INVOLVE

Webinar 2: Public Involvement in Adult Social Care Research - BME Groups

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Research with black and minority ethnic people using social care services

SSCR Methods Review 11

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Why conduct this review?

- Ethnic inequalities in life chances and living standards persist in England, including general health and long-term limiting illness or disability

- History of failure of social care research and provision to address needs of BME users

- Increasing diversity of England's population

- Also examples of good practice, but these are often localised and under-publicised

Key issues identified throughout the research process:

- Ethics
- Service user, carer and practitioner involvement
- Translation and interpretation
- Funding, commissioning and publishing
- Research design
- Sampling
- Access, recruitment and consent
- Data collection
- Analysis
- Presentation and dissemination

Ethics

- Need to avoid *reification* and *essentialisation*

- Potential for research to contribute to stereotyping and other forms of 'group harm'

- Need to account for cultural differences in what constitutes 'harm' – psychologically, socially or politically (Fontes 1997)

Service user, carer and practitioner involvement

- Need for consultation with BME service users about what research should be done and how

- Also valuable to consult and/or involve carers and care workers

- Examples of good practice Roberts and Harris (2002) research with disabled asylum seekers and refugees, also Gonzalez et al (2008)

Translation and interpretation

- Need to avoid informal translation, also dangers using professional interpreters – many benefits of active participation of research team in translation

- Key point is thorough piloting and built in measures for verification, e.g. Ruhs et al (2006), Johnson et al. (2009)

- Informed consent with linguistically diverse populations requires thought and resources, examples of good practice include Lloyd et al (2008)

- Conceptual as well as linguistic translation, e.g. Mallinson and Popay (2007), Bhopal et al (2004)

Funding, commissioning and publishing

- Limited resources require careful targeting
- Rai-Atkins et al (2002) give example of creative strategies to respond to ethnic diversity with limited funding
- Importance of encouraging effective consideration of ethnicity among publishers and peer reviewers as well as researchers
- Equalities Act (2010) requires research to engage with ethnic diversity

Research design

- Importance of considering ethnicity alongside other factors, e.g. Lawrence et al (2011)

- Importance of being clear what we mean by ethnicity, and whether it is being used as a proxy for a more specific aspect of difference such as country of origin or language group (Ellison 2005)

- Need to avoid jumping from evidence of ethnic inequalities to cultural causes (Kalra 2006)

Sampling

- Researchers often lack a complete sampling frame including all necessary data

- Need to contextualise findings on a particular ethnic group, either as part of wider sample or in the literature

- Various strategies exist to 'boost' sampling of ethnic minorities, e.g. Nazroo et al (2009), Plewis et al (2004)

- Other sampling strategies may be needed for dispersed or 'hidden' populations, tailored to that specific group, e.g. Brown and Scullion (2010), Craig et al (2010)

Access, recruitment and consent

- Sufficient time and resources need to be committed
- Lack of understanding on the part of researchers may be a barrier to access (Brown and Scullion 2010)
- Piloting recruitment strategies important
- Problems exist of some groups feeling 'over research', with little visible benefit, while others feel excluded
- Different implications for numerically smaller groups
- Improving the relevance and usefulness of research to BME service users is an important part of addressing this, e.g. Horowitz et al. (2009)
- Issues for particular groups may compromise consent

Data collection

- Important to reflect on the impact of the 'ethnic embodiment' of researchers (Sharma et al 2009)
- 'Ethnic matching' of researcher and participant may carry benefits and drawbacks
- Sensitivity in data collection can be improved by shifting information and control toward participants, Elam and Fenton (2003) suggest specific strategies
- Research where participants have uncertain immigration status carries particular issues, for which researchers need to be adequately prepared

Analysis

- It is important to consider ethnicity from the design stage, & to analyse ethnicity alongside other aspects of difference
- Rai-Atkins et al (2002) suggest a range of ways to involve BME service users and carers in and Vernon (2002) gives a detailed example that illustrates potential benefits
- When measuring outcomes we need to be clear who sets the criteria, and consider how measures can respond to ethnicity – Hepworth (2003) describes adapting carer self-assessment tools
- Detailed contextual understanding is important to avoid sweeping generalisations and essentialisation of ethnic groups

Presentation and dissemination

- Making findings accessible may require a range of formats, e.g. Roberts and Harris (2002) and Brown and Scullion (2010)

- Dissemination needs to account for potential uses of findings by the media

- Avoiding stigma may require anonymisation of national or ethnic groups

- Accountability to those the research discusses is also important here

Conclusions and Recommendations

- Research needs to both account of ethnicity's shifting and contextual nature, and the concrete impact of racism on people's lives

- We should avoid explanations that explain inequalities as determined by culture, and instead understand the role of ethnicity as contingent, alongside other aspects of difference

- Competent engagement with ethnicity should be seen as a core part of research and practice, not an optional specialism

Further resources

For references, web-based resources and relevant journals see the full methods review at: http://www.sscr.nihr.ac.uk/PDF/MR11.pdf

Involving BME communities in research

Professor Laura Serrant-Green

Introduction

- Researching sensitive issues often difficult to action due to tensions at level of individual, social group and society.

