Community-based participatory research

A guide to ethical principles and practice (2nd edition)

APPENDIX
Toolkits and cases

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Contents

Toolkit 1
Tips for managing institutional research ethics committee processes in participatory research

❯ The following tips are designed to help participatory researchers manage the process of getting their research approved.

Introduction

Research ethics committees (RECs), which may also be known as institutional review boards, research ethics boards or similar, are bodies that receive and approve research ethics applications on behalf of an institution such as a university. Preparing for and making an application for ethical approval from a REC is sometimes daunting for participatory researchers. Obtaining approval can be challenging because standard ethical principles and procedures are designed for 'objective', researcher-driven enquiries. Institutionally-based ethical review processes often involve applying standard principles and procedures universally (to all research) and members of RECs may be unfamiliar with ethical principles and procedures of relational and community-partnered approaches such as community-based participatory research. They may be guided by different principles to community-led ethical review bodies. Standard research ethics principles and procedures are sometimes in tension with those used by participatory researchers.

Although challenging, obtaining institutional ethical approval is essential and usually a valuable process by which participatory researchers can check and/or enhance the ethics of their research. The institutionally-based ethical review process can also be used as an opportunity to promote participatory research principles and practices to RECs and represent community participation in ethical review as something that should be a norm. The following tips are designed to help participatory researchers manage the process of getting their research approved, while also raising the profile of participatory research ethics in the institutional ethical review process.

Planning

Start planning for the REC application as you design your participatory research. Important steps in planning include:

- Familiarise yourself with your REC's ethical guidelines and identify tensions that you may need to address in the application (e.g. existing relationships, recognition of community partners).

- Hold a meeting or workshop with the participatory research team to consciously think about and document how you perceive the REC and its review processes, what challenges you imagine and how these might be influencing the design of your participatory research. For example, have you decided not to do some things that you would like to, because you imagine these will not be approved by the REC? You could use the Imagining the REC tool [Toolkit 2].

- Document ethical norms that are relevant to the research process through a participatory process.

- Contact the REC in advance to find out how well prepared they are to review participatory research, for example you could ask if the REC:

  » Has community representatives on the board/committee or considers decisions from community-led ethical review bodies?

  » Has previously reviewed participatory research ethics applications?

» Would like any additional information about the participatory aspects of the study?

- Start early and dedicate extra time to the ethical review process, so that you can respond to specific information requests and negotiate with the committee about aspects of participatory research which present tensions between institutional and community ethical norms.

Writing the application

Start writing the application as soon as possible, filling in relevant sections of the application as you design your research. As you prepare your application:

- Follow the REC's guidelines closely.
- Consider removing features of the research that you perceive may not be approved by the REC, if they are not important to your study.
- Provide additional information justifying the approaches you have taken to fulfil the ethical principles of participatory research that may be in tension with standard ethical procedures.
  This may include:

  » Explaining the role of community-based co-researchers, distinguishing them from traditionally conceived 'research subjects' or 'research participants'.

  » Outlining relational consent procedures, involving researchers who already know participants.

  » Considerations regarding the provision or non-provision of reimbursements or payments to community researchers or participants.

  » The possibility of identifying community co-researchers so that their contribution to the research can be appropriately recognised (e.g. as co-authors of research outputs).

  » Mechanisms for sharing data with communities.

  » Community-level consent procedures, if applicable.

  » Intentional bias in the study design, for example if your recruitment strategy is intentionally biased towards ensuring the voices of marginalised people are privileged.

  » Verbal consent procedures, which may be used when written consent procedures reinforce researcher and institutional power.

  » Approval letter from the community-led ethical review body that is guiding your study, if applicable. [See Case Example 3 about developing community-led ethical review processes].

  » Information about ethical norms and principles relevant to the community, including, for example, community norms and expectations that have informed your participatory research design.

- Make reference and provide a link to the guide produced by CSJCA and NCCPE (2022) *Community-based participatory research: A guide to ethical principles and practice* and other reputable sources that have informed the ethics of your participatory research, so that the REC members can familiarise themselves with the ethical principles of participatory research.

- Include provisions for flexibility, for example: a staged research ethics application process in which approval is gained for doing initial co-design work, followed by approval of specific methods and approaches as they are developed; and a procedure for enabling community co-researchers to decide whether or not they wish to be identified, when the study results are published.

Responding to non-approval from a REC

The REC may not provide approval for your participatory research or approve the overall study, but request amendments to certain procedures. If this happens the participatory research team will need to decide whether to accept the REC's decision or respond to it.

