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Participatory research, 'bridging' and health

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What is participatory research?

Focus on the involvement of marginalised people – traditionally objects of research - with the objective of empowerment.

Key principles:

- **Involvement in the entire research process:** from formulation to interpretation of findings and decisions about resulting action
- **Immediate and direct benefit to the population involved** - not primarily an academic exercise for the researcher.
- **Dialogue and development over time**, not a static picture at one point.
- **Harnesses creative potential and mobilises human resources to solve social problems**
- **An educational process, serves community needs and increases awareness and commitment within the community involved.**
- **Not neutral** - contains an ideological dimension

(Hall, 1975 in Rifkin, Lewando-Hundt and Draper 2000)

Sound familiar?



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‘Involving patients and members of the public leads to research that meets their needs, is more reliable and more likely to be put into practice’.

‘We want patients and the public to be involved in all stages of research. This covers:

- Setting research priorities
- Helping to decide what the research is setting out to achieve
- Choosing the methods used to carry out the research
- Recruiting people into research studies
- Understanding what the research findings mean for patients and how it can be applied in the health service
- Publicising the results

NIHR website: Patient and Public Awareness

Sound familiar?



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Shift from top down targets to more **devolved ownership**...around the needs of empowered local populations’.

‘PCTs should **identify local priorities** in discussion with their communities’

The NHS in England: The operating framework for 2009/10

‘**empower and support people** with long term conditions through a process of **collaborative dialogue** during which the individual leads the discussions based on the goals that are important to them ‘

Your health, your way 2008

Structural explanations of health inequalities



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- Health inequalities linked to differentials in capacity, power and resources within societies
- Association between high levels of mortality and morbidity and poor material circumstances.
- Social capital : ‘features of social life - **networks, norms and trust** – that enable participants to act together more effectively to pursue shared objectives’
 - Bonding : between people with similar social identity
 - Bridging: between people from diverse backgrounds
 - Linking : connections to power and authority.

(Putnam, 1995; Wilkinson 1996; Szreter S, Woolcock 2004)

Policy definitions of cohesion



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- People from different backgrounds having **similar life opportunities**
- People trusting one another and **trusting local institutions to act fairly**
- **Strong and positive relationships** between people from different backgrounds.

DCLG (2008) Government's response to the Commission on Integration and Cohesion



- Fear of unexpected consequences:
 - AB initially refused to take part because she had heard about a bilingual professional working with Social Services to take the children of Pakistani parents into care.
 - NI gave consent to interview his GP, but asked half-jokingly, “They won't come to take me away in handcuffs will they?”
- Cynicism about the benefits of research:

“So, what’s going to happen when you’ve finished the research – is it going to end up as a big report on a shelf somewhere?”
- Action / reciprocity:

“If you can't [help us get a house] then coming repeatedly is useless. Otherwise it is waste of time for you and us. The questions are fine but the illnesses don't go away with answering these questions.”

- Involvement of local women in developing the study as research partners, steering group members, research participants, formulating recommendations, dissemination.
- Design involved supporting women to develop and deliver projects that would bring communities together and evaluate these.
- Projects addressed structural inequalities and supported women to interact at higher levels of 'bridging'
- A model for evaluating cohesion activity - developed from the collective knowledge of 'key informants', people with experience of cohesion activity



1. **Hospitality** – guest/host relationship, host who sets the agenda and decides how differences in culture/values will be managed. Widens experience but can repeat/reinforce social divisions.
2. **Information gathering/Awareness raising** – promoting positive messages; asking/ answering questions but not developing dialogue or relationship beyond this interaction
3. **'Real meeting'** – getting to know/understand one another in an atmosphere of trust and finding 'common ground'. Challenging own stereotypes but not dealing with conflict.
4. **Meeting as equals** - Getting beyond what you have in common/comfort zones. A 'level-playing field', bringing together the 'part-truths' and conflicting views of participants to create a more complete picture of reality/challenge existing power structures. Implies equal citizenship rights rather than acceptance of different social status.



- Groups may prefer a Level 1 guest/host relationship if they have less capacity/resources to act on as equals – eg ‘choice’ requires having the knowledge and skills to act on information. The capacity for equal partnerships is affected by unequal resources between partners
- The model for ‘bridging’ and evaluating cohesion activity is relevant between subgroups of the same community as well as between different communities
- Exclusion within communities can particularly affect women and young people – eg space to organise, inclusion in decision-making that affects them

Conclusions



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- A shift in the resources, capacity and power is needed to empower marginalised communities through research.
- A climate of trust is needed for interaction that draws on the experience of people from minority ethnic communities to resolve their priority issues.
- Research relationships that avoid replicating social inequalities and facilitate bridging between more and less powerful groups are more likely to promote social justice and address health inequalities.



- What are the opportunities and barriers to using participatory approaches in research on ethnicity and health?
- How can research design contribute to reducing social inequalities rather than simply describing these?