

INVOLVE

NHS

*National Institute for
Health Research*

School for Social Care Research

Webinar 4: User- Controlled Research

13 May 2014



15/05/2014

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1. This is the 4th so far (general overview of involvement, BME research & end of life care research) to support the growth of attention given to involvement of people in health and social care research.
2. SSCR is committed to making its work as inclusive as possible and promoting good practice.
3. The webinar series will draw on SSCR's work, and NIHR's and Involve's experience to promote understanding of good practice in involvement.

SSCR - sscr.nihr.ac.uk/

Involve - www.invo.org.uk/

NIHR – <http://www.nihr.ac.uk>

For updates on SSCR activities join the mailing list – email sscr@lse.ac.uk

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User-Controlled Research Peter Beresford



15/05/2014



The fourth joint SSCR/INVOLVE webinar on User Controlled Research
13th May 2014

**Academic research programme bid co-
production: developing user-controlled study
proposals**

Dr Sarah Carr FRSA
www.sarahcarrassoc.co.uk



Academic research programme bid co-production: developing user-controlled study proposals

- ‘Lived Experience Advisory Panel’ (LEAP) with terms of reference and ground rules
- Move away from tokenism
- Embed peer support
- Challenge conceptions of who a ‘researcher’ is
- Determine research questions and methodology
- Add value and depth
- Ensure research relevance, acceptability and applicability



User control in academic research bids: challenges

- Perceptions of who a 'researcher' is
- Knowledge legitimacy
- Preconceptions about bias
- University and funder administrative access
- Estimating research costs
- CV diversity
- Power dynamics within the team
- Who decides?



User control in academic research bids: suggestions

- A co-chaired 'lived experience' panel of user researchers and other experts embedded in team
- Payment for work and cover for expenses
- Address access and equality requirements
- A flexible, committed bid leader working in co-production
- Challenge university and funder bureaucracy
- Respect for diverse knowledge, methods and standpoints



Thank you

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The School for Social Care Research

Mike Clark



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Adult Social Care:

- Over 16 years of age
- Non-universal services
- Central policy making, local implementation
- A wide range of needs and client groups
- Care is delivered in a range of settings
- Mixed economy of provision
- Mixed funding - growth of self funders
- Diverse workforce e.g.
 - ... 1.8 million people employed in the care and support workforce
 - Over 20,000 Social workers
 - Plus Nurses and Occupational Therapists
 - Large non-professionalised workforce
 - Personal Assistants



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About SSCR:

- Phase I: May 2009-April 2014 – about 60 projects; methods & scoping reviews
- Phase II: May 2014-April 2019
- Mission: To develop the evidence base for adult social care practice in England by commissioning and conducting world-class research**
- Intramural* research (6 academic units – LSE, Universities of Bristol, Kent, Manchester & York)
- Extramural* research, externally commissioned by us, across England

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Methods reviews:

- MR1 Qualitative methods overview
- MR2 LGBT sexualities in social care research
- MR3 A brief guide to carrying out research about adult social care services for visually impaired people
- MR4 Research governance and ethics for adult social care research: procedures, practices and challenges
- MR5 The use of 'large-scale datasets' in UK social Care research
- MR6 Overview of outcome measurement for adults using social care services and support
- MR7 Mathematical modelling and its application to social care
- MR8 Care homes
- MR9 Research with d/Deaf people
- MR10 Observational methods
- MR11 Research with Black and Ethnic Minority people using social services
- MR12 End-of-life care research methods
- MR13 Systematic reviews in social care and social work research
- MR14 Modelling social care complexity: the potential of System Dynamics
- MR15 MRC guidance on developing and evaluating complex interventions: Application to research on palliative and end of life care

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Scoping reviews:

- SR1 Prevention and Social Care for Adults with Learning Disabilities
- SR2 The Role of the Third Sector in Delivering Social Care
- SR3 Economic Evidence Around Employment Support
- SR4 The Economic Value of Community Capacity Building
- SR5 User Controlled Research
- SR6 New Conversations Between Old Players? The Relationship Between General Practice and Social Care in an Era of Clinical Commissioning
- SR7 The Impact of Advocacy for People who Use Social Care Services

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Some reasons we promote wider involvement:

- Being *inclusive as a democratic thing to do*
- Helping to ensure work is *relevant*
- *Impact* is linked to a process of *ongoing engagement*

- *We are interested in social care research having as much involvement as possible of service users, carers and social care practitioners*

- *In SSCR #2 we want to make our research ever more inclusive and to have yet more involvement in all our projects and out work*

- *We are also keen to support user/carer/practitioner-led research*
 - *We welcome your ideas on how to best do this.*

Resources

In 2010 INVOLVE published a report of seven examples of user controlled research. Service users identified the following key reasons why user controlled research was important to them:

