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Involving older adults and unpaid carers in the research cycle: reflections on implementing the UK national standards for public involvement into practice

Catrin Hedd Jones, Diane Seddon, Katherine Algar-Skaife, Carol Maddock and Stephanie Green

Abstract

Purpose – *This paper aims to share how the Centre for Ageing and Dementia Research co-designs research within a national programme of work to improve the lives of older adults and those affected by dementia. Through examples of this work, the authors identify the barriers and enablers to participatory approaches and lessons to inform future involvement activities.*

Design/methodology/approach – *This study reflects on implementing the UK National Standards for Public Involvement into practice. Of international relevance, the observations span the research process from research prioritisation and design to research implementation and knowledge exchange.*

Findings – *This study demonstrates the importance of using a relational approach, working toward a common purpose and engaging in meaningful dialogue. Only through offering choice and flexibility and actively learning from one another can co-design lead to synergistic relationships that benefit everyone.*

Research limitations/implications – *Key implications for researchers engaged in patient and public involvement are to be receptive to other people's views and acknowledge expertise of those with lived experience alongside those with academic expertise. Training, resources and time are required to effectively support involvement and meaningful relationships. A nominated contact person enables trust and mutual understanding to develop. This is an ongoing collective learning experience that should be embedded throughout the entire research process.*

Originality/value – *This paper demonstrates how the standards are implemented with people who are often excluded from research to influence a national programme of work.*

Keywords *Dementia, Carers, Public involvement, Research, Standards, Older adults*

Paper type *Research paper*

(Information about the authors can be found at the end of this article.)

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Introduction

There is an increasing expectation for researchers in health and social care to work with people outside of academia as they develop, implement and share the outcomes of research (Staniszewska *et al.*, 2017; Kylberg *et al.*, 2018; Roberts *et al.*, 2020; Malm *et al.*, 2019). Actively working with people that research is aimed at benefiting is critical to the delivery of impactful research that informs policy and practice (Malm *et al.*, 2019). This can involve people with lived experiences and unpaid carers sharing their experiential knowledge. Involvement activity is distinct from members of the public taking part in a study as research participants from whom research data is collected. Although the involvement of the public throughout the research process can bring mutual benefits, there is limited knowledge about patient and public involvement (PPI) activity amongst older adults aged

50 and over. A review by of publications between 1999 and 2019 identified just 27 papers ([James and Buffel, 2022](#)). They noted the benefits for older adults and academic researchers whilst acknowledging the workload and the time needed to develop relationships. The authors highlighted the need to provide a range of involvement opportunities, ensure that co-researchers are supported and encourage greater researcher reflexivity on the involvement of co-researchers.

Dementia rights activists assert that shared power and decision-making in research should be viewed from a human rights perspective ([Roberts *et al.*, 2020](#)) as reflected by the motto “Nothing about us without us” ([Bryden, 2015](#); [Charlton, 1998](#); [Parveen *et al.*, 2018](#)). Not all older adults will be affected by dementia, however, age is a key risk factor. This paper reports on working with adults over 50 years of age, including unpaid carers and people living with dementia.

Recent reviews highlight the growing interest in involving people with dementia in research with most studies being conducted in the UK: 60% of studies in [James and Buffel \(2022\)](#), and 95% in [Miah *et al.* \(2019\)](#). INVOLVE, the UK’s public participation charity, highlights the importance of research that is conducted *with* or *by* members of the public. INVOLVE specify six values to underpin involvement: respect, support, transparency, responsiveness, fairness of opportunity and accountability ([INVOLVE, 2015](#)).

A narrative systematic review by [Greenhalgh *et al.* \(2019\)](#) identified 65 frameworks for PPI in research grouped according to frameworks that challenged power dynamics between researchers and the public, encouraged transparent involvement and reporting of public involvement and frameworks that focussed on building partnerships between academics and the public.