- Planning and provision may be complicated by historical, political and language issues

- Aim to present a framework for researching sensitive issues and marginalised perspectives in health

The Silences Framework

- Derived from my PhD study developed over 4 years

- Recognises tensions in researching sensitive issues and 'marginalised perspectives'

- Acknowledges central role of social scripts on health and life chances

- Centralises experiences of people/communities

- Unites the 'known' and 'unknown' in pragmatic world.

Theoretical underpinnings

- Criticalist and ethnicities based approaches

➢ Research and experience is context bound

➢ Impact of inequality and power on experiences

➢ Central role of researcher

➢ Equal importance of marginalised views and personal experience

Silences Framework – 4 Stages

- Stage 1: Working in Silences (contextualisation)
- Stage 2: Hearing Silences (location)
- Stage 3: Voicing silences (verbalisation)
- Stage 4: Working with Silences (recontextualisation)

Stage 3: Voicing silences

- Data collection phase

- Verbalisation 'speaking for ourselves'

- Methods determined by question

- Must include marginalised (silent) voices and user perspectives

- Phased, reflective and cyclical analysis process which acknowledges limitations and affects of researcher bias on outcomes.

Analysis
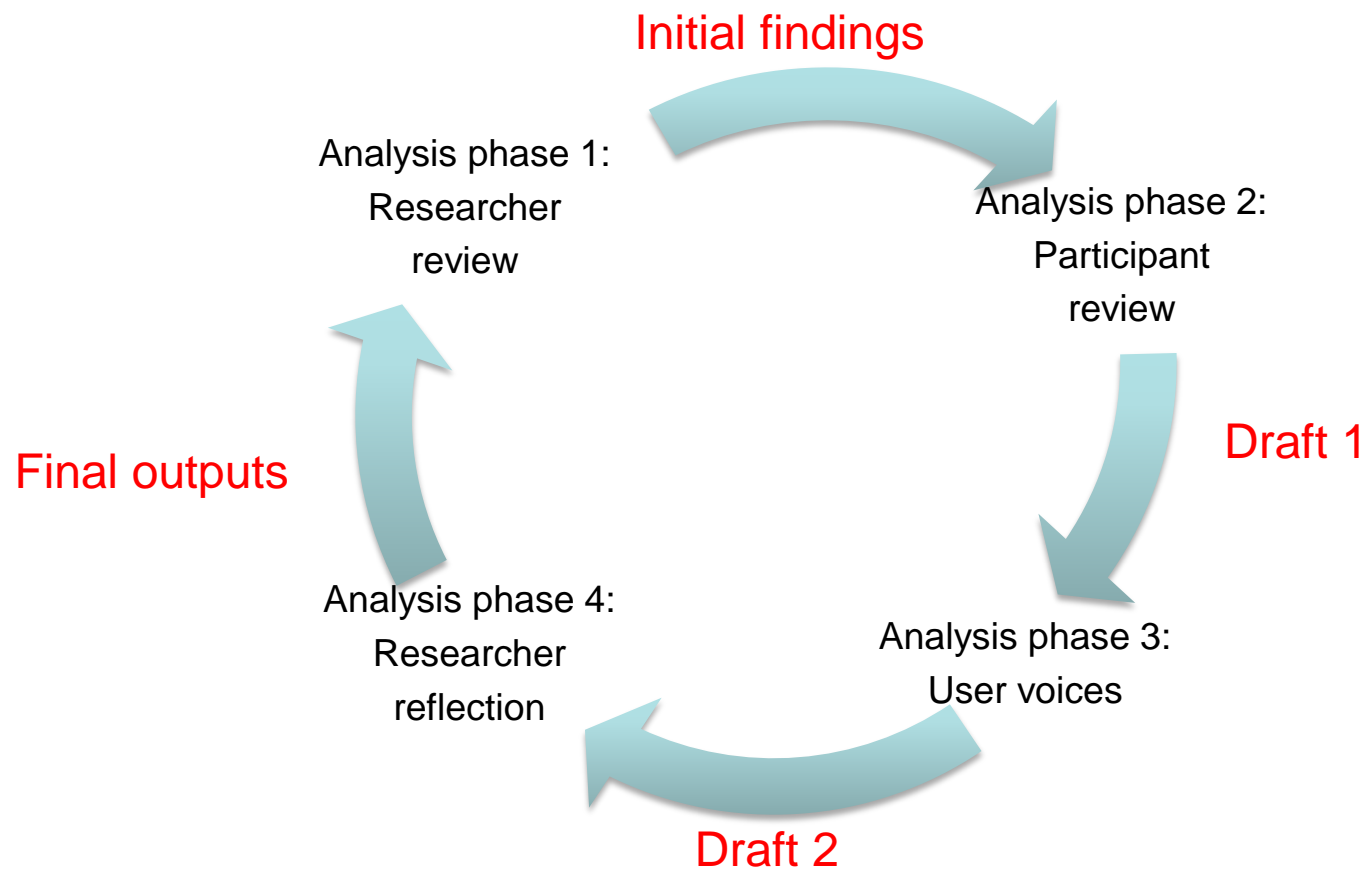
Concluding points

- Silences are situated in the personal and shared experiences of human beings

- The 'listener' determines the nature of the silences and the magnitude of the sound

- Framework exposes the dynamic relationship between researcher, subject and research participants

- Seeks answers on the hidden, devalued or silenced areas of human experience

Resources

- [Research with black and minority ethnic people using social care services.](#) Tom Vickers, Gary Craig and Karl Atkin. NIHR School for Social Care Research Methods Review 11.

- [The Sound of 'Silence': A Framework for researching sensitive issues or marginalised perspectives in health](#)**.** **Laura Serrant-Green, L** (2011 Journal of Research in Nursing Volume 16 Issue 4 July 2011 pp. 347 - 360.

INVOLVE publications

- Diversity and Inclusion: what is it about and why is it important for public involvement in research? (Oct 2012) www.invo.org.uk/posttypepublication/diversity-and-inclusion-what%E2%80%99s-it-about-and-why-is-it-important-for-public-involvement-in-research/

- Strategies for diversity and inclusion in public involvement in research (June 2012) www.invo.org.uk/posttypepublication/strategies-for-diversity-and-inclusion-in-public-involvement/

