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# Ethical Issues in Participatory Action Research on Covid-appropriate Behaviour and Vaccine Hesitancy in India: A Case with Commentaries

Pradeep Narayanan<sup>a</sup>, Michelle Brear , Pinky Shabangu , Barbara Groot , Charlotte van den Eijnde  and Sarah Banks 

<sup>a</sup>Praxis Institute for Participatory Practices, New Delhi, India; <sup>b</sup>School of Public Health, University of Witwatersrand, Johannesburg, South Africa; <sup>c</sup>Community-based Researcher and Activist, Manzini, Eswatini; <sup>d</sup>Leids Medical University Centre (LUMC), Leiden, Netherlands; <sup>e</sup>Department of Sociology, Durham University, Durham, UK

## ABSTRACT

This article starts with a case outlining ethical challenges encountered in participatory action research (PAR) on vaccine hesitancy in rural India during Covid-19. Community researchers were recruited by a not-for-profit organisation, with the aim of both discovering the reasons for vaccine hesitancy and encouraging take-up. This raised issues about the roles and responsibilities of local researchers in their own communities, where they might be blamed for adverse reactions to vaccination. They and their mentor struggled with balancing societal protection against individual rights to make choices. These themes are explored in two commentaries discussing the difficulties in balancing ethics in public health (prioritising societal benefits), social research (protecting participants from harm and respecting their rights not to be involved) and participatory research practices (maximising democratic participation and decision-making). As discussed in the first commentary, often these cohere, but tensions can arise. The second commentary also raises the issue of epistemic justice, questioning the extent to which the villagers could have a say in the design, implementation and interpretation of the research, and the dangers of not hearing the voices and arguments of people who reject vaccination. The case and commentaries highlight the complexities of PAR and additional challenges in a public health context.

## KEYWORDS

Vaccine hesitancy; India; participatory health research; ethics; Covid-19

## Introduction

### *Sarah Banks*

This article has been created by members of the Ethics Working Group of the International Collaboration for Participatory Health Research. It presents a case study comprising a

**CONTACT** Sarah Banks  s.j.banks@durham.ac.uk  Department of Sociology, Durham University, 29 Old Elvet, Durham, DH1 3HN, UK

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research mentor's account of ethically challenging moments in a participatory action research (PAR) project, which combined research about vaccine hesitancy with actions to encourage vaccine uptake. This is followed by two reflective commentaries from researchers with an interest in the topic, but no prior knowledge of, or involvement in, the case. PAR is a research paradigm entailing a methodology in which community participation and action for change are embedded in the research process. In this case, community-based researchers in rural India were recruited to research vaccine hesitancy, with a view to taking actions to encourage vaccine take-up.

The author of the case (Pradeep Narayanan), who managed the project and mentored the community researchers, gives an account of some of the ethical challenges faced by the community researchers and himself. These relate to the fact that this was an action research project, with a focus on generating positive outcomes not only for individuals but also in terms of public health, raising questions about how these apparently conflicting aims might be managed. In this sense, the PAR project embodies the ethical challenges of public health promotion itself, in negotiating tensions between public good, community rights and well-being, individual responsibility and rights to freedom of choice. Although the research is described as 'participatory' in that community researchers were trained and supported to carry it out with a not-for-profit organisation, the commentators ask to what extent the community researchers and local people were or could be actively involved in the design of the research, or interpretation of the findings. This draws attention to the fact that there are degrees of participation in research that is called PAR, and that extra vigilance is needed when working in communities where opinions, alliances or loyalties may be divided to ensure all voices are heard and understood.

## **The case: ethical issues in participatory action research on Covid-appropriate behaviour and vaccine hesitancy in India**

### ***Pradeep Narayanan***

Praxis is a not-for-profit organisation in India that promotes and supports participatory practices, especially with people who experience marginalisation. During the Covid-19 pandemic, vaccine equity was an important issue in the first phase of vaccination, when there was limited supply. Praxis has been organising a PAR project on Covid-appropriate behaviour and vaccination hesitancy since August 2021, and since October 2022 has embarked on a wider immunisation programme for children in India. The aim of the project is to understand the challenges arising from the social identities of the communities in accessing universal programmes. This case study pertains to the formative stage of piloting the programme in five locations in rural India, which later evolved into a programme that covered 700 hamlets. The pilot was organised by Praxis through its own internal resources. My role was of mentor in the intervention.