The UK National Standards for Public Involvement in Research (standards) ([National Institute for Health Research \[NIHR\], 2019b, 2022](#)) were classified as a partnership-focused framework ([Greenhalgh *et al.*, 2019](#)). These standards seek to embed PPI activity across health and social care research and improve the purpose, quality and consistency of public involvement ([NIHR, 2019](#)). They were developed through the UK Public Involvement Standards Development Partnership Group [UK-PISDPG \(2019, see Crowe *et al.*, 2020\)](#), which included the National Institute for Health Research, Health and Care Research Wales (HCRW), the Public Health Agency Northern Ireland and the Chief Scientist’s Office in Scotland. Consultation included comments from over 700 participants over 18 months and feedback from 10 test sites piloting the standards over one year.

Translating public involvement from aspiration into practice is challenging. It is often underreported in publications ([Georges *et al.*, 2022](#)), as are the voices of public contributors ([Roberts *et al.*, 2020](#)). Centre for Ageing and Dementia Research (CADR) was a test site for the implementation of the UK draft standards in 2018 ([Tarpey, 2019](#)). It was the only site in Wales, that tested all six standards and included social care research. During this period (2018–2019) CADR had research centres based in Bangor, Cardiff and Swansea universities. Staff reflected on using the standards, sharing their implementation experiences ([UK Standards for Public Partnership, 2019b](#)).

Infrastructure funding from the Welsh Government through Health and Care Research Wales (HCRW) was awarded (2020–2025) for (centre name redacted) to support and improve the lives of older adults, people living with dementia and unpaid carers by integrating research, policy and practice. Here, we report on our experiences of implementing the six standards over three years (April 2020–September 2023) within CADR under its current structure based in research centres at Aberystwyth, Bangor and Swansea universities. Implementation of the standards underpinned the centre’s work from the outset, with dedicated resources (staff and funding) to support involvement and engagement work.

Centre members work to support healthy ageing, defined by the World Health Organization as “the process of developing and maintaining the functional ability that enables well-being in older age” (WHO, 2015, p. 28). CADR adopts an ecopsychosocial approach (Zeisel *et al.*, 2016) with work packages on social inclusion, environments of ageing and dementia and cognition. Public and professional involvement and engagement are viewed as everybody’s responsibility, facilitated by the dedicated resources.

The 2021 Census stated that in Wales, 21.3% of the population of 3,107,500 were 65 years or over (Wales Government, 2022) and 12.8% of 65- to 69-year-olds provided unpaid care (ONS, 2023). Whilst not all older adults experience dementia, it is estimated that 41,603 people aged 65 or older are living with dementia in Wales. While only 53.9% of those living with dementia in Wales will have a formal diagnosis, this is predicted to increase to 79,700 by 2040 (Welsh Government, 2023).

This paper illustrates the involvement of older adults and their unpaid carers throughout the research life cycle from identifying research priorities, informing research design to research implementation and collaborative knowledge exchange. We highlight the barriers and enablers to translating the national standards into practice.

The involvement and engagement work we report did not require ethical approval and did not involve primary data collection (Health Research Authority NHS, 2020).

We aligned the involvement and engagement work of CADR to the UK national standards summarised in Table 1 and evidence examples of the centre’s activities using these standards below. There have been opportunities for researchers and public contributors to jointly reflect on their experiences and explore how the standards work in practice for them (Seddon *et al.*, 2023). This in turn has influenced our recruitment materials for new public contributors and our co-produced information and training resources.

Inclusive opportunities

Wales has two official languages. The latest census stated that 20.4% of the population aged 65 or over speak Welsh and public services are required to provide services in both languages (Wales Government, 2023). Involvement opportunities are promoted bilingually through press releases, contacts on the centre’s database ($N = 1204$), social platforms (Twitter, Facebook, Linked In, CADR App). Simultaneous translation is available at events.

Because COVID-19 social distancing regulations were lifted, the promotion of involvement opportunities has returned to include in-person events. These include stands at air shows, health fairs, cultural events and rural community groups. Events include participatory activities such as inviting members of the public to play an interactive game “Snakes ‘n’

Table 1 UK National standards for public involvement in research

Standard		
1	Inclusive opportunities	Opportunities are accessible and reach people and groups according to research needs
2	Working together	All contributions are valued, building and sustaining mutually respectful and productive relationships
3	Support and Learning	Support and learning that builds confidence and skills for public involvement in research is offered and promoted
4	Communications	Plain language is used for timely, two-way and targeted communications, as part of involvement plans and activities
5	Impact	The difference that public involvement makes to research is collected and shared
6	Governance	The public are involved in governance and leadership so that decisions promote and protect the public interest

Source: Amended from the UK National Standards for Public Involvement, NIHR, 2019

CADR's" and through their participation discuss myths about ageing and prioritise areas for research.

