**Tackling ethical challenges in community-university participatory research**

**Some case examples**

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***Contact***: s.j.banks@durham.ac.uk

**Questions for discussion**

1. What do you think are the main ethical issues in the case example?
2. Can you relate these to the ethical principles?
3. What would you do if you were the person telling the story? Relate to the practice guidelines (Planning the research; Doing the research; Sharing the research)
4. How would you justify your proposed actions?

***Example 1: Participatory research with young women at an allotment project***

A young women’s group runs an allotment in a UK city. The allotment was transferred to the group several years ago, and provides opportunities for lesbian, bisexual and transgender young women aged 14-25 years old to learn about growing and cooking together and to socialise outside their youth centre. Several youth workers work with the young women at the project. An older woman, Polly, who was involved with a previous community group at the allotment, stayed on as a member of the new group. Polly is also a university researcher and after a couple of years suggested that the group might get involved in a participatory research project documenting the work they were doing at the allotment as part of a wider research project with other groups. After discussion, the young women decided they would interview each other and make videos. Polly worked with the group to submit a successful grant application, for which the funding went to her university, with Polly named as the person responsible for coordinating the research, in partnership with the young women’s group.

As the research developed, relationships across the project changed. Polly’s role shifted from ‘adult volunteer’ in the youth project, to being both a co-researcher and a research participant (being interviewed by the young women as part of the research). At first this shift was not specifically discussed or defined, but it came to the fore when a specific situation caused the youth workers to rethink their view of Polly’s role. As a volunteer, Polly mainly participated in the allotment sessions, and not those in the youth centre. Thus she did not attend team meetings or training around child protection. The youth workers were particularly careful not to reveal to Polly any details about young people’s private lives – issues at home or at school – which they regarded as confidential. However, as one of the youth workers reflected:

The researcher [Polly] began to spend more time on the project and build deeper relationships with the young people. Decisions about what and how much information to disclose about members of the group to the researcher needed to be taken. This was both to protect the young women in the group and in some cases the researcher.

A particular situation arose in relation to a young woman who had accused one of her teachers of having a romantic relationship with her, resulting in the suspension of the teacher. The youth worker discovered that the young woman was also attracted to her and was concerned that the young woman would make allegations about her or other staff members. Prior to a residential weekend in which Polly was to participate as part of the research, the youth worker decided to tell Polly about this situation, so Polly could protect both the youth worker and the young woman by ensuring they were not left alone together and in order to alert Polly to the possibility that she too might be subject to allegations.

**Example 2: The community research and mentoring project**

Eileen is a volunteer community activist with a community organisation near where she lives. The organisation focuses on poverty and injustice and has undertaken action research on issues such as household debt and health. Eileen got involved with the organisation after having been interviewed herself as a research participant and encouraged to take part in community action and further research. She undertook training in community organising, research and mentoring offered by the community organisation. She then became a researcher/mentor with another action research project that involved collecting data on household debt and offering mentoring support to households experiencing debt and related problems.

Eileen reported that on one occasion she and another (female) mentor had called on a woman who was isolated, depressed and experiencing suicidal thoughts. Eileen reported:

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 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? 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.

The situation was reported to the manager of the community organisation, who advised them that they should not have intervened and were ‘out of their depth’. He arranged for professional help for the woman. Afterwards Eileen said she felt ‘drained and emotional’ and reflected on the experience as follows:

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?

**Example 3: The gangs and guns peer research project**

A young people’s peer research project was initiated by a local authority and a housing association, in partnership with several other agencies, in an urban area with high levels of gang-related and gun crime. A youth worker from a local youth project was employed to lead the training of the young people, who were recruited by another partner organisation. The young people were aged 14 to 25 years old and were largely black young men. The plan was that they would design a piece of research based on gaining information from other young people from the area – both those involved and those not involved in gangs. The results would be presented to a conference of 100 professionals later in the year, with the aim of helping tackle some of the issues relating to gun and gang-related crime.

