Research ethics when working in partnership with people outside of the University system: A project report

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Key takeaways

- **Responsibility:** Ethics are everyone's responsibility and should be a consideration throughout the life of a project. The chance to discuss these issues with experts is valued and desired– but doing this through the research ethics review process is not always the best or only option.
- **Processes:** Current research ethics processes can be seen as unsuitable for public involvement and engagement, as non-inclusive of public contributors, and as a "tick box" exercise.
- **Inconsistency:** Due to conflation or lack of clear definitions between research and public involvement or engagement, inconsistent decisions are being made about the need for formal research ethics approval for projects.
- **Power:** Involving public contributors in the ethics process helps to ensure that research will be considered ethically acceptable to the people who will be taking part. Equitable treatment and power sharing are key to collaboration at this stage.

We suggest some next steps on each of these areas at the end of the report. Other outputs from this project include updated UCL guidance on research ethics which can be found in our blog 'All about ethics.'

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Why we started this project

Anecdotally, it appeared that researchers and professional services staff within and beyond UCL were unclear on the ethical dimensions of their work with partners outside of academia. This included when ethical approval was needed and what constituted ethical behaviour when carrying out Public Engagement, Patient Public Involvement and Engagement or co-production. We wanted to uncover the scale of this issue through informal chats with internal and external stakeholders.

Who was involved?

This was a joint project between UCL Engagement and Co-Production Collective. The project team was made up of public contributors, UCL researchers and UCL staff members involved in public engagement and co-production.

Team members include:

Helen Craig – Public Engagement manager for Life and Medical Sciences, UCL. I am interested in supporting staff and students at UCL to be more confident in engaging with those outside academia, and my key goal for this project was to be able to support them in engaging ethically.

Jade Davies – Research Assistant at IOE, UCL's Faculty of Education and Society. I have worked with public contributors as equal researchers in some of my research and am always keen to learn how I can improve my approach to participatory research. My main goal for this project was to find examples of best practice when it comes to ethically and thoughtfully engaging with people outside of academia.

Emeline Han – PhD student at IOE, UCL's Faculty of Education and Society. I conduct participatory research with the autistic community and strive to work ethically with my public contributors. My key goal for this project was to gain clarity for PhD students who wish to involve the public in their research but struggle to find guidance on when ethical approval is needed and what constitutes ethical behaviour.

Lynn Laidlaw – Patient and public contributor, co producer and peer researcher. Member of Co-Production Collective.

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What we did

This document represents the outcome of over 50 conversations with internal and external experts, including public contributors, lay editors, public engagement/involvement managers, researchers at all stages of their career, as well as research ethics committees. Some people had a combination of different roles and experiences.

We contacted people through our networks, "snowballing" contacts who had an interest in this space. We invited them to discuss their experiences of ethics and applying for research ethics approval for their public engagement, Patient and Public Involvement and Engagement and co-produced research projects. We also used social media to seek contributors.

As a team we discussed what questions we might want to ask people in the conversations and sent our key questions to them ahead of the meetings. The questions included:

- Their views on existing guidance and training on the ethical aspects of public engagement, involvement or co-production.
- Whether people felt well informed and able to navigate the ethics process when conducting such work (or in the case of public contributors, whether they felt involved in this process.)
- The possible challenges and opportunities of navigating the ethics process when conducting such work.

While we generally covered these topics in our conversations, we also discussed any other points people wanted to raise. Over the course of the project, we realised that our initial aim, to create a definitive guide and toolkit for deciding when work needs to go through ethical approval, was not going to be possible given the complexities of the field. Instead we realised we needed to supplement the guidance we have been able to createwith a project report that captured more of the experiences shared with us.

This wasn't a research project, and this write up is not a thematic analysis – it is a snapshot of the experiences of people working in research and involvement.

It is also important to note that these conversations and findings are based on 50 people we spoke to so do not necessarily represent everybody's experiences. In particular we want to highlight that the public contributors and co-producers we spoke to were generally very experienced and had been involved in multiple different research projects. Many had overlapping roles and identities, for example, alongside being public contributors, some had an academic background.