The PAR project on Covid vaccine equity involved identifying community researchers who could collect information on non-vaccinated residents in the hamlets and develop group mechanisms to facilitate vaccination among them. A community member from a hamlet in a rural part of India was identified through partner organisations and was recruited as an action-researcher. She was provided with training on key issues concerning Covid and vaccination. She was encouraged to form a four-member group in her own

hamlet, to collect information on vaccine uptake and reasons for uptake and non-uptake. She used a participatory social mapping tool. Following this exercise, she used this information to make home visits to encourage non-vaccinated persons to go for vaccination, through a conversation process with the family. After piloting in one hamlet, a reflection process was organised with 10 PAR researchers from other hamlets to identify their challenges.

During the reflection process, community researchers raised several ethical issues. Based on conversations with our doctors in the training, the community researchers explained to local people they talked to that: 'The success of vaccination efforts lies in everyone vaccinating. Even if a few people remain unvaccinated, the chances of the virus surviving is high'. One community researcher expressed concerns: 'What if an unconvinced person gets vaccinated based on our action research process and she suffers medical problems?' Another community researcher asked: 'Is vaccination important for the individual's well-being or is it to protect the society as a whole or is it both?' In other words, is universal vaccination needed for the greater common good? Does it mean certain individuals have to get vaccinated even if they are not convinced? Is this ethical? We did not have definitive answers to these questions, but discussing them together was helpful in thinking through how the project should develop.

During the PAR there was news that government officials were discussing making vaccination a condition to access certain entitlements such as the essential commodities (wheat, rice, kerosene, etc.) allocated via the public distribution system in India. Human rights activists disagreed with this approach and argued that no entitlements could be made conditional. A community researcher remarked: 'As part of the vaccination campaign, can we tell a community member that if you do not vaccinate you may later not be able to access certain entitlements?' This raised the question of whether, as a research team, we are subscribing to the practice promoted by the government and businesses. Are we saying that compromising on human rights in the name of safety for society is fine? What are the ethics that should govern these research actions? Are we not on the wrong side of ethics? As an immediate measure, the community researchers were supported with access to medical doctors, who talked to community members directly over phone or through video recordings. This was to ensure that the community researcher was simply toeing the advisory line of the medical doctor. However, we continued organising these discussions and reflections with researchers on their dilemmas.

As mentor in the project, I found these issues challenging. They raised ethical questions for me. Public health measures are concerned with promoting the well-being of a community as a whole, which in this case entails everyone being vaccinated. However, research ethics tend to aim for every community participant to be protected from harm. Is there a contradiction?

In this PAR project, a community researcher makes herself the face of the research among other residents in the hamlet. Therefore she has a greater vulnerability to being accused by community members, if the latter are negatively affected by actions embedded in the research process, in this case, Covid-19 vaccination. I was concerned that the project had recruited a woman from the community as a researcher, and this may have made her vulnerable to harm.

## Commentary 1

### *Michelle Brear and Pinky Shabangu*

Praxis's PAR project in India linked research about vaccine hesitancy with actions to encourage vaccine uptake, both of which entailed community participation. However, community participation was limited to implementing pre-designed interventions and did not extend to making decisions about the research or action agenda. The project highlights some possible tensions between the overlapping but different ethical principles and perspectives of public health, social research and participatory research. Because this PAR project involves community participation at the intersections of public health research and practice, its moral value may be judged by any one of these three approaches to ethics. Public health ethics is concerned primarily with the common good, i.e. maximising health in the entire population (Prah Ruger 2020). Social research ethics centres on individual autonomy in research, i.e. the individual's right to decide whether or not to participate (Hoeyer and Hogle 2014). Participatory research ethics values 'democratic participation' of those affected by a problem, that is, 'encouraging and enabling all participants to contribute meaningfully to decision-making' (ICPHR 2022). This PAR project, therefore, draws on and must try to balance the different emphases of these three different ethical perspectives. The Praxis case provides important lessons for thinking about how to balance and apply ethical thinking from different disciplines within PAR.