- Discuss any recommendations to amend the study design requested by the REC, and the ethical issues involved, with the participatory research team and/or the community-led ethics board you are working with. Establish whether the REC's recommendation is practically and ethically acceptable in the context in which you are working. You may use your experiences with the REC as a case for discussions to promote ethical reflection and decision-making [see Toolkit 3]. Some REC recommendations that you may encounter, and wish to reflect on the ethics of, include:

  » RECs often expect written consent from research participants. Although written consent is supposed to protect participants, there is little evidence to support this assertion. Conversely, written consent may protect institutions from complaints. Evidence shows that participants may misunderstand written consent documents in contexts where signing forms is atypical. The REC's request for written consent reflects a REC ethical norm that is unethical in contexts where signing is atypical.

  » RECs often expect researchers to hide participants' identities, assuming this will protect the participants. Community co-researchers are often also participants, in that they contribute their own data to the study. However, community co-researchers and/or participants in participatory research may want to be identified so that their contributions to the research can be properly recognised. For example, participatory research team members may want to present the results of the research in meetings or be co-authors of research articles. A REC request to maintain anonymity (i.e. hiding participants' identities) reflects a REC ethical norm that is often unethical in participatory research, because participants may also be community co-researchers who desire and deserve recognition.

» In participatory research, community level consent or selection is often considered ethical and democratic, because it hands power to community members to influence the research. However, because different community members have unequal power, community selection might make people feel forced to take on roles that they do not want to, including to participate in research that has been approved by community leaders. It may mean community members who have less power than others (e.g. women compared to men) do not get a fair opportunity to participate. A REC request not to include community selection procedures may reflect a participatory research norm that is not always ethical.

» Respecting community norms and 'non-negotiable local cultural practices' is an ethical principle of participatory research. However, most communities have some norms that discriminate against some groups (e.g. gender, race, caste, age, wealth), which is in tension with institutional research ethics principles such as justice and respect. This can sometimes mean that there is tension between respecting community norms and institutional research ethics principles. This tension is reflected in Case Example 1 from Eswatini about developing a culturally appropriate (but gender discriminatory) survey consent procedure, which respected a patriarchal, 'non-negotiable local cultural practice'. The REC's request may provide another perspective for the participatory research team to consider, in deciding what is the most ethical thing to do in these situations.

- If the participatory research team determines that a REC request reflects ethical norms that are unethical in the community context, prepare a written response asking the REC to reconsider their requests. State specifically which requests you are asking the REC to reconsider and the ethical reasons why you are doing so. Provide appropriate supporting information and references.

- Be prepared for the negotiation process to take extra time and know that it is time well spent ensuring that the ethical principles of participatory research and voices from the study community are counted in the review process.

Further Reading

In addition to the toolkits and case examples mentioned above, these articles and chapters provide important evidence and insights about managing the REC processes:

Brear, M. R. (2020) 'Power-laden (mis)understandings surrounding written voluntary informed consent procedures in postcolonial southern Africa', *The Qualitative Report*, 25(13), 71-89. This article presents findings about the misunderstanding participants made of signed consent forms in two separate participatory research projects in Southern Africa.

Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement (2022) *Community-based participatory research: A guide to ethical principles and practice (2nd edition)*, CSJCA & NCCPE, Durham and Bristol. A useful summary of key ethical principles and how to implement them in planning and doing community-based participatory research.

Gupta, A. et al. (2019) 'Institutional ethical review processes' in Banks, S. and Brydon-Miller, M. (eds) *Ethics in Participatory Research for Health and Social Well-Being*, London, Routledge, pp. 155-180. This chapter outlines the challenges faced during the ethical review process and contains four international case studies with commentaries.

Narayaran, P. and Bharadwaj, S. (2019) 'Whose ethics counts? Ethical issues in community development and action research with communities facing stigmatisation' in Banks, S. and Westoby, P. (eds) *Ethics, equity and communty development*, Bristol, Policy Press, pp. 103-121. This chapter explores the ethical dilemmas faced by an NGO undertaking participatory research with sex workers in India, including challenges to the NGO's use of consent forms.

Wood, L. (2017) 'The Ethical Implications of Community-Based Research: A Call to Rethink Current Review Board Requirements', *International Journal of Qualitative Methods*, 16(1). This article draws lessons from experiences gaining institutional ethical approval for participatory education research in South Africa.

Yanar, Z. M., Fazli, M., Rahman, J., & Farthing, R. (2016) 'Research Ethics Committees and Participatory Action Research With Young People: The Politics of Voice', *Journal of Empirical Research on Human Research Ethics,* 11(2), pp. 122-128. This article discusses the process and ethics surrounding getting institutional ethical approval for young people to identify themselves, and receive recognition as community co-researchers in participatory research.