- a commitment to changing or improving the lives of their community of service users
- frustration with traditional research and services which exclude them
- frustration with mainstream research in failing to capture their needs or to research things they feel are important

www.invo.org.uk/find-out-more/user-controlled-research/

Changing our worlds – a report of seven examples of user controlled research: www.invo.org.uk/wp-content/uploads/2011/09/INVOLVEChangingourworlds2010.pdf

View the video to find out more about user controlled research www.invo.org.uk/wp-content/uploads/2011/09/INVOLVEChangingourworlds2010.pdf

User controlled research its meanings and potential . Michael Turner and Peter Beresford 2005.

www.invo.org.uk/posttypepublication/user-controlled-research-its-meanings-and-potential/

NIHR School for Social Care scoping review on user controlled research. Peter Beresford and Suzy Croft 2012

<http://disability-studies.leeds.ac.uk/files/library/SSCR-Scoping-Review-5-web.pdf>

“Service user controlled research is an uphill struggle and it would make an enormous difference if its value in terms of veracity and experiential validity were better recognised. Perhaps what we need is a federation of service users who run their own research projects. That would be a great thing indeed.” Patsy Staddon

Find out more about Patsy’s user controlled research on Improving support for women with alcohol issues

www.wiaswomen.org.uk./current-projects.html

Shaping our Lives

Shaping Our Lives National User Network is an independent user-controlled organisation, think tank and network. Their website includes a resources library, newsletter and publications.

www.shapingourlives.org.uk/

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Questions?



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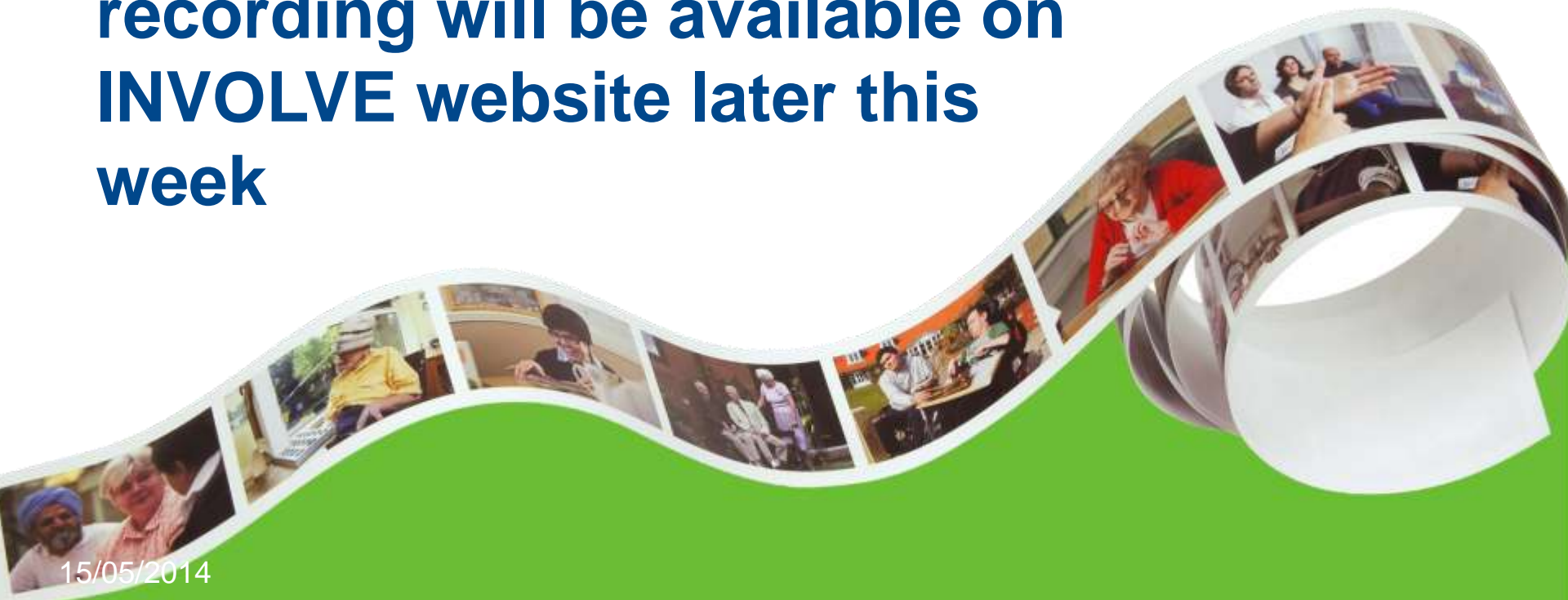


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Thank you

**Presentations and hopefully
recording will be available on
INVOLVE website later this
week**



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