

# Rights-based Rehabilitation

Harriet Cooper

11 November 2016

'The Patient Voice' Session at 4<sup>th</sup> European Congress of ER-WCPT



This is a summary of independent research funded by the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care East of England (CLAHRC EoE) Programme. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

# Overview

My current research



Me – my background and research interests



What does an interdisciplinary perspective add to a conversation about ‘the patient voice’?



Some provocations about rehabilitation

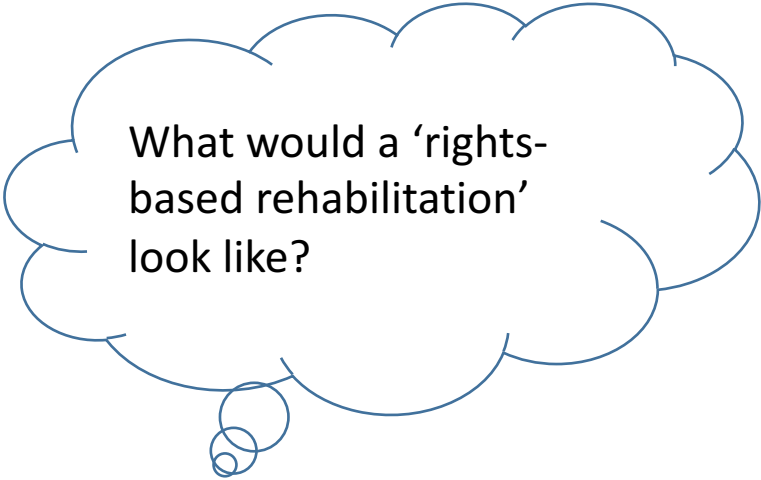
# Current research – filling a knowledge gap...

The UN Convention on the Rights of Persons with Disabilities (2008) calls upon all states to provide ‘comprehensive habilitation and rehabilitation services’.

BUT....

- systemic barriers have hampered the implementation of rehabilitation programmes (WHO, 2011).

- there has been a lack of involvement of disabled people in the design, delivery and evaluation of rehabilitation services (WHO, 2011).




What would a ‘rights-based rehabilitation’ look like?

# A gap in current knowledge...

Prominent disability rights activists criticise the rehabilitation agenda for its emphasis on the desirability of some kinds of bodies and not others (Oliver, 1990, 1993; Abberley, 1995; Finkelstein, 2004).

For Shakespeare (2014), a commitment to a 'strong' social model within disability studies has hampered the development of disciplinary alliances (for example, with medical sociology) that could lead to research promoting the human rights of all disabled people.



How do disabled people feel about their rehabilitation experiences?

# Key points from the review of the literature

I reviewed the literature on spinal cord and cerebral palsy rehabilitation, and separately I reviewed the disability studies' literature on rehabilitation

Since 2011, a small minority of articles explored rehabilitation using qualitative methods, with a focus on the views and experiences of disabled people.

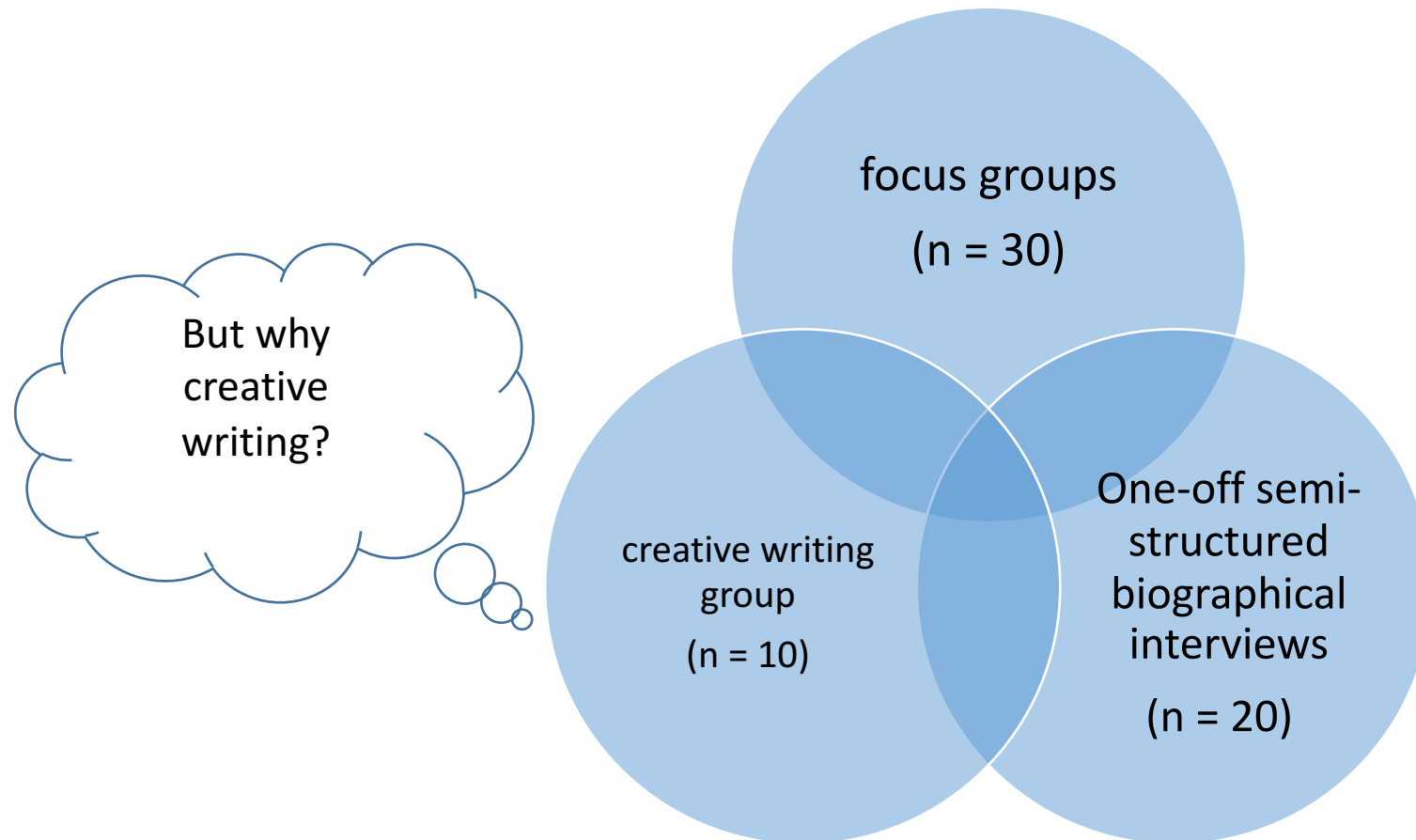
What would a qualitative research project, with embedded PPI, find out about lived experiences of rehabilitation?