The work was very challenging for the youth worker/trainer - a white lesbian woman, who was not ‘out’ to the group. There was a lot of sexism and homophobia, which the trainer did not tackle – as she was afraid it might turn attention onto herself and away from the young people as researchers. She did work with them on issues of racism and stereotyping – though she felt that sometimes they were presenting themselves as ‘victims’ of racism in cases where by their own accounts this label did not really fit. Although the young researchers were not themselves involved directly in gangs or gun crime, they tended to tell stories presenting themselves in this way. The trainer and her colleagues decided not to challenge the young people on this, as they knew that at the conference the professionals attending would want to hear young people’s stories. A group of younger peer researchers also decided to present a play at the conference depicting a scene showing how gang violence was sparked by a particular incident, which the youth worker felt was a misrepresentation of the long-standing feuds between rival gangs.

When the young people presented their findings at the conference, the professionals (from social work, probation, youth justice and other related agencies) quizzed them about gang membership rather than looking at protective factors that had influenced why they were not members of gangs. The young people presented findings of their research showing the impact of closure of a play scheme meaning that children from opposing neighbourhoods no longer met in a social context; the need for the satellite job centre to open more than one day a week in an area of very high unemployment; and the importance of the local authority encouraging building contractors in the area to employ local apprentices. However, the professionals did not seem to listen carefully or respond to what the young people had to say on these matters. They went on to talk about policing, ‘hot spots’ and reducing ‘silo working’ – terminology not understood by the young people.

Reflecting afterwards, the youth worker/trainer commented:

This research project made me think about several ethical issues around the sometimes conflicting priorities or motivations of the different stakeholders involved in a CBPR project. In this case, the funders seemed to want the research to fit with their existing agenda rather than really to listen, whereas the young people hoped to be able to educate and influence policy-makers. I also wondered whether as a trainer I could have used my own gender or sexual orientation in a more disruptive way to help the group analyse their own situation. Finally, reflecting afterwards, I considered whether the young researchers should have been more detached from the research as an outside researcher would have been, or have been more honest about their identities when they had not come from a gun- or gang-related background.

**Example 4: Issues of copyright and informed consent in a museum-based project**

Louise was a project manager, employed by a museum service, for a large-scale participatory research project that took place over a three-year period. The project was designed to work with members of the public living in a particular region of the UK to tell and make their own digital stories. These would then be displayed across the region and formally accessioned as part of the museum’s collections. By adding these stories to the collections, the project aimed to demonstrate that people’s stories were valued by the museum. This also meant that the stories would be available for future display after the end of the project.

The project team discussed how to support participants on the issue of informed consent – that is, obtaining people’s agreement for the stories to be used for a short term display and long term public access through the museum’s collection. As Louise commented:

It was felt that we needed to make people aware of what was happening to their story at the beginning so that they would create a story they would be happy to share. We decided that we would take an ‘upfront’ approach to consent and copyright. Getting a clear assignment of copyright to the museum at the start was seen as important, because the museum did not want to have to go back and seek permission every time they wanted to re-use the story. Once copyright has been assigned and the stories are accessioned into the collection they become ‘fixed’ – or so we thought.

However, two participants made requests after the project had ended that challenged the notion of ‘fixity’. These participants had told stories about partners from whom they had since split up. The first participant wanted their story removed from public display and the other wanted their story changed. In the first case, this was relatively straightforward and simply involved removing the digital story from the website and adding new notes to the collections management records for that particular story, so museum staff were aware of these restrictions. The second example was more complicated, as it raised issues about whether these digital stories should be treated in the same way as ‘regular’ museum objects. As an accessioned object, should the master copy of this digital story be changed to take into account the wishes of the story creator? As Louise reflected:

Both these situations certainly made me feel conflicted - there were the understandable wishes and feelings of the story creator on one side versus the official procedures of museum collecting on the other. This example clearly demonstrates that the ethical issues of accessioning ‘digitally born’ material that has been produced by the public needs further thought and debate.