Doing research as if participants mattered

Almost all qualitative and quantitative research into human society involves the participation of other humans. However, they are frequently rendered passively in research outputs as 'research subjects'. In this post, **Helen Kara***, argues that the way we define participants in research is outdated and presents three ways in which research participants can be made more central to research.*

Euro-Western research is crawling, slowly and reluctantly, towards a place where research participants are treated like human beings with human rights. Yet, there is still a very long way to go. I intended to start this post with a comment about how at least researchers don't talk about "research subjects" any more (implying as it does a lack of agency or personhood), then I thought I had better check. So, I put "research subjects" into Google Scholar, selected 'since 2022', and was astonished to find over 2,500 hits already this year. I looked through the first two pages of results, and while a couple were talking about subject as synonymous with topic, most were using the term to mean people who take part in research. It seems we have even further to go than I thought.

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Across all academic disciplines and beyond, the way research participants are conceptualised and treated by researchers is no longer fit for purpose. As well as using more appropriate terminology, such as 'participant' or (where appropriate) 'co-researcher', there are three other main ways in which I think we should offer more respect to the people who help us with our research. First, let's think about 'informed consent'. This concept is over 100 years old and badly out of date. The internet is now a fact of life, a boon for research dissemination, but it has also enabled people to do all sorts of things with research data, findings, and outputs that cannot be predicted. Funders are also now, quite rightly, requiring researchers to deposit data in open access archives for re-analysis and re-use – but, again, we cannot predict the nature of that re-use. For these two reasons alone, informed consent is now a myth. Yet, it is a myth to which countless research ethics committees and institutional review boards still cleave. Instead, we need to figure out how to empower potential participants to assess the risks they would face from taking part in our research, and support them in making the best decisions for their own unique circumstances.

Another thing we should do is to remunerate participants. You will note that I did not say 'pay participants', though paying them is one possibility. From the participants' viewpoint, money will often be the best option. After all, that's what (most) researchers get in exchange for the time and expertise they contribute to a research project. Some researchers are already working in this way through platforms such as Amazon's Mechanical Turk, which enables researchers to find and pay participants online, albeit potentially creating new extractive relationships. But, money won't work for every participant or for every research project. Some participants can't accept one-off or occasional financial payments because it would adversely affect their state benefits. Some researchers don't have the funds to pay participants – though I would argue this should be factored into funding bids. We have passed the point where it is OK to ask people to give their time and expertise for nothing, on the rather shaky basis that it could benefit a putative group of people at some unknown time in the future.

> informed consent is now a myth

Although remuneration is even more pressing in a time of global economic crisis, money will not always be available. Fortunately, there are other options. Some years ago, a friend of mine did community-based research to study the experiences of people living with chronic illness. Her research had minimal funding, so she offered each participant an hour of her time in exchange for an hour of theirs. She offered to do whatever they wanted that was within her power: shopping, cleaning, providing company – anything at all. Her participants felt valued and she enjoyed the experience. Perhaps, where money is not an option, a little creative thought can help us come up with a way to meaningfully recompense people for their time and expertise.

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My third suggestion is to let participants choose whether they are anonymous or named in the research. Research ethics committees and institutional review boards take a paternalistic approach, deciding that participants require the protection of anonymity, often through pseudonymisation. However, anonymity does not provide protection in the way these committees and boards seem to think it does. Also, some participants have a very different view of the value of anonymity. A friend told me that one of his colleagues conducted research in a hospice for children with life-limiting conditions. Their parents had to give consent for them to take part, and the children's anonymity was assured – but the children wanted to be named in the research report. And you can see why: they wanted, as we all do, to leave something of themselves in the world. Then there is the experience of Kristen Perry, in the US, who conducted research with Sudanese refugees. Her institutional review board required her to give participants pseudonyms. When she explained this to her participants, one key person, a community leader, refused to take any further part in her research. He told her, 'I have something important to say, and I want the world to know that I am the one who said it.' Perry investigated and found out that forced name-changing was a repressive practice used by the Sudanese regime. The institutional review board was unaware of this crucial piece of information.

Clearly no review board or research ethics committee can know everything about every culture on the planet. But they don't need to, because potential participants understand their own culture and its priorities, and the effects of their life experiences. Researchers often congratulate ourselves on amplifying participants' voices, particularly when our participants are marginalised. But, how are we amplifying people's voices if they can't have their name attached when they want to be named? We should be able to discuss the options for anonymity and naming with participants, making sure to cover all the pros and cons we can, and then let them decide.

In summary, if we seek to do research in a way that treats participants better:

1. Replace 'informed consent' with empowerment to assess risk
2. Remunerate participants for the time and expertise they contribute to research
3. Support participants to make their own decisions about anonymity or naming

There are no doubt other steps that can be taken, but these would be a good start to finally recognising the importance of all participants in our research.

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Acknowledgement: My thinking on these matters is influenced by the Indigenous research methods literature I have read, some of which can be found here and some more here. I am grateful to my Indigenous teachers for sharing their wisdom.

Image Credit: Adapted from Dylan Gillis via Unsplash.