A dedicated engagement officer has worked with six research advocates to promote diverse involvement opportunities and encourage new partnerships to minimise the risk of co-research "reproducing inequalities" (James and Buffel, 2022, p. 19). Efforts to increase the engagement of minority groups include a webinar discussing research on supporting cognitive assessments and dementia care through the medium of Welsh. This event attracted over 100 online contributors and there have been a further 114 downloads of the recording to date (20/9/2023). Feedback includes an appreciation of "hearing directly from carers, all the great research in the field and statistics".

People living with dementia contribute to a peer and reference group (Caban) to increase awareness and share good practice. The group is part of a UK network of 81 Dementia Engagement and Empowerment Project (DEEP) groups of people with dementia that work for positive change (dementia voices). People living with dementia and their carers have advised on the design, participant recruitment and outcome measures in 11 studies, including studies about communication support, resilience and dementia and anticipatory grief. The creative use of animations sees the representation of two public contributors in both real and animation forms expressing the importance of involving people living with dementia in research (CADR, 2020). These have been viewed online 585 times. Public contributors have shared their knowledge at national conferences, student lectures and public events alongside CADR researchers.

Knowledge exchange events are arranged with experts-by-experience as an integral part of the dementia research programme. This requires sensitive scaffolding to ensure that people either join online or can travel to the venue in a relaxed state. Breakout rooms are provided if anyone needs a quiet supportive area or individual support. Some unpaid carers prepare "their story" on paper ahead of the event and talks by people living with dementia usually follow a two-person or panel conversation format. Some slides with images may be developed by the authors for context and then the expert by experience is invited to share their experience. This ensures that people do not have to worry about preparing a talk or reading, as some may have difficulties with word finding on text. Online talks by Welsh speakers are delivered in their first language, and simultaneous translation is provided. This is more natural for the speakers, is inclusive and recognises that this is an important right and often clinical need.

CADR is mindful of the potential barriers to inclusive engagement. It spans a large geographical area and travel can be challenging practically and financially. CADR invested in technology to facilitate online meetings across the three sites to minimise the demand for travel *before* COVID-19. Contributing to an online meeting can sometimes be more practical for older adults and for unpaid carers who might no longer drive or otherwise may have to arrange alternative care for the person they support if meetings are held at a distance from their home. There is the opportunity to send (with everyone's approval) the recorded meeting and transcript to be viewed and digested over time with the option to respond or ask for further clarifications in the live meeting chat facility or via email later.

Support for people who were unable to engage in online meetings included the loan of digital tablets to maintain contact during the COVID lockdowns, with telephone support to help navigate the software. Useful guides were developed by DEEP on using Zoom, which were translated and shared bilingually with anyone new to the software. Rather than having to wait and remember what they wanted to share, people living with dementia were supported in meetings through bilingual "I want to speak" cards, a visual indication to the meeting leader that the holder wished to speak, developed within the DEEP network (Dementia voices, 2023).

Having a known point of contact is important for public contributors. Personalised support includes documents prepared ahead of meetings (in the required format), illustrating the

venue location and parking using Google Maps and Streetview images, purchasing train tickets in advance and greeting people at the station, should they wish. People driving to meetings are reimbursed for their travel expenses, so finance is not a barrier to involvement.

There are, however, challenges in negotiating fair acknowledgement for involvement without compromising the financial allowances that some people may receive. Historically, the university processes and procedures have presented challenges to the payment of honorariums to members of the public, who contribute voluntarily as experts-by-experience. Public involvement is a voluntary role, and no employment relationship exists, however, the procedures for reimbursement of expenses require individuals to be classified as temporary workers. This involves complex eligibility-to-work checks that can be challenging to complete. In recognition of this, CADR contributed to a UK-wide taskforce to address these challenges and promote inclusive opportunities. New guidance was issued in (NIHR, 2022). However, there remain challenges to implementing this guidance in practice.