The participatory research ethics principle of democratic participation, which is informed by an understanding that participation is primarily an empowering process, would suggest that the people affected by the problem (in this case Covid-19) would need to participate meaningfully in determining the agenda for community-participatory implementation to be ethical. Imposing a biomedical view by training action researchers from the community to 'toe the doctors' line', is ethically questionable from a participatory research ethics perspective (ICPHR 2022). On the other hand, in a vaccine-hesitant community, democratic participation in agenda setting might have resulted in a decision to discourage vaccination. This would be in tension with a core value of public health ethics, that public health 'gains public trust in part because its practices are informed by evidence' (APHA 2019). In an authoritarian setting, community participation might result in a decision to coerce (use threats) or force people to vaccinate. This would undermine respect for individual autonomy, which is an important component of most ethical frameworks and the central focus of social research ethics (Hoeyer and Hogle 2014).

From a public health ethics perspective, constraining community participation to implementation could be ethically acceptable if (compared to implementation by health professionals) it increased vaccine uptake without restricting anyone's freedom. However, even from a public health perspective focused on the common good, limiting individual freedom and autonomy would only be ethically acceptable as a last resort. All autonomy-respecting ways of encouraging individuals to decide for themselves would need to have been tried and failed, before coercing (e.g. by threatening the denial of rights) or forcing people to vaccinate could be considered ethical. These include conditional cash transfers; information, education and communication interventions; and optimising health service access (e.g. home- or community-based vaccination sites,

minimised wait times and/or free vaccines, equitably distributed or available to all). Structural approaches that are essential for developing robust public health systems, such as building quality public health facilities, expanding the public health workforce and developing mechanisms for making governments accountable, would also need to have been implemented, before threats, coercion or other measures that limited people's freedom and autonomy could be considered ethical from a public health ethics perspective (Prah Ruger 2020).

The Praxis case highlights that the three sets of ethics that can be used to judge the moral value of PAR (public health, social research and participatory research ethics) considerably overlap. Importantly, all focus on limiting coercive measures and emphasise respecting individual rights and autonomy. However, tensions between the participatory research ethics principle of democratic participation and other ethical values may arise, in contexts where participatory skills and health/scientific literacy are limited. For example, if people affected by Covid-19 democratically decided through a PAR process against encouraging vaccination, believing anti-science claims rather than robust evidence, participatory ethics would guide health researchers and practitioners to respect this autonomous decision despite evidence suggesting it would not promote the common good. The Praxis case highlights that although participation is an important ideal, if combining research and action through PAR is to contribute optimally to public health and the common good, participation requires time to enable the development of foundational participatory skills and knowledge and well as mutual trust.

## Commentary 2

*Barbara Groot and Charlotte Van Den Eijnde*

### *Context*

This case raises very important and challenging issues. Its context is a worldwide crisis we did not know how to handle. In all parts of the world, initiatives tried to do their best for the health of citizens, friends, families and communities, as in this case. It is much easier to judge how to handle challenging ethical issues with hindsight than in the middle of a pandemic.

### *Openness about agendas*

Not knowing the background of the initiators and funders of this participatory project, we had some questions about the normative beliefs and assumptions that were at the base of the project and the frames that were used in it. For example, which perspective was central to the training, and were all perspectives, including those of people who were vaccine hesitant, welcome and shared? Having an open dialogue about the motives of all could help in understanding each other and each position and perspective in this study. In participatory research creating time and safe spaces to share expectations and beliefs with all stakeholders is often an overlooked, but valuable action. This is especially so in a pandemic in which communication is not face-to-face and group-oriented due to the fear of infection.

### *Openness about aims*

We read that one of the aims of the project was ‘to encourage non-vaccinated persons to go for vaccination’. We question if this aim influences the ethical issues. It is an explicit aim, and we would like to know if the community researchers were personally committed to this aim, and besides, whether they shared this aim with the participants. We appreciate that discussing this aim at the start of the relationships with community members might be difficult. But if the community researchers did not say anything, then we understand why they might feel like undercover campaigners from business or government instead of community researchers who would explore all kinds of perspectives on vaccination without aiming to convince people to be vaccinated. Openness about the personal or professional moral motives of action research is key, we believe, although care needs to be taken about how to introduce and describe these motives.

### *Justice for all?*

One question this project raises for us is whether justice can be done to the opinions and knowledge of a non-vaccinated person who is unwilling to be vaccinated, if the project’s aim is to encourage uptake. There is a risk of ignoring or under-valuing some parts of people’s knowledge and experience, and not regarding as credible the views of people who have another worldview on the pandemic. A researcher could undermine the credibility of a speaker’s word if they have prejudice towards people who are against vaccination. This raises issues of testimonial justice and whose knowledge counts (Fricker 2007), which could be used to stimulate ethical reflection by community researchers.