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Toolkit 2
Imagining the institutional ethical review process

❯ The tool is designed primarily to facilitate learning within the participatory research team

What is it?

This is a tool for mapping a participatory research team's imaginings about the institutionally-based ethical review process and reflecting on the reasons why they imagine the process as they do. The completed map makes the team's imaginings of the ethical review process explicit. It may help counteract some unjustified fears and better prepare the research team for working on the ethics application. We will use the term 'Research Ethics Committee', shortened to 'REC', to refer to the body (sometimes also called 'Institutional Review Board') that receives and approves research ethics applications within an institution.

Why use it?

The tool is designed primarily to facilitate learning within the participatory research team through making explicit how different team members think about the REC and its review processes, why they think this way and how the team's perceptions of the REC might influence the research design. However, the results can also be documented in a written report or another format to share with the REC and or research community.

How to use it?

- Ask individual members of the participatory research team (or pairs) to write or draw what they imagine about the REC and the review process on pieces of paper. Each participant should write down as many or as few imaginings as they want to. For example, participants might record:

  » What they hope and fear will happen during the REC process.

  » Past experiences that have informed the way they think about the REC process.

  » Discussions with colleagues and community members that have informed their imaginings of the REC process.

  » How the REC defines ethics.

  » Any changes to their "ideal" study design they have considered making because they think the changes will improve their chance of getting REC approval.

  » What they think the REC will and will not give approval for. What they think the REC's reasons for these decisions might be.

  » Anything else they imagine about the REC.

- Discuss each individual's or pair's imaginings as a whole group. You could select a facilitator to collect all the imaginings and read them out (this is a good option if people might be shy or embarrassed to say their imaginings) or ask each individual or pair to read out their own imaginings. As each imagining is read out the group could discuss:

  » Who agrees and disagrees with each imagining and why?

  » Why the REC process is imagined to be this way?

  » Is there any evidence to support this imagining? Could the imagining be a false premise?

  » What are the implications of the imagining for the participatory research design?

  » How does this compare to the participatory research team's beliefs and values?

  » What are the broader ethical issues that this imagining raises? Which other imaginings is it related to?

- Ask one member of the group to make a record of the conversation (or use a recorder if the group is comfortable with that) (optional).

- Develop a mind map of the whole group's REC imaginings, showing the major groups of imaginings and how they relate to each other.

- Use the mind map and record of the discussion to write a report, which may be kept as part of the research design record and used as a point of reference when designing the study and/or submitted to the REC as part of the application.

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Toolkit 3
Applying ethical principles in participatory research: Using ethical case discussions to promote ethical reflection and decision-making

❯ This toolkit offers some ideas on how to promote ethical reflection on difficult situations using group discussions of case examples.

Introduction

Applying ethical principles in real-world participatory research processes can be very challenging. Therefore, it can prove useful for members of a research team to discuss the ethics of difficult and complex situations presented as case examples. This toolkit offers some ideas on how to promote ethical reflection on difficult situations using group discussions of case examples.

The aim of ethical case discussions is not to find the one right solution, but rather to show the diversity of perspectives and thus develop different options for action. Case discussions are also a suitable means for learning and developing people's own ethical competence.

Who participates in ethical case discussions

Participants in such case discussions might all be co-researchers involved in a participatory research project. It may also be useful to invite external, uninvolved people who have special expertise to facilitate or contribute to discussions.

Where do the ethical cases come from?

There are several ways we can arrive at the ethical cases to be reflected upon.

1. We can reflect on actual dilemmas or issues that arise in the ethical review process or during the participatory research process.

2. We can develop our own cases, based on anticipated dilemmas or challenges in the context.

3. Finally, we can use cases provided by others, such as the case examples in this Appendix, those produced by the Centre for Social Justice and Community Action (Banks and Armstrong, 2012), or presented in journal articles or books such as *Ethics in Participatory Research for Health and Social Well-Being* (Banks and Brydon-Miller 2019).

How does an ethical case discussion proceed?

The starting point of an ethical case discussion is presentation of the case example. A case is usually a narrative describing a particular situation or incident that raises ethical dilemmas (e.g. whether to break confidentiality or not) or challenges (e.g. how to handle racism in the group). It may be presented in writing or orally. The case description should be limited to the essentials (such as: who was involved, where, what happened to create an ethical dilemma or challenge, why was it challenging?) so that there are opportunities to add or elaborate on details as the case discussion progresses.