Working together

An initiative co-hosted by CADR and the DEEP (Andrews *et al.*, 2015) Programme is the Social Care Innovations Lab (#SCIL). #SCILs provide opportunities for people to work together to develop research ideas. Each #SCIL forms a connecting hub for people with academic, practice and lived experiences based on shared interests in research and a desire to make a positive difference in social care (Seddon *et al.*, 2021). Groups meet in actual or virtual spaces and whilst each #SCIL is unique, they offer safe spaces for people to share ideas, experiences and understandings. They are guided by three key principles:

1. involving – making meaningful connections and having candid discussions;
2. innovating – creating safe spaces for testing out ideas; and
3. improving – generating evidence and the confidence to use science in social care.

This model has supported the development of successful research funding applications. An in-person event involving unpaid carers and social care professionals reflected on their experiences of respite care and short breaks. Areas for future research were identified and prioritised. Collaborative working with unpaid carers and a third sector organisation resulted in funding for a two-year study about short breaks provision (Toms *et al.*, 2023). Unpaid carers were engaged as experts-by-experience on the Project Advisory Group, supporting the research and knowledge exchange activities.

Honneth's Recognition Theory (Honneth, 1996, as cited in Toms *et al.*, 2020) suggests that relational approaches to building research capacity within the care home sector can better generate evidence to inform practice. Enabling Research in Care Homes (ENRICH) (CADR, 2023) is co-hosted by CADR and HCRW with the aim to build meaningful relationships with stakeholders in care homes across the research cycle. One example of this approach includes care home staff being invited to be part of an advisory group with the ENRICH network, identifying the most appropriate methods and measures for a pilot project evaluating the role of paramedics as prescribers in care homes (Kingston *et al.*, 2020).

Early career researchers work with people living with dementia. This supports their understanding of how to make research as accessible and inclusive as possible for people living with dementia. A public contributor living with dementia is a co-supervisor and co-researcher for a PhD study on resilience. This relies on building and maintaining meaningful relationships and open communication. Reflections on the experience are shared in publications (Seddon *et al.*, 2023) and public presentations (CADR, 2023b).

The shift from providing feedback on research plans to driving work was evident when members decided to create two peer-to-peer booklets of information that supports their daily life with dementia. The booklets were developed following an iterative creative

problem-solving approach (Treffinger *et al.*, 2006) which involves adopting a novel approach to develop a useful solution to a problem. Initial discussions with researchers on what may support resilience following a diagnosis of dementia included an open forum of experts-by-experience and those working in the health and social care sector. Ongoing discussions with Caban members on their own experiences informed three significant outputs: a conceptual model of resilience for people living with dementia, involvement in co-creating a new measure of resilience for people living with dementia and booklets sharing information on useful support and strategies following a diagnosis of dementia. The conceptual model of resilience highlights the importance of interactions between individuals, community, and societal resources with an emphasis on adapting to maintain connections and activities (Windle *et al.*, 2023). These are central features within the Knowledge is Power booklets and are reflected in the relational approach adopted in the centre. Funding for $N = 8,000$ booklets that have been distributed across Wales and promotion by the members of the group and researchers has enabled the information to be cascaded. Adaptations have also been launched in two other UK regions with interest within other European countries.

Mindful of the importance of extending our reach and engagement with people across Wales, the UK and beyond, CADR members have contributed to the development of the Participatory Approaches to Ageing Research (PAAR) Network, which is an international network seeking to involve older adults as experts-by-experience in the research process. Members of the PAAR Network have produced a handbook of participatory approaches in ageing research (Urbaniak and Wanka, 2023). They will develop training and resources to support researchers and public contributors to work together.

Our considerable experience in working together with older adults and unpaid carers within health and social care research has informed involvement and engagement work in other areas, including a renewable energy project the active building centre research programme. Members of the public were invited to an initial “open event” at a low-carbon home and provided with role descriptions linked to positions on an advisory board. The public contributed to a conceptual model underpinning the research and advised on research activities including the design and testing of surveys and qualitative interview schedules relating to tenants’ well-being outcomes when moving to or agreeing to a retrofit process to achieve low-carbon homes.

