes are often cumbersome, time-consuming, and alienating to researchers as well as participants. For example, information sheets are dense and heavy-handed, while consent forms seem like a written contract to many participants. In certain nationalities and with people in certain legal situations (e.g., an asylum seeker) there is a hesitancy and fear in signing documents. The 'legalese' that comes with data sharing agreements may be off-putting. The principle of non-maleficence (do no harm) appears to have been warped into ever-expanding sections on the ethics form which are there to safeguard institutional reputations and ensure that institutions do not get fined for breach of GDPR.

The bureaucratisation of university and hospital ethics meant that it can quickly become a tick-box exercise for researchers and participants. Many participants do not understand the purpose of ethics, and these can require many months of work as well as a knowledge of academia to fully understand. The one-size-fits-all requirements of university and hospital ethics can also discourage, impede, or forbid these more extended and/or fluid and trust-based relationship-building interactions.

#### *The Survivor Farers*

Survivor, service user and lived-experience perspectives had a strong voice in our discussions. Though these are distinct positionalities, all three groups were concerned with the vulnerability framing of university ethics processes and the associated pledge to "protect" participants. This caused challenges around agency and autonomy. Survivor and lived-experience researchers recounted how the vulnerability framing of research ethics could be obstructive. Ethics committees frequently asked the offensive question, "How can someone who is a survivor of mental distress or traumatic events be an independent, lead researcher?" and then proposed additional protective measures often in the form of a non-survivor or lived-experience co-lead. This vulnerability framing clashed with request from committees and research departments to demonstrate meaningful patient and public involvement.

Relatedly, in our experience, ethics committees often position people with lived experience as those to whom things are done and extracted from. In their mission to protect "the vulnerable", they police the boundary between researcher and researched. So preoccupied are the committees with that boundary that, increasingly, researchers must argue that people with lived experience or service users in advisory groups are not participants and therefore are not required to submit written consent. The discourse of vulnerability leads to gatekeeping under the guise of care. There is the implicit message that participants and those with lived experience should know their place.

#### *Cross-Cultural Navigators*

Those focussing on cross-cultural research often struggled in imposing Western university ethics values on participants who had a different set of values linked to their culture. In the experience of our group, cross-cultural values are not respected in university and hospital ethics. In migration research, for example, there can be a difference between the principles prioritised in researcher ethics and migrant community values. For example, in their work, one of the group members found that 'ethical principles in

Iranian and Afghan diaspora communities centred on engagement, responsibility and personal relationships' (Author 2022). Participants were supported through the diaspora and there was an associated expectation that everyone had to contribute. People often, therefore, engaged in research out of a sense of community obligation.

Landfall: Potential solutions to the problem of research ethics

We do not want to stop at identifying problems with ethical processes. We also hope to guide what good ethical practice in our fields might look like. Thus far, our group has proposed several suggestions on how to address some of the ethical dilemmas we, and others like us, have raised. These will be developed, challenged and complicated through further investigation of relevant literature, discussions with other researchers, and workshops with research participants.

*Reforming university and hospital ethics*

University and hospital ethics committees could begin to address the above issues by adopting a model of relational ethical dialogue (as suggested by Larkin et al. 2008). Ethics committees could engage with researchers on the 'nature and value' of their work and adopt a shared decision-making model. This could include open meetings with the researcher, getting to understand their project goals and meeting potential participants to discuss ethical values. In this spirit of transparency, ethics committees could be clear on who sits on their board, how long they sit for, how many members are non-academics etc.

In the context of participatory research, ethics committees could consider dropping consent forms. If something is really co-led, why should a partner sign a consent form? Research projects could instead create terms of reference that all partners help write and sign on to. Terms of reference could outline everyone's roles and responsibilities and how they should behave, as well as potential risks and how they will be dealt with. This could be reviewed by an ethics committee to ensure that all the necessary protections are in place.