The case is usually presented by the person who contributes the case or by a facilitator, but there are also different ways to present a case such as acting it out as a group role play. If the case is presented orally, it can be helpful to have a brief factsheet with some basic information about the context to which the case relates. Participants may want some time to read and think about the case on their own or with a partner before the group discussion starts.

After the case presentation, the group discussion and reflection process starts. It can be useful to have a facilitator to guide the discussion by asking specific questions and providing a summary. In the following section, we present various questions that can be used to stimulate and/or structure the discussion.

Guiding questions for the discussion

The guiding questions we present below to structure and ethical case discussion use Leget et al's. (2009, p. 231) five-step analytical process to study social practice as a general framework. The five steps in the process are: (a) determination of the problem, (b) description of the problem, (c) study of effects and alternatives, (d) normative weighing and (e) evaluation of the effects of a decision. This approach, which they call 'critical applied ethics', allows ethical questions and cases to be analysed in a way that considers both empirical data (observations of the real world) and normative theories (sets of ideas about right and wrong) in constant relation to each other. As Leget et al (2009, p. 230) comment: 'A social practice can and should be judged both by the gathering of empirical data and by the normative ethics. Both methods of looking at a social practice are open to readjustment and refinement and each can perform this role for the other'.

We developed the following questions, which can be used to structure the discussion, drawing inspiration especially from principles and ideas of appreciative inquiry (Ludema and Fry, 2008; Zandee and Cooperrider, 2008). We developed the questions as part of our participatory research practice, working as a group to discuss ethical dilemmas in our own research. We tested which questions worked best to stimulate discussion and multiple perspectives and adapted the questions accordingly. The questions do not have to be worked through in any particular order. It can be helpful to organise the discussion contributions based on these questions with the help of a visualisation (e.g. flip chart or whiteboard).

1. Enquiries

- Are there any parts of the case that are unclear – for example, about what happened or who was involved?

2. First spontaneous remarks/reactions/questions/comments

- What inner images did you have in mind when you read the case?
- What associations and feelings does the case trigger in you?
- What surprises you?
- What makes you curious?

3. Problem definition

- What does the case say about what is important to the narrator and the people involved?
- What values and assumptions do you notice in the narrator and the other participants and how are they confirmed or challenged?
- What do you think the narrator would like to happen - e.g. what would they like to see happen more/often?
- What resistance or difficulties do you perceive or expect?
- What is the ethical problem/dilemma in the case?
- What ethical principles are at stake?
- Who benefits and who loses if this ethical problem is not resolved?

4. Description of the problem

- What are your experiences from your research practice with these problems/principles?
- What insights from research can you contribute?

5. Impacts and alternatives

- What actions, no matter how small, feel realistic and feasible for the narrator and others involved to move towards their desired impacts/goals?
- What could each of them do?
- Who or what could help?
- What are the risks and what could help the narrator to overcome them?
- What are the possible actions in the specific situation? What are the alternatives?
- What consequences/effects are conceivable?

6. Normative considerations

- How would you weigh up the dilemma? What would you choose?
- How would you proceed?

7. Evaluation of the case

- Think of the different ways the situation presented in the case might proceed, depending on how the dilemma is handled. What might the narrator and the other participants see, say, feel or do?
- How might the narrator and the others notice that they are doing a good job/making the right (ethical) decision?

8. Meta-level reflections

- How was the reflection process for you?
    - » What was good?
    - » What was difficult?
    - » What did you miss?

- What came out of it for you? What insights did you gain?
- Which reflection questions were difficult to answer? Which ones were stimulating?

References

Banks, S. and Armstrong, A. (eds) (2012) *Community-based participatory research: Case studies, cases examples and commentaries*, Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement, Durham and Bristol, UK. research: Case studies, cases examples and commentariesBanks, S., and Brydon-Miller, M. (eds) (2019) Ethics in Participatory Research for Health and Social Well-Being. London & New York, Routledge.

Leget, C., Borry, P., & de Vries, R. (2009) '"Nobody tosses a dwarf!" The relation between the empirical and the normative reexamined', Bioethics, 23(4), pp. 226-235.

Ludema, J. & Fry, R. (2008) 'The Practice of Appreciative Inquiry', in Reason, P. & Bradbury, H. (eds), *The SAGE Handbook of Action Research - Participative Inquiry and Practice, 2nd ed.*, Los Angeles, Sage, pp. 280-296.

Zandee, D. & Cooperrider, D. (2008) 'Appreciable Worlds, Inspired Inquiry, in Reason, P. & Bradbury, H. (eds), *The SAGE Handbook of Action Research - Participative Inquiry and Practice, 2nd ed.*, Los Angeles, Sage, pp. 190-198.