The team is grateful to everyone who shared their insight, knowledge and concerns with us.

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What did public contributors and co-producers tell us?

Ethical behaviour

We asked people if research that didn't have any patient or public involvement was ethical but there wasn't a consensus. The people we talked to did, however, mention very specific issues that they had broad ethical concerns about when being involved in, and co-producing research. Often, concerns were around equality, diversity, and inclusion. For example, we were given an example of a public contributor being racially abused but there being no process to report this. Another issue highlighted was so called "faux production", projects being billed as co-production when they weren't. People asked is it ethical to state you are co-producing research when there isn't equality in decision making? One person also posed the question- can research ethics be divorced from changing societal norms and influences that result in unequal power distribution, such as the impact of the current "hostile environment" towards refugees and asylum seekers? Other topics that people felt had important ethical implications included remuneration for public contributors' and co-producer's time.

The people we talked to also told us that they didn't want another "tick box" set of guidance on ethics but instead a process to facilitate conversation about both "pure" research ethics and wider ethical issues. People acknowledged that although Public and Patient Involvement and co-production weren't the same as participating in research, and didn't require ethics approval, they felt they still raised ethical issues that required discussion.

Some mentioned that there can be a lack of clarity about the distinction between qualitative research and Patient and Public Involvement and Engagement and co-production. They described personal experience of research teams billing their qualitative research as Patient and Public Involvement and engagement as it was seen as "easier" and ethical approval wouldn't be required.

Barriers to their work

Whilst some public contributors had accessed training in Patient and Public Involvement and Engagement and co-production, none had been offered any education on issues surrounding ethics related to this work. This raised the question of whether the process of ethical approval, including for Patient and Public Involvement and Engagement and co-production is being done to people, not with them.

Some public contributors spoke of feeling inequitably treated, for example being asked to provide their qualifications or experience in a way they felt their academic partners were not, or being classified as vulnerable or fragile when similar considerations were not given to the researchers working on a project. Meaningful involvement of public contributors at all stages of the research process (including ethical review) and clear communication about what to expect from the process can avoid some of these pitfalls.

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What did those working within university systems tell us?

Ethical behaviour

The people we spoke to who had worked with various ethics committees and valued a place to discuss the wider moral and ethical issues involved in Patient and Public Involvement and Engagement and co-production, even if ethical approval wasn't required. But they questioned whether applying for research ethics committee approval was the right process and place to have these conversations about involving patients and the public and co-producing. For example, some questioned if this is "othering" public contributors and co-producers, seeing them as people who need to be protected rather than a full member of the research team?

Many researchers spoke of strained relationships with the members of the public they worked with, due to the demands of the research ethics process. Some examples shared were relationships deteriorating due to delays caused by waiting for research ethics permissions, or conditions imposed by the research ethics committee that that were felt to be insensitive, such as sharing basic information with experienced participants.

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People asked the question, do ethical considerations stop after approval is given? They talked about the need for a process to highlight ongoing or new ethical concerns that is open to both research teams and public contributors. Having good role models amongst senior staff was perceived as very important, but their understanding of Patient and Public Involvement and Engagement and co-production was questioned. This was identified as a particular issue for PhD students and early career researchers who wish to involve patients and the public in their research and can struggle to find appropriate advice and assistance on this topic.

Barriers to their work

We came across several cases where researchers had become discouraged from pursuing their plans to engage with patients, public groups or other stakeholders, because they did not understand if or when they needed to obtain research ethics approval for this work.

Public contributors, early career researchers and other groups trying to navigate the process often feel they have no power to change the current system and were left trying to go through processes that did not suit their project. In other cases, research ethics review panels themselves were unclear on the goals of public involvement or how it differs from research and sought more clarity.

Publishing research was one particular area where researchers felt they need ethical approval even when their projects may not be research (e.g., reporting on Public and Patient Involvement and Engagement.) They had experience of journal editors asking for proof of ethical approval, even when not required for this kind of work. This issue was perpetuated by some research ethics committees who take the same position and state that publishing always requires ethical approval. The question was asked – 'does this situation impact on community led co-production projects?' These are currently very rarely published, as they don't go through a formal ethics process.

