Co-production in dementia research

Reflections on the journey as a researcher

Anne Killett
What did co-production ever do for us?
What’s in a name: the burgeoning of terms

- Participatory research
- Patient and public involvement
- Co production

I noticed changes about seven years ago when I was working
Participatory research

Emancipatory origins and principles of Participatory Action Research:

- Involves an oppressed group
- Full and active participation of the community in whole process
- The subject of the research originates in the community
- The goal is radical transformation of social reality – beneficiaries are the community
- The process can create greater awareness of own resources
- Facilitates more accurate and authentic analysis of social reality
- The researcher is committed participant and learner, not detached observer

Hall 2001
Participatory research: Implications for dementia related research

• The meaning of community
• Considering oppressions – in relation to dementia
• Can research projects involving academia benefit the communities
ResPECT: Organizational dynamics of respect and elder care

• Aimed to examine the organizational dynamics associated with mistreatment of older people living in care homes

• Combined participatory research and ethnographic research in comparative case studies.

• Concluded that interaction between factors (infrastructure, management and procedures, staffing, resident population characteristics and culture) could lead to ‘good’ people delivering bad care and mistreatment
Following on from ResPECT

• Emancipation – considering oppressed groups

• Tackling funding – work on innovations

• Colonizing paper
Patient and Public Involvement (PPI)

Key ideas

- The term used in NHS policy for working with patients and the public in developing services and in their own care.
- The concept is underpinned by legal duties on NHS bodies.
- The latest guidance (2017) sets out 10 actions including demonstrating public involvement, promote and publicise public involvement, provide support for effective involvement.
PPI – Implications for our research

- Government funding streams mandate PPI
- Increasing discussion of identifying and demonstrating ‘good PPI’ (Public Involvement Standards Development Partnership [UK wide], has developed a set of standards which will now be piloted).
- Ongoing relationships and resources
- Recognition by funders
Do people who are living in care homes want to be involved in research in ‘PPI’ roles?

How do we find ways to talk together about research?
What is research in care homes?

Here are some examples of topics that have been researched in care homes:

- Food
- Falls
- Infections
- Involving families
- Quality of care
- Abuse
- Activities
- Care for people with dementia
- Staff training

How does research affect you?

As a result of research, many care homes have changed. Here are some examples:

- Care homes provide more activities.
- There are more measures in place to ensure people stay safe.
- Many care homes have improved infection controls in place.
- Care home nowadays often think how they present food and there are more choices available.
- Research has led to improved medication.
- Often people are more supported in making their own decisions.

How were residents involved in other research projects?

<table>
<thead>
<tr>
<th>Were many residents involved in advising researchers or working with them?</th>
<th>11 studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 small ones</td>
<td>2 medium ones</td>
</tr>
</tbody>
</table>

Different ways of working

- Working in partnership with researchers
- Giving advice to researchers

Barriers to involvement

- lack of time and money
- some people dominate groups
- university regulations
- long and complicated documents
- unsupportive management
- research is seen as threatening

Factors that support involvement

- encouragement and support
- trust
- suitable rooms
- flexible researcher
- valuing all perspectives
- sharing power

Present and Past Research with Care Homes at the University of East Anglia

November 2015
In our first step, we looked at how past studies had involved older care home residents in research processes. We found:

**Residents had been involved in research in two ways**
- In small scale studies as part of the decision making team
- In large scale studies as advisors to researchers

**Barriers to residents' involvement**
- Residents' ill health or low confidence
- Researchers inflexibility in approach
- Lack of resources for involvement

**What helped residents' involvement**
- Good relationships between residents and researchers
- Residents' involvement was valued and supported
In the next step, we interviewed 15 care home residents and 6 care home staff from 7 care homes. We aimed to find out more about how residents could be involved in research processes. We found out that the key things to help residents’ involvement in research were: motivation, resources, support, and flexibility.

**Motivation**
- Some residents were interested in all aspects of research, others in certain aspects of research, while some had no interest at all.
- Giving residents too many research activities can stop them from becoming involved in research.
- Residents have different reasons for taking part which include "keeps the mind ticking", having a voice, interest, meeting people, improving care homes, enjoying being asked.
- Some residents felt that they lacked knowledge to play a part in meaningful ways.

**Resources**
- It is easier to support research when the care home is fully staffed.
- Meetings at external venues require extra resources including transport and staff.
- The manager/owner controls resources and access to care homes. Their attitudes can affect residents’ involvement.
- Care homes are potential venues for study teams to meet. Staff may be needed to support residents’ involvement.

