

Negotiating independent ethical review of co-produced disability research: issues and lessons

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Presenters: Peter Scott and Alison Koslowski, on behalf of:

Disability Research on Independent Living and Learning (DRILL) Ethics Committee

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With analysis by Kieran Lyddon, University of Southampton

Outline of presentation

1. Background
2. Ethical issues and co-production
3. Negotiating informed consent
4. Confidentiality and safety
5. Concluding observations

1. DRILL and DRILL Ethics Committee

- **DRILL** is a four-nation, five-year programme funded by National Lottery Community Fund
- Co-production by and with disabled people central to programme's philosophy
- 32 research projects
- <https://youtu.be/W3Gwbxjzlvk>
- **DRILL Ethics Ctte** specifically constituted to ethically review the 13 DPO-led projects not run or reviewed through a university
- All four UK nations represented on Committee
- Unique initiative → lessons to be learned
- Initial evidence synthesis from review of Ctte's work undertaken by intern at University of Southampton (Kieran Lyddon)

2a. **Inter**-organisational ethics issues in co-produced disability research

Between DPO-led research organisations and ethics committee

- Power dynamics - we tried to break power imbalances down and to build mutual capacity where possible
- Rebalancing of Ethics Committee / DPO relationship because of composition of DRILL Ethics Ctte
- In a minority of cases, communicating the need for ethical review of project as a whole, or of participant documentation already co-produced with other organisations

2b. Co-production **within** DPO-led projects: ethical issues

- Ensuring adequate opportunity to feed back and / or disseminate to participants
- Trying to ensure disabled participants are not disadvantaged where participation potentially involves participants in expenditure, e.g. participation in physical focus groups
- Possible use of less formal data collection settings to increase accessibility for participants
- Despite importance of subject matter to researchers, minimising risks that participants might feel pressurised to take part
- Provision of sufficient training to project researchers with limited research experience

3. Negotiation of informed consent in the projects

General importance of consent well understood by projects, detail of ability to demonstrate its achievement throughout a project less so. Issues:

- a) Ensuring reconsent over time and facilitating participants' ability to withdraw data, where practical
- b) Ensuring project information is clear about what constitute the minimum preconditions of participation

c) Disaggregation of consent... Good example from Project A: breaking down what consent means

Consent form for DRILL Research

 I am an adult over the age of 18.

 I have a learning disability.

 I believe that I have the right to decide, for myself, whether to take part in this research or not.

 I have volunteered to take part in the DRILL research about decision-making.

 I understand what decision-making means.

I understand that I can leave at any time and not answer any questions I do not want to answer.

I understand that I can ask for support from anyone if I need help to understand something.

I do not feel that anyone has pressured me into taking part.

I give my consent for the researchers to ask me questions about decision-making and about my experiences and thoughts and ideas on decision-making and to use those things in the report.

I know that anything I say will be anonymous. This means the report will not say what my name is. No one will know what I said in the Focus Group.

Signed _____

Date _____

Credit: Project A. Images
credit: Photosymbols

d) Expressing information and consent in terms participants will understand and in appropriate formats. Examples from Project M

Easy read, itemising consent

 I have read the **project information sheet** or someone has read it to me. I understand it. I was given the chance to ask questions about the research. My questions were answered and I am happy with the answers.

 I know that I do **not** have to take part in this research if I do **not** want to.

 I know that I do **not** have to answer all the questions I am asked. I know that I can stop taking part at any time and I do **not** need to give a reason.

 I understand that if I withdraw from this project and I request my information to be removed from the research, the information I provided can only be removed from the research within eight weeks of the completion of the interview or focus group.

 I know that taking part in this research means being part of a **focus group** and/or an interview. I know that what is said at the **focus group** and interviews will be written down.

A focus group is a group of people that meet to talk about their ideas and experiences. They give feedback on something.

Page 3 of 9

Easy read info sheet, defining unusual terminology

 • **peer researchers.**

Peer researchers are people who help carry out research. **And** have experienced the issue being researched.

 We also want to find out what is difficult about doing coproduced research with **peer researchers** and people who work at universities.

 We are looking into 1 main question:
[REDACTED]

 **DRILL** stands for Disability Research on Independent Living and Learning.

 DRILL is a special **research** programme. We have money from the **Community Fund** for DRILL.

 We are doing lots of **research** through DRILL on what makes it difficult for disabled people to live independently.

Page 5

Credit:
Project M.
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4. Issues around confidentiality and participant safety

- Use of audio and video data and constraints on anonymity
- Confidentiality in discussing sensitive subjects in focus groups
- Encouraging novel forms of dissemination (e.g. online vlogs) while simultaneously safeguarding participants
- Safeguarding procedures if allegations surface of potential harm to participants or others

Good practice ethics points summary

- Clarity about the detailed implications of key ethics concepts for project participants and how these concepts can be realised in practice
- Need for a broad appreciation of appropriate formats to transmit project information and ensure informed consent. Easy read proved to have considerable potential
- Alertness that ethical considerations include measures to build capacity and to reduce power inequalities and distance, both between:
 - researchers and researched, and
 - ethics committees and researchers.