We also heard about the importance of being able to "reach out" to research ethic committees chairs for advice but the perception is that they can be "faceless", especially in large institutions. One person described

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attending a research ethics committee meeting and not being given the opportunity to ask questions and have a conversation about ethical issues. Does this imply the process is essentially transactional and not two-way?

Some institutions research ethics committee processes were seen as "overly cautious", with researchers being told to treat Patient and Public Involvement and Engagement and co-production like qualitative research. One person suggested that research ethic committee approval was viewed as akin to having house insurance; research teams applied for it "just in case". Several people we spoke to commented on who should be on a research ethics committee, asking whether they should always include "lay" members. Concern was expressed that often academics and other members of research ethics committees don't receive any education on Patient and Public Involvement and Engagement and co-production as part of the training process. Could this be a particular issue amongst academic disciplines which arguably don't have a tradition of involving people in research, so don't have personal experience to inform them? It was suggested that "people (researchers) do what they have always done because they have always done it". This leads to the question, - is this what the current system of research ethics committee approval requires, as opposed to an evolving understanding of, and conversation about, ethics?

An argument for involving public contributors in ethics applications.

Involving public contributors (i.e., representatives of the target participant group) in the ethics process helps to ensure that research will be considered ethically acceptable to the people who will be taking part. For example, it gives public contributors the opportunity to shape the research design, ensuring it reflects the interests of the people who will stand to benefit, and helps to ensure participants' practical support needs will be met. The people we spoke to felt there was benefit in including the perspectives of people from different backgrounds, which lead to unique insights and more thoughtful and thorough discussions around ethics. The public contributors reported their involvement as meaningful and felt like their voices had been heard. Researchers should feel encouraged to involve public contributors at this stage, while being aware of, and prepared for, the potential challenges that may arise.

Involvement at this stage could include:

- Discussions about the rationale for the research, and how the research should be undertaken.
- Discussions about the specific ethical considerations that should be made for this target participant group.
- Group completion of the ethics application.
- Co-design of study materials (e.g., information sheets, consent forms).

In recognition of the importance of public involvement in ensuring the ethical acceptability of research, more researchers are being encouraged to involve public contributors at this critical stage. For example, the Integrated Research Application System (the Health Research Authority's Research Ethics Service) asks researchers to identify the stages of the research cycle in which they have involved the public and provide justification if there has been/will be no involvement. The ethics committees at UCL and IOE, UCL's Faculty of Education and Society also recommend working collaboratively at this stage.

Below, we summarise some of the specific challenges and opportunities that researchers and public contributors highlighted to us, regarding collaboration at this stage:

- Very few public contributors we spoke to had been involved in the University Research Ethics Committee application process. Often ethical approval is sought before public contributors become involved, including co-production projects. If public contributors are involved in the process of applying for ethical approval, we were told their involvement is sometimes limited to developing and commenting on the participant information sheet. Some public contributors felt they were dismissed and were perceived as not having important input at this stage. As a result, they had to fight to have their say.

- Some were asked to write a letter to an ethics committee or intervene in some other way with the "patient" perspective when the research team ran into challenges obtaining ethical approval, which was perceived to be tokenistic.

- Many challenges around power dynamics were highlighted. For example, some researchers questioned how they could recognise and involve public contributors at the research ethics stage if they had not yet received funding. Similarly, the nature of being "employed" by the university was felt to provide academics with more power than their public contributors. The use of university-led templates (e.g., for information sheets and consent forms) was also felt to reduce the opportunity for power-sharing – these should ideally be used as a guide but often weren't.

- Some public contributors reported experiencing lines of questioning by ethics committees that made them feel uncomfortable and as though they were not worthy to be involved. For example, being asked what relevant qualifications they had, and being asked about their capacity to be involved. This fed into feelings of imposter syndrome, and discouraged involvement at this stage.

- There were also concerns about what constitutes a low- or high-risk project, and what the impact for a public contributor is to believe they are considered 'high-risk' just for being themselves. In one

specific case, a reviewer questioned the mental capacity of the participant group, which caused significant offence to the public contributors involved.