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Toolkit 4
Dilemmas cafés: Promoting ethical dialogue in participatory research

> ❯ Ethical dilemmas are situations involving difficult choices between alternative courses of action relating to rights, responsibilities and well-being, when it is not clear which is the right choice to make.

What is a dilemmas café?

A dilemmas café involves people coming together to discuss their experiences of specific situations that raise ethically challenging issues for them. The idea was developed by Durham University's Centre for Social Justice and Community Action (UK) to explore ethical dilemmas in participatory research. It draws on the World Café approach, with a particular focus on ethical dilemmas.

Ethical dilemmas are situations involving difficult choices between alternative courses of action relating to rights, responsibilities and well-being, when it is not clear which is the right choice to make. Dilemmas often involve choosing between less-than ideal possibilities. For example, participatory researchers may experience a choice between excluding a person behaving in a disruptive way from a research team, tolerating the disruption or spending a lot of time and energy supporting and challenging the person.

The dilemmas café approach is ideal for discussing ethical dilemmas in larger gatherings of diverse people, who may not know each other. This distinguishes it from ethical case discussion described in Toolkit 3, which is designed for use by a research team.

Aims of a dilemmas café

The aims of a dilemmas café are to:

- raise participants' awareness of ethical challenges in participatory research;
- encourage collaborative dialogue, including critical listening and questioning;
- stimulate learning through hearing about different ways of seeing and understanding issues;
- uncover factors contributing to the dilemma at personal and structural levels;
- explore a variety of recommendations for action;
- offer a structured and supportive environment in which to discuss alternative understandings of issues and possible courses of action.

What happens?

In a facilitated gathering of 15-40 people, set up caféteria style with round tables each seating five to ten people, several people present a specific dilemma (anonymised) from their own experience to the whole group. Participants choose a dilemma to work on, and join a table with the presenter of their chosen dilemma and a facilitator. They tease out, discuss and record the issues. After 30 minutes, participants either move tables and tackle a different dilemma or remain at the same table. Presenters and facilitators stay at their tables and brief new participants on the earlier dialogues. Depending on time (allow two to three hours if possible), there can be two or three rounds of dialogues. After this, participants reconvene in a large group to share insights and learning.

A guide for facilitators is available on the web, with details of how to organise a café and how to structure the questions for group discussions (see *Centre for Social Justice and Community Action, 2015*). It is important to agree a set of guidelines at the start regarding confidentiality in relation to sensitive issues raised and respectful communication. Facilitators have a key role in ensuring smooth running of the groups.

Two models of working

1. **Dilemmas chosen and prepared in advance.** The description above and in the guide is based on a model that involves the facilitator seeking volunteers to offer dilemmas in advance of the café, and giving guidance about how to present their dilemmas. The advantages of this model are that it allows the presenters time to prepare, considering if they really want to share their dilemma and how they will anonymise it. The facilitator can also anticipate any sensitive issues that may arise. The disadvantages are that it requires preparation by presenters and facilitators, it may be difficult to find people to volunteer in advance, and it removes the possibility of other more interesting dilemmas being offered during the café.

2. **Dilemmas chosen in the café.** Another option is to choose the dilemmas on the day. After introducing the dilemmas café method and agreeing ground rules with the whole group, then at tables (comprising five to ten people with one person as facilitator), each person thinks for a few minutes about a dilemma they might be willing to share. Each person briefly shares their dilemma (if they have one) with others at the table and one is chosen that resonates with everyone and has potential for fruitful discussion. If a short time is available, people can remain at the same table and discuss the dilemma they have chosen. If a longer period is available, the people whose dilemmas have been chosen briefly summarise their dilemmas for the whole group. Participants then decide which table to go to, according to which dilemma interests them. After 30 minutes they can change tables and discuss another dilemma. The disadvantages of this model are that people may find it difficult to think of good examples and do not have time to consider carefully about sensitivity and confidentiality issues. The advantages are that this allows for spontaneity on the day and requires less advance planning.

References

Centre for Social Justice and Community Action (2015) *Dilemmas cafés: A guide for facilitators,* Durham University, UK: Centre for Social Justice and Community Action, The World Café, www.theworldcafe.com/

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Case example 1
Developing a culturally appropriate (gender discriminatory) survey consent procedure

Background

The case presents our reflections on the ethical tensions of developing survey consent procedures in participatory health research. The participatory research was based in a rural community in Eswatini (formerly called Swaziland). It involved eight community researchers (including Pinky Shabangu) participating in a series of co-design workshops developed and facilitated by Michelle Brear. Michelle had participated voluntarily and independently (i.e. without pay and not attached to an organisation) in establishing and operating the community's preschool since 2007. She was conducting research about the community for her PhD at Monash University (Australia) in 2013 when the events described in this case took place. We refer to these nine people as 'the participatory research group'.