However, some in our group felt that university and hospital power structures limit the potential for reform and a move towards relational ethics. Firstly, the university is designed to protect itself legally and reputationally, before participants. Secondly, many Western institutions have inherited a colonial legacy that prioritises certain forms of knowledge. Thirdly, universities are increasingly neoliberal and cannot cost in the time needed to adopt a more relational ethics.

*Community ethics boards*

Our discussion on reformation led us to think about creating community-based ethical power outside of these institutions. We were inspired by the Six Nations Elected Council (2015) in Canada, that created a Research Ethics Committee to 'approve and monitor' research conducted in the area. They ensure that research conducted in their land fits their values. Similarly, the Nunavut Research Institute and Inuit Tapiriit Kantami, for example, created a guide (2006) for researchers working with Inuit communities covering community concerns and appropriate involvement. Community ethics boards might initially involve a hybrid approach whereby approval must be sought from community ethics board as well as a university or hospital board. In the immediate term, university ethics boards could pass over or relinquish certain ethical elements most likely to jeopardise trust/be inaccessible/inapplicable to them, funding those community boards appropriately.

Community ethics boards could allow for a more nuanced discussion of researcher positionality and its ethical consequences. Their creation involves, by definition, a discussion of how community identities

relate to university and hospital institutions. This includes how they are or are not represented in these institutions, and how some members of the community might live on the shore between these worlds. Some in our group complained that CBPR and ethics committee guidelines were written with the blanket assumption that White cis-gendered researchers are working with a marginalised population that needs 'empowering'. Community ethics boards are less likely to follow this reasoning.

Nonetheless, our group were worried that community ethics boards might be a risk replicating centralising university structures, as well as embedded oppressions within community groups. Organising ethics boards around place, rather than bounded communities, might be a way of reducing the replication of embedded oppressions.

#### *Ethical researchers as opposed to ethical research*

To think more creatively about possible ways forward, our group has been inviting people from outside our university to contribute to discussions. For one of our meetings, we invited Leslie Cannold, a leading ethicist. In describing her work on medical scepticism with Centric, she emphasised the need to train ethical researchers, rather than designing an ethical project per se (Khan 2021). Ethical researchers engage in ongoing learning and gain understanding about what ethics might mean for different people. Stout et al. (2020) argue that researchers should develop the 'identity of an ethical researcher' and highlight some of the qualities of an ethical researcher (e.g., 'ethically important moments that arise during the project are an opportunity for reflection' p183). A few members of the group were, however, concerned that the term 'ethical researcher' suggests that a researcher can be ethical in all contexts. We, therefore, propose the term 'reflexive researcher'.

The idea of developing reflexive researchers suggests that we might be able to remove ethics boards entirely and consider alternative structures that are more accountable to research participants, flexible and efficient. For instance, working with relevant communities to develop ethical practices for a particular piece of research, as per Centric and Leslie Cannold's work on medical scepticism (Khan 2021), followed by an assessment and certification process from a board authorised to de-certify and take complaints. Developing specific ethical values and rules each study should be seen as a meaningful form of community engagement, and part of the trust and relationship building process.

The next voyage: Where Inspiring Ethics goes from here

We have conducted rapid literature reviews, hosted discussions with interested colleagues and members of ethics committees, as well as produced a detailed map of the issues we face. We're now keen to share our thoughts with people outside our group and include more people on our ethical ship.

We're planning to host events on ethics between and within the communities and participants we've worked with. We aim to be creative in how we engage people, having an open space technology event (Owen 2008). We will provide space for people to come up with their own topics and questions, and encourage them to imagine a perfect world of ethical research.

We will continue our work collecting ethical knowledge by building our charity partnerships and speaking to them about their experiences. Charities have a different way of interpreting ethical laws that might be useful to explore and learn from, and a grey literature review may prove beneficial. Through our reviews, we aim to create a library of useful resources and host this on our website.

Finally, we do not want to forget the spirit of solidarity with which we began Inspiring Ethics. We hope, therefore, to host a regular drop-in session for people to talk through their ethical issues around research in a confidential and supportive space.

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