### *An incendiary issue*

We do not know if there were polarising discussions about vaccination in India, but these discussions were severe in our context in the Netherlands. Most people did not want to discuss this topic with each other at all, because of fights in families, groups of friends and cities. Because this project is in small communities, we wondered if putting this topic on the agenda always leads to a heated conversation. If the project’s aims lean more towards encouraging vaccine uptake, this could create difficulties for community researchers. Besides, it could feel for community members that the project is less about mutual understanding and collaborative working toward action but rather it is about taking information about their attitudes to use in a vaccination campaign. Is it a collaborative process with the community, with, for example, a collaborative sensemaking part? If all data were analysed collaboratively with the community and the community could benefit from the findings and actions, this could reduce some of the moral stress.

### *Framing common goods*

Finally, we understand the concerns that the community researchers might be harmed by involvement in the project, including contracting the virus and impacting the community by spreading it, and the risk of being seen as representing the government or vaccination business, without support of these parties. They are in between worlds. Having a higher-level aim shared by both the community researchers and members of the rural communities could perhaps bridge these worlds. For example, a focus on working together to

explore pandemic preparedness might resonate with both community researchers and community members.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Notes on contributors

**Pradeep Narayanan** is a Director, Research, Praxis Institute for Participatory Practices, New Delhi, India. He is a practitioner of participatory methods and approaches. He works on participatory monitoring and evaluation with community mobilisation, ethics, child rights and bonded labour as themes.

**Michelle Brear** is a postdoctoral research fellow at the University of Witwatersrand in South Africa. Her research focuses on community-participatory health research and interventions in rural southern Africa contexts. She is currently conducting an anthropology of participation in informal caregiving for people with dementia.

**Pinky Shabangu** is a community-based researcher and activist in a participatory health research project in Eswatini. She is currently working as a research assistant, a role that has enabled her to reflect on her experiences of being a community researcher. She has an interest in social research, particularly about gender issues, women and children's health and development in the Global South.

**Barbara Groot** is a senior researcher at the Leids Medical University Centre (LUMC) in the Netherlands. Her research focusses on the ethical reflection of co-researchers in participatory health research and extreme citizen science. She teaches qualitative and participatory research.

**Charlotte van den Eijnde** is a PhD candidate at Leids Medical University Centre (LUMC), Netherlands. She conducts participatory research into the moral relational learning of healthcare professionals, together with stakeholders from education and healthcare practice.

**Sarah Banks** is a Professor in the Department of Sociology and co-founder of the Centre for Social Justice and Community Action, Durham University, UK. She coordinates the Ethics Working Group of the International Collaboration for Participatory Health Research and has a particular interest in ethics in participatory research.

## ORCID

Michelle Brear  <http://orcid.org/0000-0002-5990-5061>

Pinky Shabangu  <http://orcid.org/0000-0002-5175-6348>

Barbara Groot  <http://orcid.org/0000-0001-7495-3048>

Charlotte van den Eijnde  <http://orcid.org/0000-0003-3170-1822>

Sarah Banks  <http://orcid.org/0000-0002-2529-6413>

## References

- APHA (American Public Health Association). 2019. *Public Health Code of Ethics*. [https://www.apha.org/-/media/files/pdf/membergroups/ethics/code\\_of\\_ethics.ashx](https://www.apha.org/-/media/files/pdf/membergroups/ethics/code_of_ethics.ashx).
- Fricker, M. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Hoeyer, K., and L. F. Hogle. 2014. "Informed Consent: The Politics of Intent and Practice in Medical Research Ethics." *Annual Review of Anthropology* 43: 347–362. doi:10.1146/annurev-anthro-102313-030413.



ICPHR (International Collaboration for Participatory Health Research). 2022. *Participatory Health Research - A Guide to Ethical Principles and Practice (2nd Edition) Position Paper 2*. <http://www.icphr.org/position-papers-discussion-papers/position-paper-2-2e-participatory-health-research-a-guide-to-ethical-principles-and-practice>.

Prah Ruger, J. 2020. "Positive Public Health Ethics: Toward Flourishing and Resilient Communities and Individuals." *The American Journal of Bioethics* 20 (7): 44–54. doi:[10.1080/15265161.2020.1764145](https://doi.org/10.1080/15265161.2020.1764145)