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Societal Engagement

Ethics in Participatory Research

How to make sure we are using participatory approaches ethically

This guide will help researchers and engagement practitioners use participatory approaches to research ethically. It will draw attention to the difference between ethical research and research ethics approval, emphasising the importance of always working ethically and highlighting key points to consider when applying for ethics approval.

It has been produced in collaboration with members of the Imperial research community, including ethics committee members, academic researchers, and local community partners.

What do we mean by Participatory Research?

In participatory research, academic researchers and non-academic publics collaboratively produce new knowledge by designing and delivering research projects together.

Generally, these collaborations take place between people with academic expertise in a particular area alongside people with lived experience of the area being researched. As collaborators, both groups work as equals to decide which questions get asked, how they get answered, and what happens with the knowledge that is created.

Different language can be associated with participatory research, often referring to specific approaches to working in this way, including community-based or participatory action research, as well as public involvement, co-design/co-production and so on.

In this guide, we will use the term participatory approaches to refer to this entire spectrum of practices. From single co-design interventions involving publics in one aspect of a research, to fully co-produced participatory research projects.

Getting ethical versus getting ethics approval

It is important to draw a distinction between research ethics and research ethics approval processes.

Research ethics is a broad area concerned with the rights and responsibilities of everyone involved in a research process. This includes understanding potential harms or adverse effects that taking part may create as well as asking who benefits from any positive outcomes from research.

In this context, **research ethics approval** refers to specific institutional, regulatory, and policy processes through which research projects demonstrate that they are adhering to a formalised set of ethical standards. It is a good opportunity to review, reflect and be reassured that you are conducting your research ethically!

It is important to understand this difference because ethics approval is not necessarily required every time we are using participatory approaches. But this doesn't mean that we don't need to take ethical considerations into account!

Even if we have been granted research ethics approval by an institution, this does not mean that we can always assume that we are working ethically or that we have thought about every possible ethical challenge that might arise in our work.

The purpose of this guide is to help us think about ethical practice whenever we are using participatory approaches, so that we can still follow ethical best practice, even when we don't technically need research ethics approval.

Ethical participatory research

A general tip for thinking about research ethics is to try to anticipate the ethical challenges or issues might arise in your work and consider how you will address these.

There are several ethical considerations that are of particular importance when using participatory approaches.

1. **Relationship building**

When we are planning on using participatory approaches, it is important to invest time into building relationships with your collaborators before you can start to work on a research project or apply for funding. This is central to building trust and ensuring that everyone understands what working together will involve.

This process should include:

- **Meeting people where they are** both physically, in terms of going out to community spaces instead of always expecting people to come to us, but also in terms of not asking more of public partners than they feel ready to give (e.g., time, resources, expertise, experiences etc.). As part of this...

- **Valuing people's contributions** by remunerating them for the time spent working with you is an important consideration. The National Institue for Health Research guidance on remuneration is a helpful resource to refer to here and, where possible, funds to remunerate participants should be built into project budgets.

- **Sharing your plans** as a researcher so that your collaborators understand how your work together fits into a broader context. This is particularly important if you are only working together on one aspect of research where it may not be clear how it contributes to a broader project.

- **Outlining aims** for your work together, including sharing your aims as a researcher as well as listening to the aims of your public partners and what they hope to get out of your work together.

This early relationship building helps develop shared understanding about what everyone expects of one another and how the work can be made meaningful to everyone involved.

