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The ethical implications of facilitating the involvement of groups considered 'vulnerable' in the development of research

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April 2017

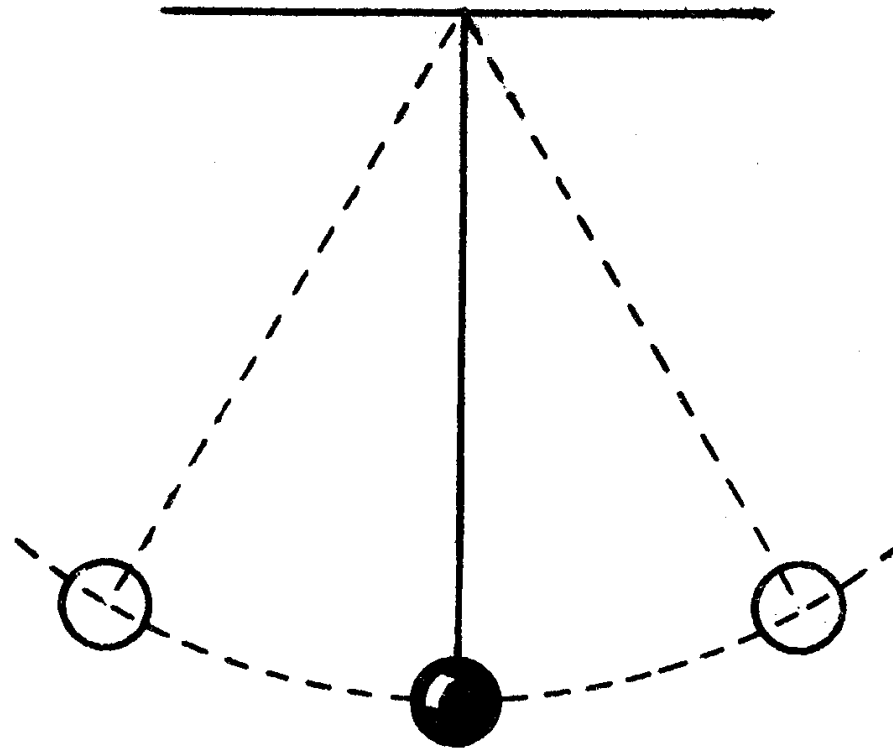
Aim

To explore what ‘involvement’ means when seeking to promote involvement in the development of research and how this may be facilitated when working with groups who may be considered vulnerable.

Areas to be addressed:

- The importance of involving groups who may be considered vulnerable in the development of research
- The nature of vulnerability
- The ethical considerations of promoting involvement

The Changing Context



Problem:
Exploitation
Coercion
Harm

Response:
Exclusion
Marginalisation
Harm

How best to promote involvement in an ethical manner?

Involvement

- To what extent?
 - As participants?
 - As decision makers?
 - As researchers?
- At which stages?
 - Deciding what to research?
 - Developing proposals?
 - Undertaking the research?
 - Disseminating the findings?

‘Vulnerable Groups’



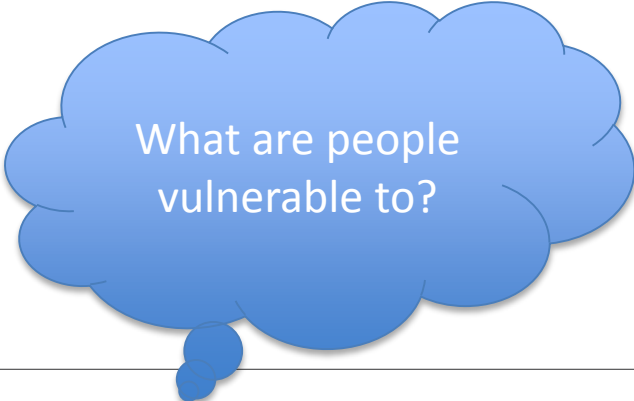
- Children
- Young people
- Older people
- People with learning disabilities
- People with mental health problems
- People with dementia
- Prisoners
- People receiving end of life care

Problems With Using the Label 'Vulnerable Group'

- Too inclusive – almost anyone could be included
- Too restrictive – focuses on single aspects of personal experience
- How best to address intersectionality?

Definitions of Vulnerability

- ‘...common to all of them is the notion of harm, danger or threat to the individual which can be physical or psychological’ (Hewitt-Taylor and Heaslip, 2012:31)
- ‘A precise definition of vulnerability is difficult as it is a contested term’ (Witham *et al*, 2014: 2845)



What are people
vulnerable to?

Ethical Principles

(Beauchamp and Childress, 2013)

- Autonomy
- Beneficence
- Non-maleficence
- Justice

Epistemic Injustice (Fricker, 2007)

Two forms of epistemic injustice:

- Hermeneutical injustice – someone is wronged in their capacity as a subject of social understanding who makes sense of their own social experiences
- Testimonial injustice – someone is wronged in their capacity as a giver of knowledge to others

A Way Forward

The nature of involvement

- What level is sought / desired?
- Building on existing relationships
- What knowledge, skills and resources may be required?

Vulnerability

- What are / might people be vulnerable to?
- Can these factors be eliminated or reduced?
- What barriers may exist?
- What knowledge, skills and resources may be required?

Ethical involvement

- Respecting autonomy
- Promoting beneficence
- Non-maleficence
- Promoting justice

References / Further Reading

Beauchamp, T.L., Childress, J.F. (2013) *Principles of Biomedical Ethics*, 7th edition, New York: Oxford University Press

Fricker, M. (2007) *Epistemic Injustice. Power and the Ethics of Knowing*, Oxford: Oxford University Press

Hewitt-Taylor, J., Heaslip, V. (2012) Protecting children or creating vulnerability? *Community Practitioner*, 85 (12) 31-33

Northway, R., Howarth, J., Evans, L. (2014) Participatory research, people with intellectual disabilities and ethical approval: making reasonable adjustments to enable participation, *Journal of Clinical Nursing*, 24, 573 – 581

Witham. G., Beddow, A., Haigh, C. (2015) Reflections on access: too vulnerable to research? *Journal of Research in Nursing*, 20 (1) 28 - 37