Eswatini is a Kingdom in southern Africa where one in four adults is living with HIV. Gender discrimination is pervasive. Eswatini's traditional laws and customs, which govern rural areas, give women the status of minors (e.g. they cannot hold property) and make polygamous marriage legal for men but not women. Social norms expect women to obey their husbands and take responsibility for women's work such as cooking, cleaning and looking after children in the home. Our participatory research took place in a Swati (formerly Swazi) community where women do not hold the same status as men, for example they cannot make decisions on their own (even when the decision is about them) but need a man's approval.

The influence of cultural norms on the research process

These cultural norms influenced decisions about sampling, consent and design in a Demographic and Health Survey (DHS) that was part of our research. As members of the community, the participatory research group knew that men were considered heads of homesteads (extended family units, e.g. of multiple generations or wives) and households (single family units). This was true even if the men lived in town most of the time for work while women ran the households on a daily basis. We wanted the women, who because of their social position and domestic responsibilities knew the most about the household, to respond to our DHS. However, we were concerned that if we interviewed the women without their husbands' consent, we might get them in trouble or be seen as disrespecting the men and the Swati culture. We were also worried that the women might not agree to participate in our DHS or would not be comfortable sitting around answering the researchers' questions when knowing that the head of the homestead did not give permission. As the participatory research group comprised women and young unmarried men from the community, we were worried about being seen asking women questions about a homestead or household without the approval of the 'owner' of that homestead. The group was also concerned that if we asked the men to leave when the women answered questions, they might think that we wanted to gossip about them. Getting the husband's permission was partly to give them assurance that we were not going to talk about them behind their backs or ask their wives to reveal secrets.

We decided to add a short homestead survey, in which we asked the head for permission to interview the person in charge of domestic work (referred to as 'the head cook') in each household in his homestead. This procedure was intended to show men that we were valuing and respecting them as

heads of the homesteads and assure women that they would not get in trouble with their husbands if they chose to answer the questions. We also decided not to ask a lot of sensitive questions and not to ask to do the interview in private, so that homestead heads or other family members could sit and hear the questions.

Practical and ethical issues raised by our approach

We feel like this approach met the community norms and expectations. For example, at a community meeting where we introduced the survey, one older man asked what would happen if the researchers went to his homestead and found his wife alone. In many homesteads the head (or other family members) would sit and listen to the entire survey interview. Some women chose not to answer questions about household members' chronic illnesses (e.g. HIV, diabetes) when their husbands were present.

However, it also raised some ethical issues, which need to be considered in the future. For all the surveys completed, no head cook declined consent after the head of homestead had consented to the woman being invited. We wonder if getting permission from their male 'heads' to interview the female head cooks might have made women feel forced to complete the survey even if they did not want to. We don't think this happened because about two-thirds of the women that responded to the survey consented alone, because their husbands (i.e. the male heads of their homesteads) were away in town working or had passed away. But we don't know, and we believe there is potential for our process of getting the homestead head's permission to be a source of third-party coercion (i.e. coercion to participate from someone outside the PHR team). In this context, where women do not hold the same status as men, it would not be easy for a woman to decline consent after her husband had given permission, even if she was told by the researchers that she could still say 'no'. If she did not consent after her husband had done so, he might be angry as this would be considered as a sign of disrespect.

Conclusion

We think we would probably use the same strategy if we had to do the research over again, but this time with greater recognition of the potential for third party coercion (i.e. women feeling forced to consent because their husbands had agreed to them being invited to participate). We think that doing the survey within a participatory health research study was beneficial because the co-researchers were familiar with the community norms and knew what was acceptable and what was not acceptable in the study community. Michelle was a student from an international university and helped the community researchers (including Pinky) think about gender discrimination in ways they might not have if they had designed the study all alone. So, coming together to design the study allowed us to find a balance between respecting gendered community norms while raising awareness in the participatory research group about gender inequalities. It allowed us to think from a different perspective and understand the ethics of what we did more deeply.

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Case example 2
Issues of disclosure and intrusion: Challenges for a community researcher

❯ This case example focuses on two related dilemmas that came about for a community researcher during the transition from 'research subject' to 'community researcher/mentor'.

