



Visioning change: Co-producing a model of involvement and engagement in research.

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Title page

Visioning change: Co-producing a model of involvement and engagement in research.
(Innovative Practice)

Journal: Dementia: the international journal of social research and practice:
Innovative Practice

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Abstract

The involvement of people living with dementia in research has traditionally been located in the realms of 'subject' or 'participant'. However, there has been an increase in demand for greater transparency by academic bidding teams (particularly within the UK) in demonstrating how people with a **lived experience** have been and will be involved in the research process. Located within the ESRC / NIHR-funded Neighbourhoods and Dementia Study (2014-2019), led by The University of Manchester (UK), this paper outlines the development of the CO-researcher INvolvement and Engagement in Dementia (COINED) Model, which was co-produced alongside three independent groups of people living with dementia: Open Doors, the Scottish Dementia Working Group and EDUCATE.

Keywords

Dementia; Involvement; Engagement; Co-production; Co-research

Background

Over the last decade or so within the United Kingdom (UK), research funding councils and charities have demanded greater transparency from academic bidding teams in demonstrating how people with lived experience (of the proposed topic under study) have been, or will be, involved in the research process. This may range from mapping out how people with lived experience have been involved in proposal development to a detailed consideration about future plans for the person's involvement in data collection, data analysis and project dissemination. This is often referred to as Patient and Public Involvement, or PPI for short. Indeed, nowadays, it is not uncommon for those with lived experience to be integral members of academic bidding teams in order to demonstrate an authentic commitment to PPI engagement with Wright, Foster, Amir, Elliott, & Wilson (2010) viewing such partnerships as a "core component of good research practice" (p. 359).

In advancing such academic / lived experience partnerships, a number of generic frameworks and public agencies have emerged, such as INVOLVE (<http://www.invo.org.uk/>) which is funded by the UK's National Institute for Health Research (NIHR). Established in 1996, INVOLVE's role is to promote and support public involvement in the UK's National Health Service, as well as in social care and public health research. Subsequently, numerous training programmes have been developed in order to support public involvement, namely within service delivery and care planning domains. As an illustration, the NIHR-funded (Programme Grants for Applied Research) EQUIP Study, 'Enhancing the quality of service user involved care planning in Mental Health Services' (<http://www.invo.org.uk/equip/>), was recently highlighted nationally as an example of good research practice by both INVOLVE and the National Institute for Health and Care Excellence. Whilst the feasibility and application of programmes such as EQUIP in fields outside of mental health, care planning and service delivery have not yet been established, there are several generic key messages for meaningful user involvement in research: 1) People with lived experience should feel enabled, not disabled, to take part; 2) Support and facilitation should be provided to meet the needs and abilities of the individual, not the condition; and 3) The relationship between academic researchers and those with lived experience should be based on a collaborative and reciprocal partnership.

Set against these key messages, developments within the PPI arena are increasingly important in the field of dementia studies (Harris & Sterin, 1999; Tanner, 2012), albeit at a slow rate. For example, Alzheimer Europe (2011) set out their principles of research encouraging a change in ideology from research 'on' people living with dementia to research 'alongside' or 'with' people living with dementia. Building on this foundation, the Scottish

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3 Dementia Working Group (2013) developed their own core principles for involving people
4 living with dementia in research, such as “we want to be valued, and to be kept involved and
5 informed” (core principle 1) and “we are often involved in answering research questions, but
6 we are not often asked about research priorities” (core principle 2). This change in direction
7 has also entered the UK political discourse, first through the Prime Minister’s *Challenge on*
8 *Dementia* (DH, 2012, p. 5), which identified three key commitments: driving improvements in
9 health and care; creating dementia friendly communities that understand how to help; better
10 research. This inclusive agenda recognised the citizenship of people living with dementia
11 (Bartlett & O’ Connor, 2007). This was further endorsed through the Prime Minister’s second
12 Challenge on Dementia (Department of Health [DH], 2015), which highlighted the
13 partnership in dementia research ‘*between patients, researchers, funders and society*’ (p.
14 46).

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23 However, despite this high profile association, Harrison and Johnson (2015) draw attention
24 to the lived experience movement in dementia as being in its infancy. The primary reasons
25 for this, the authors argue, are threefold: 1) people living with dementia have traditionally
26 been positioned as either a ‘subject’ or ‘participant’; 2) there have been a lack of
27 opportunities for people living with dementia to be involved and engaged in research; and 3)
28 the time-consuming and legislative requirements of establishing capacity, obtaining consent
29 and safeguarding anonymity in the research process. As Higgins (2013) and McKeown,
30 Clarke, Ingleton, & Repper, (2010) have contended, such obstacles are barriers for the
31 person with dementia’s inclusivity, egalitarianism and full citizenship in society. Moreover,
32 according to Marjanovic, Robin, Lichten, Harte, MacLure, Parks, Horvath, Côté, Roberge, &
33 Rashid (2015, p. 81), there remain unanswered questions about how people living with
34 dementia and their carers can “*best be involved in dementia research initiatives*”.