The national standard of working together has been implemented by researchers within a solar energy community-building project in a rural village in India. Participatory art-based methods through a capabilities-based approach (Frediani, 2015) helped to develop individual, collective and structural processes of empowerment. Continued participation in the research process ensured ongoing community input into the solar building design and purpose (Maddock *et al.*, 2023). Principles and a Strategy for Public Involvement and Engagement were developed and adopted by the strategic university network to revolutionise Indian solar energy (SUNRISE) to facilitate a wider project understanding of the context and cultural values linked to working within the community and providing the support to enable this to work effectively (SUNRISE, 2023).

Support and learning

Research advocates are championing the work of CADR. Recent activity with six research advocates involved the co-design of a Research Advocate role descriptor, a training needs assessment and a new learning programme. The learning programme reflects what the advocates considered as essential knowledge to perform the role, alongside additional resources they considered useful. Going forward, advocates will keep a journal reflecting on their experiences. This will inform our future activities, helping us to identify what works well and what we might need to do differently to support them in this role.

Support and learning, in practice, costs money. The infrastructure funding for CADR has enabled support and learning to be integral to the centre's work. Recent calculations by the author (CHJ) based on supporting travel costs, refreshments and vouchers for six members to attend a group meeting and excluding staff time amounted to £320 per meeting. Further work by [De Simoni et al. \(2023\)](#) offers guidance on how to budget for PPI to ensure a sustainable and mutually beneficial model for all throughout the research life cycle.

Communications

This standard relates to generating greater awareness about research to build interest and empowering people to shape future research. By varying our public engagement and promotional events and expanding our media formats, we aim to attract wider and more diverse audiences. Since 2020, there have been 29 public webinars with 1,022 attendees and the library of 93 recorded presentations is available on the YouTube platform under @CADR with 4,555 views to date (20 September 2023).

The increase in the use of platforms such as YouTube, Facebook, LinkedIn and Twitter have supported communication with the public. Our new App, launched in 2021, includes immediate access to all CADR notifications, including research development opportunities and knowledge exchange events. Currently, 211 people have installed the app with 138 active members. The website records over 2,000-page views per month. Plain language summaries ($N = 30$), co-produced with public contributors, communicate research findings. They are promoted alongside academic publications and shared in public events and on social media.

We appreciate that there is a risk for some to become digitally excluded as estimates by the Older People's Commissioner for Wales state that 33% of people aged 75 or over in Wales do not use the internet ([Older People's Commissioner, 2023](#)). In response to this, we share information through traditional media platforms such as monthly news bulletins available as a paper version and interviews on national news (radio and television) programmes. Printed calendars that promote positive images of older adults, tackle ageist stereotypes and raise awareness about research opportunities are produced annually. The 2023 edition involved working with the Weles Parliament Cross Party Group on Intergenerational Solidarity to highlight the mutual benefit of different generations sharing quality time together. A national competition was launched, and the selected images were exhibited during Global Intergenerational Week within the seven national museum sites in Wales.

Impact

Understanding the impact of involvement for researchers and public contributors is challenging, especially when activities are online. Feedback forms are promoted at each event, though completion rates are sometimes low. For example, an online webinar included 11 speakers sharing their involvement in an evaluation of a new service to support people following a diagnosis of dementia. Three speakers shared their own lived experiences. Whilst 42 people attended the live webinar, only 18 feedback forms were completed. Recent introductions of reflective journals for research advocates will increase our understanding of the impact of involvement for older adults.

Governance

As researchers we are mindful of the principles of co-research and research governance ([Cotterell and Buffel, 2023](#)). The CADR advisory board ($N = 27$) meets biannually and has a diverse membership of academic and support staff, third-sector representatives and four members of the public (three of whom are older adults). An Involvement and Engagement Group meets every two months to oversee the work across CADR and facilitate

communication between Advisory Board members and members of CADR's Executive Group.

Discussion

The standards were integral to the establishment of CADR and to our subsequent work to research the priorities identified by older adults, people living with dementia and unpaid carers.

