UNIVERSITY of York

DEPARTMENT OF HEALTH SCIENCES

c/o Department of Philosophy
Heslington
York YO10 5DD

Telephone [redacted]
Fax [redacted]
E-mail [redacted]

Dr Stephen Holland

[redacted]

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Dr M Berghs
University of York
Department of Health Sciences
Area 2, Seebohm Rowntree Building
YO10 5DD

Dear Maria

Implications for Public Health: Research of Models and Theories of Disability

Thank you for submitting the above project to the Health Sciences Research Governance Committee for approval. Your application was considered by the committee at its meeting on Monday, 18 May 2015.

The committee has approved the project with the following feedback:

Submission form

1. S12 states that a fee will be paid to organisations but does not provide details. The committee is happy to leave it to you to devise a fee schedule but asked me to reiterate that payments to organisations must be reasonable and equitable.

2. S13, the first sentence ('There is no reason …') seemed odd since it is natural to think of disabled participants as vulnerable in many ways.

Study documentation

3. Various terms are used, such as deliberating panel, focus groups and interviews. The committee recommends that one term is consistently used so that participants are clear that there is only one sort of event.

Permission to contact form

4. The committee felt that the two picture images were slightly off-putting and might be revisited since the point of the form is to attract participants.

Both Information Sheets

5. The Information Sheets could be distinguished by clarifying titles ('… for Professional participants', '… for disabled participants' or some such).

6. 'What is the study about?': the committee felt the comments could be more positive and appealing, which might help incentivise potential participants and improve recruitment to the project; e.g., on the information sheet for disabled participants, the sentence, 'This project is a review of interventions (randomised control trials – RCTs)' is rather academic-sounding.

7. 'What happens to the information?': the comment, 'Nor will we share what you tell us with anyone else' might be misleading given the point of the deliberating panels. Also in that section, the committee felt that a comment should be included about what the researchers will actually do with the data (at present, the comments are reassuring about how data will be handled, but there's no indication as to how data will be used).

8. 'Who is organising and funding the study?': the name of our committee is 'Health Sciences Research Governance Committee'.

9. 'Contact for further information': the contact details of someone who is not part of the research team should be provided (typically, a senior colleague in an appropriate position, such as Chair of Research Committee).

Information Sheet for Professionals

10. 'Why have I been approached?': the phrase, 'around 20-5 people with disabilities will be invited …' is unclear because this is information sheet is for professional (as opposed to disabled members of the panels).

Consent Form

11. Statement 1. should include the year as part of the Information Sheet date.

I must emphasise that these comments are intended as helpful feedback points which the committee is confident will be dealt with by this experienced research team, and no further scrutiny is required.

In addition, thank you for the covering letter which was discussed at the meeting. As a result of this prompting the committee decided to change its practices in two ways. First, a section will be added to the Submission Form requiring information on PPI. Second, the Guidance Notes relating to that new section will contain a comment to the effect that the Department supports the principle that PPI should inform our research. However, it was decided that it is not the role of the HSRGC to approve PPI activities which do not culminate in research projects: this would not be practicable; and the committee is of the view that colleagues should be trusted to undertake PPI activities sensibly. The committee is very grateful for your thoughtful comments which have motivated this improvement in our practices.

If you make any substantial amendments to the research design, or have any questions regarding the committee's decision, then please contact me.

Yours sincerely

Stephen Holland

Chair: HSRGC