35 36 37 38 39 40 41 42 43 **The Neighbourhoods Study: Developing a Co-Research Model**

44 To try and respond to this dilemma, this article will outline the development of what we have
45 termed a ‘CO-researcher INvolvement and Engagement in Dementia’ Model, or the COINED
46 Model for short, which has been co-produced with and alongside people living with
47 dementia. The COINED Model was developed during the application stage of the
48 subsequently funded Neighbourhoods and Dementia Study [2014-2019], which is a large,
49 multi-centre international study on neighbourhoods and dementia (Keady, Clark, Ferguson-
50 Coleman, Hellström, Hydén, Pendleton, Reilly, Swarbrick, Ward, & Young, 2014;
51 www.neighbourhoodsanddementia.org, accessed 1st June 2016). Funded by the Economic
52 and Social Research Council (ESRC) / NIHR, the Neighbourhoods and Dementia Study
53 comprises eight Work Programmes, of which the primary foci is to centralise the vision and
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3 values of people living with dementia and their carers in research practice; embrace
4 creativity, innovation and shared stories; and empower the experience of people living with
5 dementia, their carers and neighbourhood networks. Work Programme 1: Member
6 Involvement (www.neighbourhoodsanddementia.org/work-programme-1/) has a dual aim: to
7 facilitate the involvement of people living with dementia in all of the Work Programmes as
8 co-researchers and; to co-design and lead a neighbourhoods-focused research project. The
9 term 'co-researcher' reflects a desire to move away from references to 'user' and 'patient
10 and public involvement', towards a more collaborative partnership between groups of people
11 living with dementia, academic researchers and service providers. We will, therefore, use the
12 term 'co-researcher' - whereby 'co-' incorporates collaboration, cooperation and community -
13 to further consolidate that partnership.
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20 21 **Methods**

22 Open Doors (Howorth, Riley, Drummond, & Keady, 2011), located in Salford, Greater
23 Manchester (UK); EDUCATE (the Early Dementia Users Co-operative Aiming To Educate;
24 www.educatestockport.org.uk), based in Stockport, Greater Manchester (UK); and the
25 Scottish Dementia Working Group (Scotland, UK) are awareness-raising and information-
26 giving groups of people living with dementia. All groups led the development of the COINED
27 Model, which was facilitated by the lead author. The groups met independently with the first
28 author acting as a conduit for the exchange of ideas and thoughts. Whilst this was
29 theoretically a 'PPI' activity, the principles of Participatory Action Research (Morgan,
30 Crossley, Stewart, Kirk, Forbes, D'Arcy, Dal Bello-Haas, McBain, O'Connell, Bracken,
31 Kosteniuk, & Cammer, 2014; O'Sullivan, Hocking, & Spence, 2014) were adopted, with a
32 focus on "*collaborative, equitable partnership in all phases of the research*" (Blair, & Minkler,
33 2009, p. 653). Using INVOLVE's generic research cycle (INVOLVE, 2012, p. 40) as a
34 starting point (see figure 1), the remit of discussions was to identify ways in which members
35 of the groups would like to be involved as co-researchers across the research trajectory.
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Insert figure 1 about here