2. **Mutual benefit**

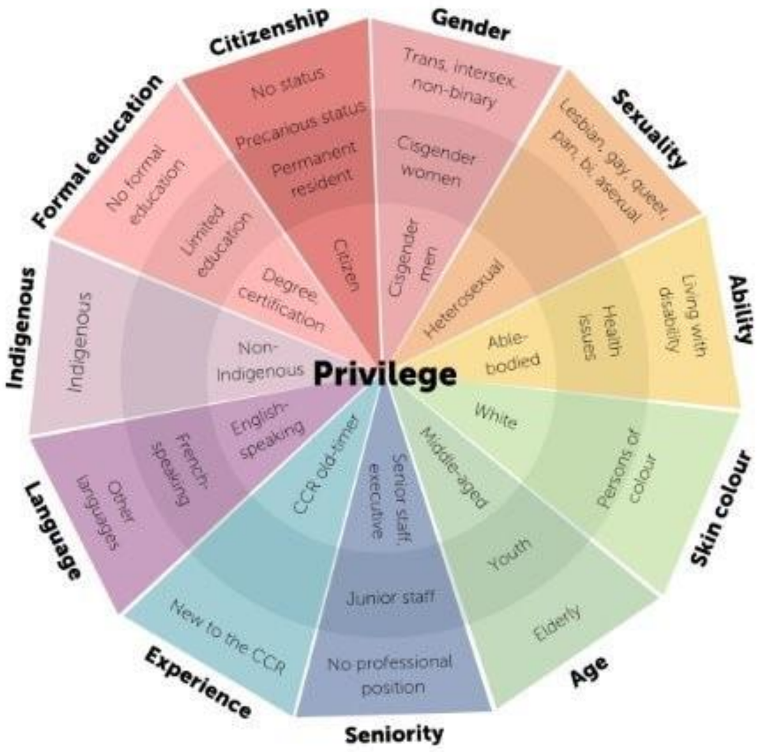
When using participatory approaches, we have a responsibility towards mutual benefit for our collaborators.
Here, it is important to ask your public partners what they want to get out of a project. Take time to consider all the potential benefits that a piece of research might produce. For example:

- Will it lead to further funding?
- Does it develop new skills and knowledge for those carrying it out?
- Will it build datasets and what will these be useful for? Will these be available to the public partners involved or other researchers? (See UKRI guidance on publishing your research findings)
- Will it lead to publications or opportunities to engage with conferences and other events?

Next, ask who will benefit from each of these outcomes and how many of them will be shared between the researcher as well as the public partners. Are the benefits shared equally?

If not, what steps can you take to address this? For instance, are there opportunities for everyone on the project to share in these benefits by being involved at every stage? In cases where this might not be possible, can people be remunerated fairly for their contributions?

3. **Power dynamics**



If we do not use time and resources to consider how benefits can be shared equally, we run the risk that most of the benefits from research will be skewed towards the researchers. This is because of the underlying power dynamics that are inherent to any collaboration.

When we use participatory approaches, we aim to collaborate as equals. So, it is important to consider these power dynamics. They can be as simple as the research being more important to some people than to others or as complicated as intersecting forms of social, cultural, and economic privilege that we all bring into the collaboration with us.

The Canadian Council for Refugees' 'Wheel of Privilege' (left) provides a helpful starting point for considering some of these issues. Think about where you and your partners sit on the wheel. What steps can be taken to ensure everyone is as able as possible to access and contribute to the best of their ability and share in the benefits of your work together?

Navigating complexity when using participatory approaches

Participatory research uses innovative and novel approaches that do not always fit easily into research ethics approval processes, particularly when compared with more traditional approaches to research. Below we will explore some of the complexity that can arise in participatory approaches and consider what can be done to give everyone confidence that we are using them ethically.

Peers versus participants

One reason participatory approaches can bring up challenges is that more traditional research approaches have quite clearly defined roles, for instance, between researchers and participants. In participatory research, however, we are often working with non-academic publics as peers, or co-researchers, rather than participants. There are two points to consider as we navigate this merging of traditional research roles:

1. **Are the public peers or participants?**

This can raise questions. If you are collaborating on a piece of research, designing and delivering research interventions together as with academic colleagues, you are peers. In these instances, we do not need research ethics approval to work together. However, if you are collecting research data from your public partners that you will later analyse to answer your research question, they are participants.

Sometimes we are doing both things as part of a participatory project. So….

2. **Be mindful of what kinds of data you are collecting and from who.**

Here, it is helpful to think about two kinds of data that you may be collecting: **research data** and **personal data.**

Research data refers to any data that you will analyse as part of answering your research question. This could include, surveys, interviews, observations of participants, data collected at workshops and so on. **If you are collecting research data from human participants, even if they are also collaborating as peers on a project, then you need to apply for research ethics approval before you do so.**

Personal data, on the other hand, is any information that relates to an identifiable person. Names and contact details are the most common examples but personal data also refers to audio recordings, film, photographs and so on. **You do not need research ethics approval to collect personal data. However, as part of working ethically and within the law, it is important that personal data is handled and stored securely in line with GDPR and data protection law.**

Of course, these two categories of data are not mutually exclusive of each other. **Research data can also be personal data, and you may have to consider UK data protection law as part of a research ethics approval process. Any project using personal data needs to be registered with the Imperial College DART process.**

So, as part of using participatory approaches, you may be co-designing a piece of research, co-producing a proposal, or co-authoring a paper. **But you could do all these things without collecting research data from your public partners.**

However, you will still likely be collecting personal data in some form and this data needs to be handled correctly. So, anytime we are sending a group email, recording a video or audio call, or taking photos at an event, we need to make sure that everyone knows what data we are collecting, what we will do with it, and there is a legal basis for processing this data (often consent).