Introduction to the case example

This case example was written by a volunteer community activist (Kath), who worked with a community organisation focussing on issues of injustice and poverty in an urban neighbourhood. She became involved in several community-based action research projects as a community researcher and mentor for households in poverty. These projects were initially undertaken independently by the community organisation with which she was involved, and later by the community organisation in partnership with a local university (where Sarah works). Kath started off as a participant in a research project, then became a community researcher/mentor and community activist involved in campaigning work. The research was action research and involved community researchers/mentors who would support householders in making changes to their lives, whilst also collecting details of finances, debt and wellbeing as data for research and campaigns. This case example, written by Kath, discusses two related dilemmas that came about for her during the transition from 'research subject' to 'community researcher/mentor'. These relate to the issue of intruding into people's personal lives for the purposes of research and the responsibilities felt by the community researcher/mentor for the emotions and feelings generated by asking questions about difficult or sensitive topics.

The case example

I (Kath) started off as a participant in a research project. I became involved after there was a knock on the door from two people from a local community organisation asking if I would like to take part in a research project. They were collecting details of household income, debts, employment, strengths, weaknesses and so on. As there was nothing on the television I asked them in. The visit lasted two and a half hours as there was a long questionnaire to fill in. At the end I was asked to fill in a 'happiness line' [Warwick Edinburgh Mental Wellbeing Scale] to assess on a score of 1-8 the various different aspects of my life. I scored 8 as I was quite happy at the time.

Speaking to other people on the estate where I lived who were also research participants, I found that they couldn't handle the 'happiness' scoring because it made them look at their lives. The accounts of people's lives as shown by the research - lives controlled by debt, drugs and family dynamics - were sometimes very different from their own views of their lives. One woman broke down in tears when she was talking to me as through participating in the research she had realised she was supporting her daughter but not helping her. Another said she wondered what use it was to place herself on the well-being scale as nobody listened, understood or cared.

Over time I became more involved with the community organisation. I became a community researcher and mentor myself on a related research project that was focussing on household finance and linked with a local university. I reflected on the feedback from the happiness score and worried about the disruption to people's lives that had been reported to me. This was very personal to me as during a meeting at the University when relating my experience, I realised the score I provided when I completed the survey was wrong.

Working with the community organisation and the University, using my brain to think about other things, had lifted [relieved] my depression and I felt immensely different to when I filled that happiness score in. It should have read a 4 then, because now I was an 8. Before becoming a community activist and researcher, apathy had ruled my life and I was co-dependant on the family to fulfil my needs and for my life to have a purpose. Now I had my own personal purpose in life, and was not dependant on anyone, I had choice.

The happiness score was not used in later projects, but the idea of community mentors who would both collect research data and provide support to households over a period of time was introduced. It was during this time that a situation arose that made me think again about issues of intruding and disrupting people's lives as part of the research process. In this instance, I and another mentor (who was male) visited a household where a woman lived alone in a flat. On the first visit she didn't open up very much so on the second visit I went with a female mentor. On this occasion the participant opened up to us and revealed some very personal details. She became very emotional and started to cry. She was very depressed and experiencing suicidal thoughts due to what had happened in her personal life. To console her, the other mentor who was with me revealed details from her own personal life. She did this as she had experienced very similar issues. The two women opened up to each other and both cried. I was there but mainly observing by now. The mentor offered friendship to the woman and other help. The woman was very pleased to meet someone who had similar experiences, who did not just show empathy, but had a shared experience.

What was exchanged between these two women was very personal and private - including feelings and emotions rising to surface that had been hidden by shame and fear. Both these women bared their souls to each other as only people with shared experiences can. I sat listening and watching, unable to do anything - an outsider with no power to intervene as each sentence meant something to them. I thought to myself: 'who am I to interfere? What damage will I do if I call a halt, and what damage will I do if I let things calm down and take their course?' When things settled, we left on good terms with arrangements for financial information on benefits to be given to the woman we had visited.

When we went back to the community organisation office we explained to the project manager what had happened. He said we shouldn't have done what we did, as we were out of our depth and not capable of looking after the woman. The project manager intervened and arranged for professional help. I was left feeling drained and emotional. To witness first hand people laying their lives bare about a situation I cannot really comprehend left me with many questions. We met to mentor this woman about her financial situation and signpost her to help. She had not received help in the past due to self-imposed isolation caused by her life experiences. How is anybody to know how life has treated the people we are mentoring until we start to talk? Many can hide these problems, but some cannot and they come rushing out when somebody takes the time to listen to them for whatever reason. To stop the interview in such a highly charged emotional atmosphere should have been my responsibility. Why I didn't is still is a question I have not answered. Was I inexperienced, caught up in the moment, or just listening to the woman unburden herself as to why she lived as she did and apologising for herself? Everybody likes

to be heard and are you out of your depth if you listen and then arrange for help?