Despite the challenges, working collaboratively on ethical considerations and applications was, overall, perceived positively by both researchers and public contributors. Many of the challenges we list above are likely to have been avoidable if more time was taken to express what the committees, researchers and contributors were all aiming for.

Considerations and questions

Does the current research process promote and understand the difference between "getting" ethical approval and working with public contributors in a moral and ethical way? Does this then lead to a tick box approach to ethics rather than thinking about and applying fundamental ethical principles to research activities?

Does the current research process concentrate on foreseeing and avoiding the possibility of attack or criticism for institutions? Does there need to be a change in the culture of academic institutions to move away from these concerns?

Do we conflate research ethics with other responsibilities too much – such as data protection or child protection?

Who should have responsibility for making research ethic committee applications? Should it always be the specific responsibility of researchers, and should the process always involve public contributors and co producers?

There is an increase in peer-and-patient led research using participatory methods such as co production. Do we have knowledge and understanding of these often-complex methodologies and potential ethical implications? Do we need formal processes and/or guidance to make the necessary ethical considerations of this work, outside of research ethics?

Are researchers applying for ethical approval for patient and public involvement and engagement and co-production projects, despite there being no "pure" research ethics issues, because it's easier to do so than try to justify their decision not to? On the other hand, are researchers not applying for ethical approval for projects that would qualify as qualitative research, because the processes are so difficult to navigate?

Next Steps

Responsibility

There was a consensus that ethics are everyone's responsibility but at the moment may be siphoned off to academic research teams, and ethics advisory boards in large projects. Public contributors to research and co-producers were also concerned that ethical approval was viewed as a moment in time. Many stakeholders felt that ethical behaviour was important as an informed choice when involving, engaging and co-producing, not just viewed as another thing to do as part of the research process. And we have had suggestions that researchers themselves should be more open with participants about the research ethics process and communicate more deeply with them and with their ethics committees.

Processes

There was a suggestion that there needs to be a process to revisit ethical issues throughout projects, including specific pathways for public contributors and co producers to flag ethical concerns. People mentioned the value of creating time and space to reflect and discuss ethical issues for everyone in research. Safe spaces to highlight ethical concern throughout the lifetime of a project, and not just at the end, would be an excellent step forward. This may include naming an independent person, who isn't part of the research team, whom people can contact.

Inconsistency

Due to lack of clear definitions between research and public involvement or engagement, inconsistent decisions are being made about the need for formal research ethics approval for projects. In addition, people felt more clarity was needed on multiple issues, "fudge" was used as term by many! An example given was the merging of involvement, engagement, and co-production with participation in research.

Power

Do research ethics committees acknowledge and consider potential power imbalances between researchers, public contributors and co producers? In the same vein who should sit on ethics committees and

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make the decisions, including how committees operate? Should all research ethics committees have public contributors as members?

It's important to note that there was no blame to be ascribed in many of these situations – often they arose because the worlds of participation and of more traditional research culture just seemingly could not speak to each other. A "common language" and understanding from both researchers, public contributors and research ethics boards of the varied ways people can be involved in research is key to support ethical research practices. Many described the current research ethics process as "opaque" and felt that there were limited opportunities for them to be involved with the process.

We'd like to see the ability for research ethics review to work with those experienced in Public Engagement, Patient and Public Involvement and co-production to triage requests and determine when and if they require full research ethics review. This should come with a focus on equity, for example if public contributors are felt to require mental health support this should be made available to the whole project team, including academic researchers, and not just peer researchers.

We'd urgently suggest more clarity is needed from journals on their willingness to publish work that is not considered research and therefore is not required to have ethical approval. Anxieties around publishing are very influential, especially on early career researchers, and we fear that they are driving people to avoid these areas of work or to seek ethical approval when not required.

In summary, a focus on relationship building and power dynamics is a key component of any cooperative research work, and this is an area where research ethics review can, and should, help that process, rather than hinder it.

We hope to spur more conversations on this topic that will be useful for everyone who is considering how to engage with public groups ethically, and when to apply for formal research ethics. Please let us know what you think on coproduction@ucl.ac.uk