52 **Co-Producing the COINED Model**

53 Framed around the themes outlined in figure 1, group members developed a more
54 comprehensive compendium of themes of co-researcher involvement and engagement (see
55 figure 2). Each component of the Model represents inclusivity, mutual respect and
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3 empowerment which are at the very core of the Neighbourhoods and Dementia Study
4 agenda (Keady et al., 2014, p. 17).
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13 Underpinning the COINED Model is training and support for co-researchers, which we
14 recommend should be provided for the duration of the research. Group members were
15 insistent that support should be provided from an academic standpoint (Work Programme 8
16 involves a Wellbeing Service, facilitated by a Clinical Psychologist) in parallel to peer
17 support, either through formal agencies (including dementia support organisations, such as
18 the Alzheimer's Society) or informal peer support network. The voice of people living with
19 dementia is principal to the mode of inquiry as 'experts of experience' and representation
20 must be embedded as a continuous presence throughout the research. In parallel, the
21 importance of peer support in providing a community network is essential in maintaining
22 wellbeing, self-confidence and a sense of security within an ever-changing environment.
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28 An insightful discussion focused on the collection and analysis of data, and more specifically
29 around the level of objectivity expected by the co-researcher and the extent to which
30 someone with **lived experience** is able to deliver that objectivity. Group members
31 acknowledged the potential risk that the co-researcher may influence the responses given by
32 the participant by sharing their own experiences, inadvertently extending their own peer
33 support discourse. Conversely, however, group members were aware that shared
34 experiences (between the co-researcher and participant) have the potential to enrich the
35 responses given. On balance, group members were aware that the data collected by a co-
36 researcher would inevitably provide different levels of richness, depth and context compared
37 to data collected by an academic researcher. It was noted that this in itself would provide an
38 interesting evaluation at a later stage.
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44 Exploring the data and understanding the meaning of the results were key discussion points,
45 whereby disparity between the collection of data, its presentation in the final report and the
46 lack of transparency was noted as devaluing the role of people living with dementia in
47 research (both as co-researchers and as participants). 'Accessibility' featured at the very
48 heart of effective communication, particularly in terms of language and terminology used.
49 Knowledge exchange was regarded as fundamental to the advancement of learning for all.
50 There was a general feeling that the process of translating research into practice was often
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3 disparate and fragmented. Subsequently, group members advocated the involvement of
4 people living with dementia in presenting research findings alongside academic colleagues
5 in ways which **would be** creative, accessible and meaningful to all.
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9 Several members of the groups (who also had an academic background) raised the issue of
10 'impact'. Given the different meanings and interpretations of the term, we agreed that in the
11 context of the COINED Model, we will use the term 'impact' to refer to the effectiveness of
12 the research or the effectiveness of the involvement of people living with dementia as co-
13 researchers. Discussions extended to narrative of 'evaluation', which was regarded as an
14 integral mechanism of the research in 'measuring' impact, which was necessary to ensure
15 that we are 'getting it right'. It was felt that the processes and outcomes of any evaluation
16 would be crucial to our learning and should be embedded within further decision-making.
17 Thus, our learning from the research findings will help to identify, shape and frame further
18 research priorities. Group members appreciated the ongoing shift in research priorities to
19 meet the needs of the changing landscape of dementia care and fluctuating needs of people
20 affected by dementia. Involvement in future work was regarded as pivotal in positioning
21 people living with dementia at the centre of research in the context of collaboration and
22 focus.
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32 **Discussion**

33 Whilst discussions in the wider literature focus on whether people living with dementia [as
34 co-researchers] are able to engage in ways that are 'meaningful' to the research process
35 (Tanner, 2012), our approach is to ensure that co-researcher involvement is, first and
36 foremost, meaningful for the individuals themselves, thus respecting and empowering the
37 personhood of people living with dementia (Kitwood, 1997). One of the key messages of the
38 Model was to ensure that its implementation allows for creative methods and expressive
39 output and should not be constrained by traditional research methods and processes. For
40 example, Lee and Adams (2011), Capstick (2011) and Bartlett (2012) offer a collection of
41 visual methods to engage co-researchers in the data collection domain of the research
42 process.
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50 The involvement of people living with dementia as co-researchers is not without its ethical
51 debates. Particularly within the remit of data collection, analysis and dissemination (see
52 figure 2), anonymity and participant confidentiality must be ensured. Whilst academic
53 researchers **in England** are bound by the Research Governance Framework for Health and
54 Social Care (DH, 2005), there are no parallel frameworks for co-researchers and to our
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3 knowledge, this issue has not been addressed in the literature. Therefore, the need to
4 formalise the expectations and responsibilities of the co-researchers is a natural next step.

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6 The development of the COINED Model has identified ways in which people living with
7 dementia have expressed their wishes to be involved as co-researchers across the research
8 process. The COINED Model is currently being piloted in the Neighbourhoods and Dementia
9 Study with the necessary ethical permissions having been sought. In order to assess its
10 application, we plan to evaluate the implementation of the COINED Model towards the end
11 of the Study during 2018-2019.
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15 16 17 **Declaration of Conflicting Interests**

18 The authors declared no potential conflicts of interest with respect to the research,
19 authorship, and / or publication of this article.
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22 23 **Acknowledgements**

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25 Health Research (NIHR) is gratefully acknowledged. This work forms part of the ESRC /
26 NIHR Neighbourhoods and Dementia mixed methods study
27 [www.neighbourhoodsanddementia.org], Work Programme 1: Member Involvement.
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31 for assessing the quality and impact of user involvement in research. *Health Expectations*,
32 13, 359-368.

