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Participatory Health Research: a science for promoting health.

The Hallmarks of Participatory Health Research (PHR)?

- The design ensures that communities affected by the issue being studied, representatives of organizations and researchers, are fundamentally engaged in all aspects of the research process.
- each person's contribution to the co-creation of knowledge is valued, irrespective of the type of knowledge they bring
- relationship building is the essential element for critical enquiry/generating change

Why we do it: ethical grounds

- to exclude the voices of those with lived experience in relation to the issue or practice being researched, challenges our notions of the moral, the fair and the just.
- if authentic voice is not afforded to the currently marginalised, issues relating to their lives are over-shadowed by the voices of others who may have different experiences, needs and interests.

Why we do it: methodological rational

- knowledge constructed without the active participation of those with real lived experience can only ever be partial
- knowledge constructed from undisturbed understandings of practice is less likely to hold the potential for change
- shared learning means that the new knowledge lies with those who can make changes

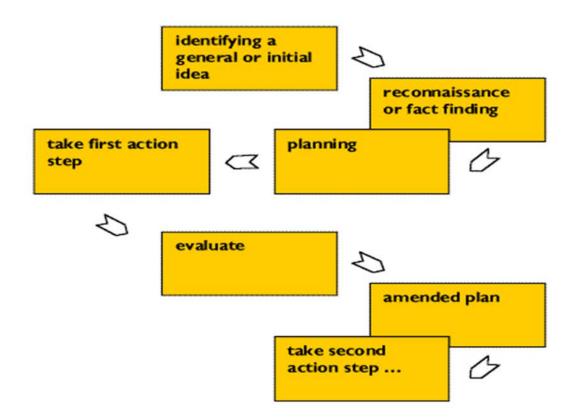
Blumer (1969:86) warned:

- remaining aloof as a so-called 'objective' observer, risks:
 - ...the worst kind of subjectivism the objective observer is likely to fill in the process of interpretation with his own surmises in place of catching the process as it occurs in the experience of the acting unit which uses it.

What it's not!

- Research that is designed by somebody who then goes and interviews participants, even if that somebody comes from the same community.
- Research that has service users on the advisory board for the research
- Research that co-opts people to carry out the data gathering on behalf of external researchers
- Research that uses a participatory method

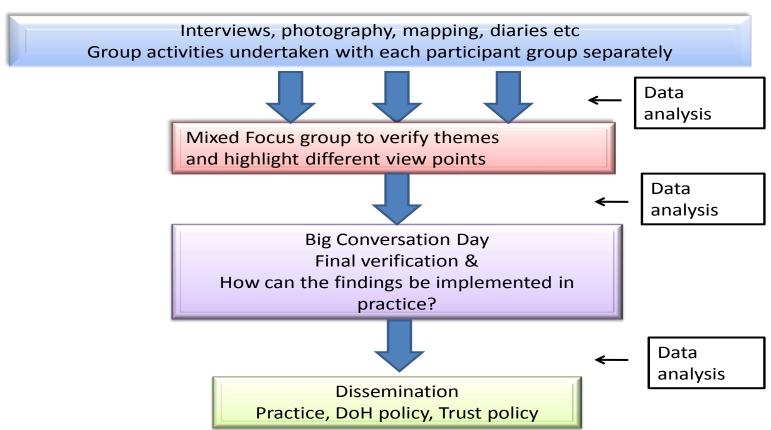
Research cycle



Towards Inclusive Living

Methodology

(Modified Delphi Technique)



Why do it?

- Social Justice
- Rigour
- Punctures rhetoric
- Improves quality of knowledge generated
- Is meaningful to those who it has an impact upon
- Has impetus for change built into it
- Powerful dissemination
- Builds capacity
- Has unexpected impacts
- Impact is more likely to be sustainable

...in the messy area (Cook 2009)

- Collaborative discussion and critique
 - pushes at boundaries really makes people think (together)
 - digs into tacit underpinnings that frame perceptions of reality
 - challenges current orthodoxies: things we currently believe to be vitally important for practice
 - Pulls apart rhetoric and well rehearsed notions of practice
- Leads to the re-examination and sometimes relinquishing of ways of thinking and practicing
- What is known cannot be unknown has a direct effect on behaviour

Bibliography

- Blumer, H.(1969), Symbolic Interactionism: Perspective and Method. Berkeley, University of California Press.
- Cook, T. (2004) Reflecting and Learning together: action research as a vital element for developing understandings and practice. Educational Action Research Vol 12 (1) pp77-97
- Cook, T. (2006) Collaborative action research for development and evaluation: a good fit or the road to myopia? *Evaluation* Vol 12(4) pp418-436.
- Cook, T (2009) The Purpose of Mess in Action Research: building rigour through a messy turn.
 Educational Action Research Vol 17(2) pp277-292.
- Cook, T, Atkin, H & Wilcockson, J (2018). Participatory Research Into Inclusive Practice: Improving Services for People With Long Term Neurological Conditions. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, Vol 19 (1), Art. 4.
- Cornwall, A & Jewkes, R (1995) What is participatory research? Social Science and Medicine. Vol 41
 (12) 1667-1666
- Duckworth, E (1996) The Virtue of Not Knowing In The having of wonderful ideas and other essays on Teaching and Learning Teachers' College Press, New York.
- Gergen, K &. Gergen, MM (2008) Social Construction and Research as Action, In P Reason and H Bradbury (eds), Handbook of Action Research. Sage.
- Hart, E & Bond, M (1995) Action Research for Health and Social Care: a guide to practice. OUP

Bibliography cont:

- International Collaboration for Participatory Health Research (2013) Position Paper 1: What is Participatory Health Research? Editorial Group: Professor Michael T. Wright, Germany (lead); Professor Irma Brito, Portugal; Dr Tina Cook, UK; Dr Janet Harris, UK; Dr. Maria Elisabeth Kleba, Brazil; Dr Wendy Madsen, Australia; Professor Jane Springett, Canada; Dr Tom Wakeford, UK www.icphr.org
- International Collaboration for Participatory Health Research (2013) Position Paper No. 2: Participatory Health Research. A guide to Ethical Principles and Practice Editorial Group: Professor Sarah Banks, UK (lead); Professor Irma Brito, Portugal; Dr Tina Cook, UK; Dr Felix Gradinger, UK; Professor Jane Springett, Canada; Dr Hella von Ungar, Germany; Professor Michael Wright, Germany. www.icphr.org
- Israel BA, Schulz AJ, Parker EA, Becker AB (1998) Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review Public Health*. Vol 19: 173–202.
- Kemmis, S & McTaggart, R (2008) Participatory Action Research: Communicative Action and the Public Sphere In N Denzin and Y Lincoln (eds) *Strategies of Qualitative Inquiry*. Sage Pub.
- McTaggart, R (1997). Guiding principles for participatory action research. In Robin McTaggart (Ed)
 Participatory action research: International contexts and consequences pp.25-43. New York: Albany.
- Noffke, S (2009) Revisiting the Professional, Personal and the Political. In S Noffke, S & B Somekh, B (eds) Handbook of Educational Action Research. Sage
- Winter, R (1998), "Finding a Voice –Thinking with Others: a conception of action research", Educational Action Research, Vol 6 (1) pp 53-68.