The five-year funding period with a dedicated budget and clear PPI responsibilities for staff has enabled diverse involvement opportunities. This not only benefits the research itself, in terms of its relevance and reach but also benefits members of the public. Feedback from older adults, people living with dementia and unpaid carers confirms that involvement can lead to synergistic relationships that benefit everyone. Members of the public who have contributed to research prioritisation, design, implementation and knowledge exchange activities welcome the opportunity to learn new skills, build confidence and meet new people:

When you get a diagnosis, it's like you've got no purpose in life anymore [...] So, when people ask you to be involved in research you feel valued again [...] I've learned from the professionals [...] I've learned so much myself that I didn't know [...] We all work together and then it will work together. (Teresa quoted in Seddon et al., 2023, p. 335)

These personal benefits were also reported in the review by [Baldwin et al. \(2018\)](#). Our public contributors describe their sense of purpose and fulfilment in making a valuable contribution to research that has the potential to affect positive changes for people who may also be living with dementia. This is also reflected in the work of [Reynolds et al. \(2021\)](#) and [Waite et al. \(2019\)](#). Going forward, it is important to think about how best we can capture the positive difference working together makes.

Working with older adults and unpaid carers extends the reach of our research through collaborative dissemination and knowledge exchange activities. People who feel a sense of ownership of the research disseminate the findings and champion the research recommendations among their peers and networks.

Collaborating with experts-by-experience throughout the research life cycle requires sufficient resources ([Goeman et al., 2019](#)) and a commitment to offering choice and flexibility to establish and sustain co-creative relationships. By providing opportunities for meaningful dialogue underpinned by a mutual respect for people's experiences and their expertise, we can work and learn together. Another member of the public living with dementia described the value of working together as "By myself I am a twig, but together we make a strong branch".

Respectful and meaningful relationships take time to nurture and for people to feel that their experiential knowledge is valued ([Beresford, 2020](#)). Caban members have formed strong links both with CADR researchers and with each other describing their peers as a second family. This association with staff working within an established institution should help to promote continuity of involvement going forward.

The level of involvement by Caban group members in the co-design of booklets to support resilience following a dementia diagnosis reflects the core elements of co-design. It involves creatively identifying the problem "considering a solution; building and deepening equal collaboration between users and designers" ([Tseklevs et al., 2018](#), p. 6). This was applied when developing booklets with experts-by-experience and researchers employing designers and printers. The content was submitted according to individuals preferred communication with an iterative editing process. Finally, [Tseklevs et al. \(2018\)](#) stated that co-designers share "ownership and agency both in the process and in the resulting...artefact". Funding and infrastructure development time provided by CADR has

enabled the work to progress from dialogue to resilience guides distributed across the health and social care sector. The booklets have been actively promoted and distributed by the experts-by-experience through existing local and international networks providing a greater reach and acceptance in terms of the perceived application of the information provided (Bangor University, 2023) to inform others following a diagnosis of dementia Roberts *et al.* (2023).

This paper demonstrates the range of involvement achieved through open communication and sustaining relationships with older adults, people living with dementia and unpaid carers across the research life cycle applied within the context of the standards.

A key area for future work is understanding the impact of involvement activities. Our research advocates' journal reflections will offer important insights. Challenges remain in terms of ensuring that those involved represent the diversity of the demographic and that new experts are recruited and supported. This naturally needs to include provision for expenses to be reimbursed irrespective of the individual's circumstances (Reynolds *et al.*, 2021). The co-designed training for research advocates and extensive promotion within public events will encourage new advocates and greater involvement from people within less represented groups. Building trusting relationships takes time and the significant infrastructure funding for the centre has supported this work to be developed by researchers alongside a team of dedicated facilitators. The work certainly requires a flexible and person-centred approach (Parveen *et al.*, 2018) where the individual's interest and capacity are matched to the opportunities and a willing curiosity to provide opportunities for creative dialogue.

There is always room for improvement, but by sharing our approach we hope to encourage others to invest the time and resources to build collaboration with experts-by-experience in their research.

Key implications for researchers engaged in patient and public involvement

- Be receptive to other people's views and acknowledge expertise of those with lived experience alongside those with academic expertise.
- Training, resources and time are required to effectively support involvement and meaningful relationships.
- A nominated contact person enables trust and mutual understanding to develop.
- This is an ongoing collective learning experience that should be embedded throughout the entire research process.

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