An assessment of the accommodation and health and social care needs of Gypsies and Travellers

- Members of the Gypsy and traveller communities were involved in the steering group, helped to run focus groups and were recruited as peer interviewers.

- www.invo.org.uk/resource-for-researchers-case studies/

Understanding and improving transitions of older people: A user and carer centred approach

- In Leicester, eight people from Leicester's BME communities contributed to this project as co-researchers.

- www.invo.org.uk/posttyperesource/howto-find people-to-involve/case-study-one/

- Full report and further information

- www.nets.nihr.ac.uk/projects/hsdr/081809228

Born in Bradford

The project started in 2007 and is looking to answer questions about our health by tracking the lives of 13,500 babies and their families and will provide information for studies across the UK and around the world.

http://www.borninbradford.nhs.uk/

SSCR projects

What do people with learning disabilities from minority ethnic groups want from social care services?, Dr Michael Larkin (University of Birmingham)
http://www.sscr.nihr.ac.uk/PDF/Insights/IN29.pdf

Talking to carers of stroke survivors to understand ethnic differences in satisfaction with social care, Dr Nan Greenwood (St George's University of London and Kingston University)
http://www.sscr.nihr.ac.uk/PDF/Insights/IN36.pdf

SSCR projects

Why are people from ethnic minorities less satisfied with social care services? Dr Margaret Blake (National Centre for Social Research) http://www.sscr.nihr.ac.uk/PDF/Insights/IN22.pdf *(forthcoming)*

Trying to go beyond cultural stereotypes to gain a sophisticated understanding of experiences with social care, Dr Rosalind Willis (University of Southampton) http://www.sscr.nihr.ac.uk/PDF/Insights/IN24.pdf *(forthcoming)*

SSCR projects

What are the social care experiences of people with physical disabilities from a Chinese background? Professor Fiona Irvine (Glyndwr University) http://www.sscr.nihr.ac.uk/PDF/Insights/IN27.pdf *(forthcoming)*

Further information on all of SSCR's funded studies is available at www.sscr.nihr.ac.uk

Resources

- Race Equality Foundation
  www.raceequalityfoundation.org.uk/

- Better Health: using evidence to promote race equality in health www.better-health.org.uk/

- Race for Health www.raceforhealth.org/

- Social Care Institute for Excellence
  www.scie.org.uk/publications/reports/report14.asp

- www.scie.org.uk/socialcaretv/video-player.asp?guid=4286962f-9825-4322-81c7-a87253c347a4