This situation made me think about several issues around whether it is ethical to intrude in people's personal lives and in the process to disclose details of your own life? I became aware of the responsibilities of this and wondered whether this would happen if as researcher/mentor you have not experienced similar life circumstances to the people being visited? When going into people's homes as part of research there is an element of the unexpected – by this I mean you cannot always plan and prepare for what people will say. How they will respond? How they will feel? How will you as the community researcher/mentor feel?

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Note and acknowledgements

Case example 3
Establishing community-led ethical review boards in India

> ❯ Praxis supports the formation of community-led ethical review boards.

Background

Praxis - Institute for Participatory Practices is a non-governmental organisation working in India (www.praxisindia.org). It undertakes community development and participatory research, with a particular focus on groups that are experiencing severe marginalisation. This case is written by Pradeep Narayanan, Director of Research for Praxis.

Setting up community-led ethical review boards

Based on long experience of work in this field, Praxis decided as an organisation to support the formation of community-led ethical review boards. The core assumption is that the voices of communities of place, identity or interest need to count in defining the ethics that govern research with those communities. Generally, communities are not represented in the forums in which the ethics of research is debated, such as institutional research ethics review processes.

Keeping the above in mind, Praxis formed three community-led ethical review boards: one of transgender community members; the second of denotified (formerly 'criminalised') nomadic communities; and the third of Dalits (the community facing adverse discrimination based on caste). The essential selection criteria for members of the community-led ethical review boards were that they should identify with the respective social identity of the board and have lived experience of discrimination faced by that community. We also had as a desirable criterion that the members should have experience of organizing or being involved in research of some kind in the past. A team of three senior members in Praxis selected the four members for each of the boards based on the above criteria.

Capacity-building workshops

After the selection of the members of the boards, we organized a series of capacity building workshops. The workshops covered material relating to: (a) multiple ideological standpoints including feminism and anti-caste philosophy; (b) activities that form part of any research assignment; (c) discussion around community stereotypes; and (d) typical institutional research ethics review processes. The workshops used several case studies to stimulate discussions and debates and assist members to understand and reflect on the influence of differences in ideological positions in determining what is ethical. The case studies were generally about everyday ethical issues that arise in research, such as researchers providing gender stereotypical toys as gifts to children after a study. To delve more deeply into ideological positions, we showed a poster that was part of a campaign against female foeticide (abortion of female foetuses). This depicted a child telling a pregnant woman (the mother), "Do not kill me". The point of discussion was to consider whether blaming pregnant women for foeticide is appropriate, even though research would have identified the significance of this poster. In that way, we showed how the concept of ethics is related to any research.

After these workshops, an internal research team of Praxis staff presented research protocols used in an ongoing research project on COVID-19 vaccination equity to the members of one of the community boards, and the board provided its recommendations. The recommendations included suggestions like the following: given community researchers have to convince residents as part of the study about significance of vaccination, the research team should evolve certain protective mechanisms for eventualities that community researchers could face, in case some residents blame researchers if they have any side effects owing to vaccination.

Some challenges in the capacity-building process

While offering the capacity building workshops for board members was important, the challenge is the potential to shape the ideologies and worldviews of members in a particular direction. Praxis believes in anti-caste and feminist ideology, for example. Hence the capacity building would surely be influenced by those world views. The community boards may end up becoming an ideological extension of the organisation, and thereby of Praxis's own institutional ethical review board. If this were to happen, the community boards would not only represent the interests of their communities, but possibly also the ideology of Praxis.

Exerting an ideological influence is a common ethical dilemma for all community development practitioners doing capacity-building work. The practitioners' role is to encourage critical questioning and consciousness-raising about received community norms and values, whilst also respecting community members' rights to express themselves and to hold alternative views. However, practitioners also bring their own and their organisations' values into their capacity building work. For Praxis, some values are non-negotiable, and therefore it is important to be up-front about this and to encourage critical questioning by community members of Praxis's values as well.

As Director of Research at Praxis, I believe that having a community-led ethical review process is not just an option, it is an integral part of any participatory research. For ethics is embedded in any research questions and methods. In that sense, there is a need to promote community-led ethical review processes across research themes, across regions and across communities. There is a need to document and gather experiences required to legitimise community-led ethical review as a process that could supplement, complement or even substitute for institutional research ethics committees. The experiences of community-led ethical review processes may also impress upon us the need to put institutional research ethics committees/boards and the ideologies that inform their work through a similar microscope.

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