There was a paucity of research showing evidence of public and patient involvement being systematically woven into the methodology from the outset.

# My anticipated contribution to knowledge

By doing research at the intersection of rehabilitation science and disability studies, assumptions on both sides can be challenged about what rehabilitation is for, and who decides what rehabilitation is: this could help to make rehabilitation more relevant to the patients who undergo it.

# What kind of data collection methods?

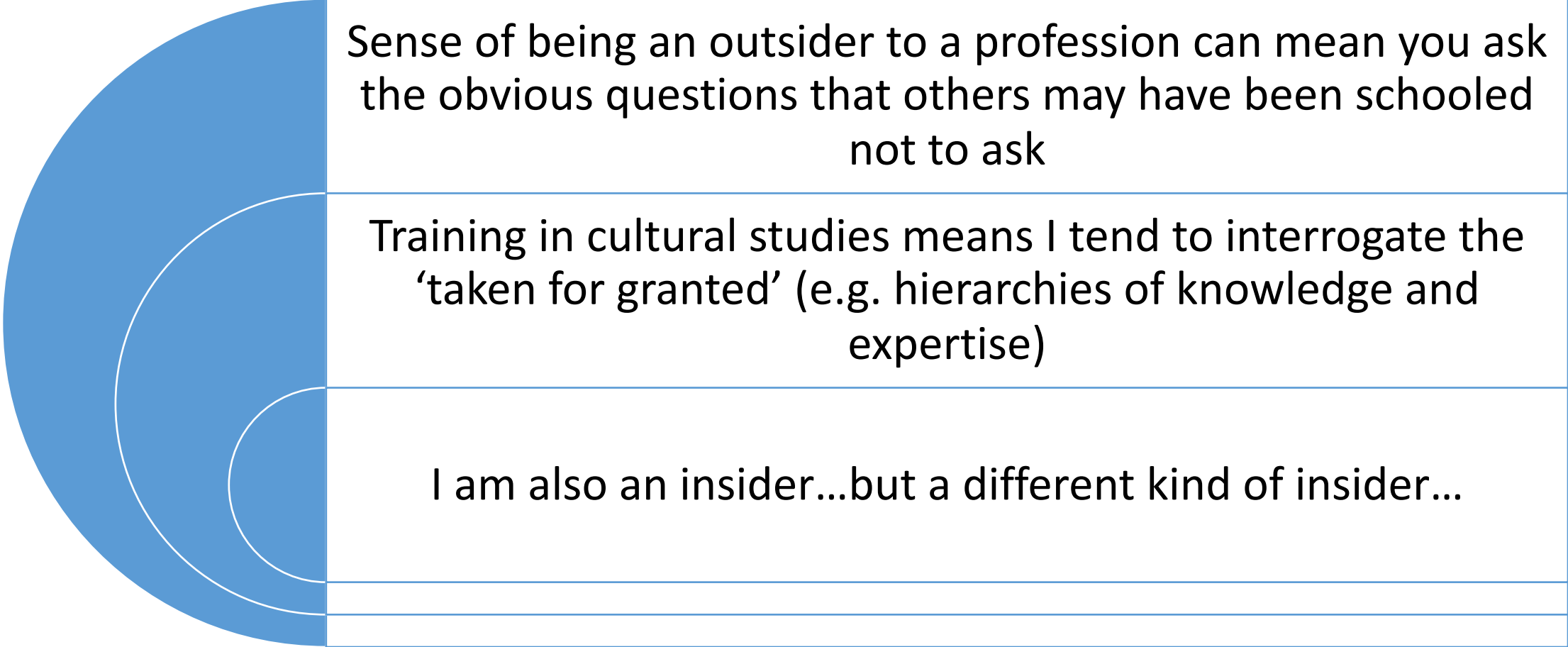


# My background, and previous research

- BA in English Literature
- MA in Cultural and Critical Studies
- PhD in Cultural Disability Studies
  - literary representations of disabled children
  - theorising own lived experience of growing up with a disability



# What does an interdisciplinary perspective add?



Sense of being an outsider to a profession can mean you ask the obvious questions that others may have been schooled not to ask

Training in cultural studies means I tend to interrogate the 'taken for granted' (e.g. hierarchies of knowledge and expertise)

I am also an insider...but a different kind of insider...

# Some provocations about rehabilitation

Who gets to decide how rehabilitation is defined?

Should we assume that rehabilitation is always a 'good thing' / always makes life better for the patient?

What kinds of assumptions underlie rehabilitation policies and practices?

How do these assumptions make patients feel?

Do we have different assumptions about what rehabilitation should do for adults, and what it should do for children, and why?