

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

Social Research Association Annual Conference,  
10 December 2019

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

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

Dr Bronagh Byrne, Queen's University Belfast; Dr Jackie Gulland, Prof. Alison Koslowski (chair), University of Edinburgh; Prof. Sarah Parsons, University of Southampton; Dr Peter Scott, University of Portsmouth

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.  
Images credit:  
Photosymbols



## 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.