**Support**
- Researchers need to work with care home staff to support residents’ needs.
- Written and verbal information should be altered for residents’ preferences and needs.
- Some residents may need additional information before and after meetings.
- Staff can be helpful in supporting residents at meetings.
- Health issues and/or energy levels can affect residents’ involvement in research.

**Flexibility**
- Residents should be offered choices about how they could be involved in research.
- Researchers need to fit in with residents’ schedules and care home routines.
- Some residents prefer meetings in their care home. Other residents are happy to attend meetings outside of their care home.
- Fixed structures of research can work against the ad hoc involvement of residents.
Co-production

Key ideas

• In the health context – that service users and providers both have a central role in ‘creating health’
• Based on sharing of information and decision making
• Originated as transformative approach
• ‘Clients are acted upon. Co-production implies that citizens can play an active role in producing public goods and services of consequence to them’ Ostrom 1996 cited in Boyle, Clark and burns 2006)
• Cahn developed idea of Time Banks, refers to Hrdy’s ‘Mothers and Others’; as humans we are equipped to cooperate
Co-production

• 5 elements of co-production (Cahn 2015)

1. Informal support systems between families, friends
2. Transforming the relationship between cared for and carer – friendship, reciprocity. Importance of meaning as well as happiness
3. Response to financial challenges – documenting the contribution
4. Advancing social justice – for those most excluded, empowering self-definition as co-producer, worker
5. Effecting system change – from ‘how can I help you?’ to how can we do this together. Enlisting universals of the human condition to be here for each other
Co-production – implications for dementia related research

- Creating inclusive research communities
- Reciprocal relationships in research activities
- Documenting the time, expertise, contribution
- Consider exclusions, including cross-cutting, and practices to challenge disempowerment
- Think of co-production through all research activities, including methods, findings and implementation.
Implications for research design and implementation

• Communication

How can we communicate when communication is challenged?

How can we involve people?
Particular issues in research

• Access

• Authority, decisions such as
  • Priorities for research
  • Forming research topics or questions for which funding calls are issued
  • Which funding applications are selected
  • Development of research projects – refining questions and designs
  • Who can be involved in research
Ethical review

• In England the Mental Capacity Act (MCA 2005) provides a legal, ethical and regulatory framework governing capacity and consent.

• Erring on the side of caution by researchers and ethics committees can lead to the exclusion of people who seem unable to give informed consent.

• We have just been funded by Nuffield Foundation to:
  • Investigate current practice in the involvement and consideration of adults with impairment of capacity and/or communication in ethical and governance frameworks in England and Wales
  • Investigate current practice in the development and ethical review of research
  • Develop guidance including practical strategies and resource.

(Bunning 2018)
ASSENT: Development of an assent-based process for the inclusion of adults with impairments of capacity and/or communication (AwlCC) in ethically-sound research

• Using principles of co-production, a working group comprised of AwlCC and their supporters, facilitated by research team members, will develop questionnaire content and interview topic guidance with questioning route

• To help with conceptualisation we will use multiple media, e.g. pictorial images, key word writing and examples drawn from the participants’ own experiences
DEMCOM: National evaluation of Dementia Friendly Communities in England

Aims:
Understand what makes a community dementia friendly and how this can be sustained
Arrive at a way of measuring dementia friendliness
DEMCOM: Involvement of people living with dementia and their supporters

- Study steering group
- Research Management Team
- Experts by Experience – commenting on research documents
- Existing PPI groups
- Steering groups in case study sites
- Co-researchers in case study sites
Conclusion

Where can co-production can take us?

Challenge our view of ourselves as listeners

Potentially disruptive

Fresh insights
RReACH

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ResPECT

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DEMCOM Research Management Team
University of Hertfordshire
Prof. Claire Goodman, Dr Marina Buswell, Nicole Darlington, Dr Elspeth Mathie, Dr Andrea Mayrhofer

University of East Anglia
Prof. Tony Arthur, Dr Anne Killett, Dr Chris Skedgel, Michael Woodward

University of Cambridge
Dr Louise Lafortune, Dr Stephanie Buckner

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Images

3. Slide 4 https://www.youtube.com/watch?v=2gwgOvbyShg&index=1&list=PLAwhBH4G05iKAMS5wIMSFsuncvoBYuRM linked to http://dementiaillawarra.com/illawarra-dementia-services-network/
7. Slide 21, Christine Matthews http://www.geograph.org.uk/photo/2252067
8. Slide 15, 17 and 23, courtesy of Christine Atfield