Research corner: ethics of researching - a continuing process

Image
This photo shows a closed padlock resting on a computer keyboard.

Photo by FLY:D on Unsplash

This image relates to the importance of keeping research participants’ data secure.

In our latest blog, Sameerah considers the need to handle participants' stories responsibly.

Ethics of researching - a continuing process

by Sameerah Mahmood

I remember the moment I saw the advertisement for the community researcher role at Migration Yorkshire. As a graduate from a human rights institution and knowing all about the ethics of research, I knew I would be a good fit. In addition, nowadays recruiting researchers with lived experience i.e., ‘experts by experience’ (EBE), such as myself, as part of a project, is becoming an important element in the credibility of research into social issues. What these EBEs bring is their own stories, plus an understanding of the lives of the participants. But how can the stories that these researchers and the fieldwork participants share be handled responsibly?

Although the ethics of research are given serious attention by universities and other research organisations, there are still hidden challenges when fieldwork begins. Ethical protocols are not merely ‘keeping participants unidentified’. It is more than that. It is a range of responsibilities that we as researchers have towards the participants, the institution we represent, the stories we hear. Here I want to focus on our responsibilities towards the stories: the ‘data’ we collect from the participants.

The responsibilities we have toward the stories we hear is as important as maintaining confidentiality and privacy. This becomes even more crucial when a vulnerable population, such as refugees, is involved in the research. A study entitled

‘“Stop Stealing Our Stories”: The Ethics of Research with Vulnerable Groups’ tackled considerations such as ‘the responsibility to the story’: ‘where does knowledge about the story come from and how is it passed on?’ (Pittaway, Bartolomei, Hugman, 2016). I was moved by the statement of a refugee participant in this report. This quotation shows how participants may feel that their voices are taken from them, and how we, as researchers, have a duty to protect participants by keeping the voices of the owners of these stories clear and heard:

> *‘You know many of the organizations came to the refugee camp and they see the refugees in many ways as the monkeys ... like a monkey in a cage ... and then they thought that if we show this monkey to ... the big countries of power like the EU (European Union), they will have a lot of money and it will benefit us (the non-governmental organizations) ... They documented things (stories) of the women that is oppressed, then when they get money they use some for the refugees but mostly they use for themselves. (Discussion with a refugee men’s group, Thai–Burma border, 2009).’*

A drawing by one of the participants published in the article was worth many words. This single drawing, which depicted a monkey in a cage as described above, showed the lack of responsibility the researchers took towards the stories they heard from the participants. How many researchers are represented by the researcher in the illustration? How many participants are represented by the participant in the cage?

In the research I work on at Migration Yorkshire, we aim to ensure the involvement of participants by trying to encourage a sense of ownership of the research. We ask if the participant would like to be informed about the final research report. Many of them were willing to be updated. Our research ethics procedures mean that the stories told to us are only used for the purpose of that specific research project. I’ve never been part of research that uses that data more than once, but if there was any intention to reuse the data collected, this would be explicit in the participant consent form.

We complete a Data Protection Impact Assessment (DPIA) about what personal data we are collecting, storing and sharing, and the consent forms we use for MY’s projects have to be approved by the Leeds City Council information governance team. Our academic research partners follow their own ethics procedures that address these issues.

As a community researcher with MY, I felt during fieldwork that the participants were reassured by my presence. For example, how important are the information and consent forms I use and explain to participants at the start of interviews? I explain to them what we do with their stories, who has access to them, and why – so the participant knows what our purpose is and can make an informed decision about participating. Employing these practices helps ensure we act responsibly in relation to the stories we hear.

My previous experiences have made me aware of the risks and challenges of fieldwork, however, it should not be taken for granted that every researcher is aware of their responsibility towards the stories they hear. Updating training regarding research ethics should not be a one off. As a community researcher, my experience, my research skills and knowledge of research ethics, all contribute to make me as responsible as possible with people's information and stories.

Reference

Eileen Pittaway, Linda Bartolomei, Richard Hugman, 'Stop Stealing Our Stories': The Ethics of Research with Vulnerable Groups, *Journal of Human Rights Practice*, Volume 2, Issue 2, July 2010, Pages 229–251, https://doi.org/10.1093/jhuman/huq004

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