33 34 35 36 **Author Biographies**

37
38 **Caroline Swarbrick** (corresponding author) is a Research Fellow in the Dementia and
39 Ageing Research Team at The University of Manchester. With a passion for working
40 alongside people living with dementia as co-researchers, she is driving forward the
41 empowerment agenda through the facilitation of numerous co-researcher-led projects.

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45 **Open Doors** is a support service facilitated by a person living with dementia (employed
46 through the NHS), based in Salford, Greater Manchester (UK). Located within Greater
47 Manchester West Mental Health NHS Foundation Trust, Open Doors provides a friendship
48 and support network for people living with dementia, including a dementia café and book
49 club, as well as participating in local service planning and design.

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53 **The Scottish Dementia Working Group** are a national awareness-raising and campaigning
54 group, and an independent voice of people living with dementia. Affiliated to Alzheimer
55 Scotland, the Scottish Dementia Working Group strive to improve societal attitudes towards
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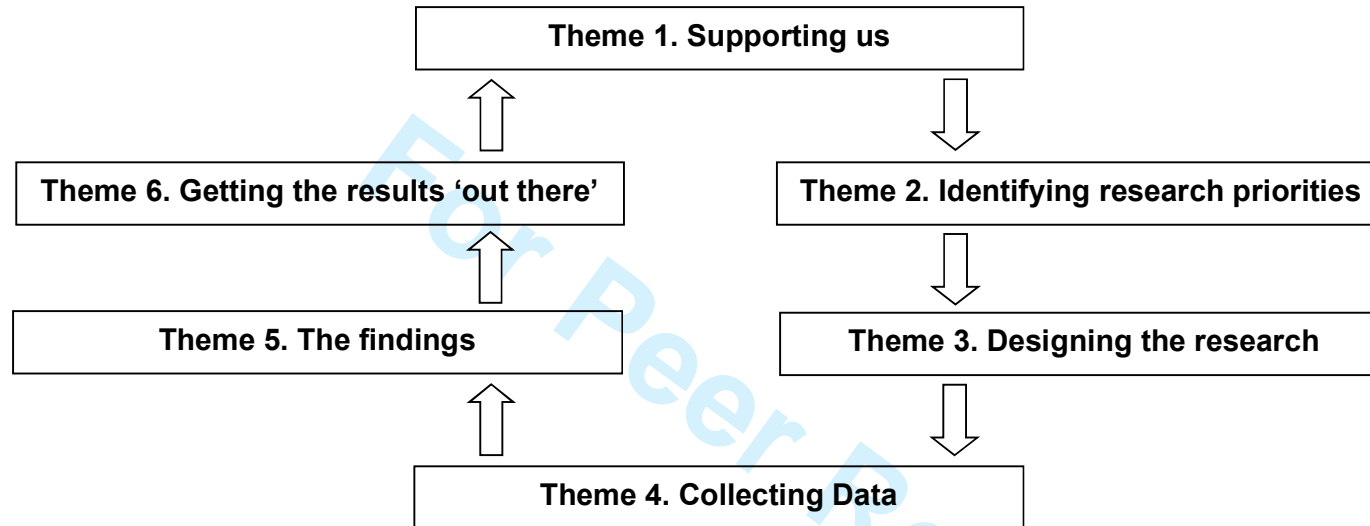
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3 people living with dementia as well as influence policy in order to improve services for
4 people living with dementia.
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7 **EDUCATE** is an awareness-raising group of people living with dementia, based in Stockport,
8 Greater Manchester (UK). On both a local and national level, group members share their
9 experiences of living with dementia, through talks and presentations and are involved in a
10 wide range of initiatives. EDUCATE is supported by Pennine Care NHS Foundation Trust
11 and Stockport Council.
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16 **Katie Davis** is a registered nurse with a background in working with people with dementia in
17 the NHS and in the third sector. Katie is currently undertaking a full-time PhD in Nursing at
18 The University of Manchester as part of the 'Neighbourhoods and Dementia' study. She
19 plans to work collaboratively with people with dementia on her doctoral project.
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24 **John Keady** is a Professor of Mental Health Nursing and Older People at The University of
25 Manchester, UK and a Senior Fellow at the NIHR School of Social Care Research. He is
26 founding and co-editor of *Dementia: the international journal of social research and practice*.
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Figure 1. INVOLVE's research cycle (2012, p.40).



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Figure 2. The CO-researcher INvolvement and Engagement in Dementia (COINED) Model.