When and where to seek consent

It is important that public partners give informed consent to collaborate on a project, for their insights and ideas to be used, and for their personal data to be collected.

So, when and where do we seek consent?

If you are collecting research data, this consent will be given by participants formally at the start of a process. Usually this involves providing a participant information sheet detailing precisely what their involvement will entail and a consent form for them to sign if they decide they are happy to participate.

Where this consent is not given formally at the start of a process working together (and even when it is!) collecting consent should be an ongoing part of your work together.

This means that every time you work together, at the start of each meeting or workshop for example, you should share information and explain clearly what data you will be collecting (e.g., this meeting will be recorded/we will be taking photos etc.), explain what this data will be used for, and tell people how they can opt out of their data being collected.

Sharing decision-making power

When applying for research ethics approval, we are required to outline the approaches that we will be using as part of our research. But if we are genuinely sharing decision-making power as part of a participatory approach, it is necessary for work to be open-ended and iterative, allowing research interventions to emerge bottom-up from our work together. This means that you may not necessarily know the methods you will use at the time of applying.

Here are some things to consider when working in this way:

1. **Know when you need research ethics approval**

Research ethics approval is required whenever you are collecting research data from human participants. If you are co-designing a research project with public partners, they are not necessarily participants in your research. Rather, you are collaborating as peers on a project. **In these cases, you do not need to seek research ethics approval until after you have co-designed your research.** At this point, it is more likely that you will know and be able to explain clearly the methods you plan to use.

However, in some instances, you may want to gather insights from a participatory process that you can later analyse as research data. **In these cases, you will need research ethics approval before you begin work together.**

One way we can know whether our work is research is by asking if it is designed to produce generalisable or transferable findings. For example, does the information you are collecting help you understand how your research area is relevant to your public partners, the kinds of research questions they would like to see answered, and how they would like to go about answering them? If so, you are developing an idea collaboratively with public partners. However, if you are learning something broader that could be applied generally outside of your project and to different groups of people you may be doing research.

For some more detail on this difference, you can refer to the Health Research Authorities guidance. Below are some additional tips for when you find yourself in this situation as part of a participatory process…

2. **Give indicative examples of the kinds of methods you might use**

Even when we are working with an open-ended and iterative approach as part of sharing decision-making power with public partners, we likely have some sense of the kinds of methods we might use as part of a research.

If you need research ethics approval before you begin work with your public partners, try to give indicative examples of the kinds of approaches you might use, any ethical issues that these approaches might raise, and what measures you will put in place to minimise the likelihood of these.

Once you begin work with your public partners, you will then have a set of methods available to you that you might use to answer your research question and for which you have ethical approval.

Of course, this does limit the amount of decision-making power public partners are able to exercise over how the research takes place. So, you can also…

3. **Build in time for amendments**

If you are aiming to gather research data from your participatory work **and** provide genuine decision-making power to your public partners, it is important to build time into your project to gain ethics approval for any amendments.

Consider when in your project timeline this is likely to be. This may be after a co-design workshop in which you will be outlining your research approach for example. Bear in mind that seeking amendments to your ethics approval may take several months.

Further information and support

The best approach with research ethics approval is always to build sufficient time into your project timeline and to seek advice early.

Below are some links to further resources and support.

- If you have further questions that you would like to discuss directly with a member of our team you can book a public engagement one-to-one advice session.
- For more information about the difference between working with the public as peers rather than participants you can read the NIHR's guide to public involvement within health research.
- For more detail on ethical considerations in participatory research you can read this guide from the University of Durham's Centre for Social Justice and Community Action.
- For more information about Imperial's research ethics approval processes you can have a look at the ethics approval overview page.