

# How do we meaningfully engage stakeholders in developing a best practice approach to post-diagnostic dementia support?

Empowering engagement with people with dementia and other stakeholders in developing best practice is hard to achieve. **Greta Brunskill** and colleagues explain how they set up a “Dementia Care Community” to inform their research to improve post-diagnostic dementia support and got positive results

Involving the public in health and social care research is widely recognised as beneficial. Patient and public involvement (PPI), as it is known, draws on a number of approaches such as consultation with the public about their views, ongoing collaboration between researchers and the public, and user-controlled research where members of the public design and deliver a study (INVOLVE 2012).

Two recent reviews suggest that the involvement of people living with dementia and their carers in research is growing (Bethell *et al* 2018, Burton *et al* 2019), but that more needs to be done to establish best practice approaches and

explore impact (Burton *et al* 2019). In addition, few studies have involved the broader range of stakeholders, including health and social care professionals, with an interest in dementia care (Burton *et al* 2019).

Among the benefits of PPI generally are contributions to the quality, relevance, effectiveness and conduct of research, as well as the utility of research outputs (Gove *et al* 2018). There is an ethical basis too: people have a right to have a voice and should be involved in research that is about their care (Alzheimer Europe 2019). A framework of standards has been developed to improve the quality of PPI in the UK (NIHR 2019).

Our aim here is to describe a more inclusive approach to involvement in dementia research, the “Dementia Care Community” (DCC), which was formed in 2018 at the start of a four-year programme to develop a new primary care led approach to post-diagnostic dementia support (PriDem). We will reflect on our learning so far to highlight key factors in building and maintaining meaningful involvement, and make recommendations for others planning for involvement in dementia research.

## Methods

The DCC is a group of what we term “stakeholders” – people living with dementia, carers, and professionals from health, social care, third sector and private organisations involved in dementia care. Among them are carers with current or past experience of caring for someone living with dementia, including family members and friends.

It is an inclusive group which provides ongoing stakeholder perspectives to PriDem and it was first conceived during the development of the application for research funding; two carer representatives were co-applicants and are also part of the programme

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management board.

Active contributors to the DCC are summarised in the table below.

One of the co-authors, Greta Brunskill, is lead facilitator for the DCC. In this role she is the main point of contact, plans and organises involvement, and keeps in touch with contributors. She is also a researcher and part of the PriDem research team.

To reach individuals to be part of the DCC various approaches were

### Summary of active contributors in the DCC (August 2021)

Type of contributor	
Person living with dementia*	4
Carers*	20
Health professional	5
Social care professional	4
Third sector professional	3
<b>Total</b>	<b>36</b>

*\*not including those involved through an existing group*

## Summary

The involvement of people living with dementia and their carers in research is growing. We established a mixed stakeholder group, the “Dementia Care Community”, to inform a research programme focused on improving post-diagnostic dementia support. The group includes people living with dementia, carers, and professionals involved in providing dementia care.

We have used a range of approaches to establish and facilitate the involvement of a diverse group of stakeholders in our research. A number of factors have been important in enabling and maintaining meaningful involvement, including time and resources, having a lead facilitator, and offering a flexible approach.

Our experiences so far suggest that there are multiple advantages in involving a mix of stakeholders, with reciprocal benefits for the research and contributors. We reflect on our experiences and share key learning to support others planning for involvement in dementia research.

## Key points

- We established an inclusive group with personal and professional experience of dementia to inform our research to improve post-diagnostic dementia support
- Offering choice and having consistent facilitators were helpful in successfully engaging an active and committed community
- The pandemic necessitated a shift to remote ways of working but with some additional support, involvement continued
- Involving different stakeholders in discussions together has been a positive experience with benefits for the research
- Our recommendations for involving people in dementia research focus on flexibility and good communication

employed. Connections were made with local groups and networks such as memory services, charitable organisations, and special interest groups using a flyer and expression of interest form. Visits were made to sources of support for people with lived experience of dementia including memory cafes, local dementia hubs, and a local event for carers. An advert was circulated to the Alzheimer's Society Research Network of volunteers with lived experience of dementia.

The lead facilitator made contact with everyone who expressed an interest. It was a chance to learn about their experiences and discuss getting involved in the research, but key to the initial contact was a person-centred approach which offered choice and flexibility. How could each individual best be involved and what support might they need to enable their involvement?

We had no formal expectations about how often or how long people would be involved. It was acknowledged that their circumstances may change. For individuals with lived experience of dementia, this initial conversation was held in person at a time and place that suited them, typically their own home.

To engage a wider audience than just those who were able to join our DCC group meetings, home visits were offered to people with dementia and carers as an alternative way of being involved. In addition, the lead facilitator arranged to make regular visits to a memory café and an activity group to hold discussions with people in their existing group



**So far, group meetings have largely been attended by carers and professionals, and people living with dementia mainly involved through home visits and visits to existing groups.**

settings. By doing so, we were able to involve a further 20 people with dementia and 11 carers.

## Involvement approaches

Prior to the pandemic the DCC were mainly involved through in-person contact, with additional contacts by email, post, and phone to keep in touch. We held group meetings in a university building with a range of meeting room facilities and reasonable transport links. Meetings were typically 2–3 hours with breaks to keep things manageable and provide opportunities for the group to socialise.

An agenda of topics and key questions was circulated in advance so that everyone knew what to expect, and meetings typically included an update on the research and a combination of whole and small group discussions depending on the topic and activity. For small group discussions, we tailored groups to the topic, combining people with dementia, carers and professionals where helpful, and separating them where people may have felt constrained by the presence of a different stakeholder type.

To capture ideas, discussions were audio recorded and photos taken of written materials (eg, flip charts) with the agreement of the group. Views and ideas were then summarised and shared with researchers and the DCC group.

The presence of additional research and administrative staff helped meetings to go smoothly, for example by helping with meet and greet, and providing extra facilitators for small group discussions. Administrative staff also arranged transport to and from meetings where needed and sent gift vouchers to those involved in a non-professional capacity to thank them for giving their time.

We gathered feedback with anonymised comment cards at the end of meetings to inform future discussions and activities. In addition, a representative from the programme management team with experience of public involvement in several projects has attended some meetings to provide feedback on how they were working. See Box 1 (p24) for feedback given by two DCC contributors.

We have used a range of methods to stimulate discussion and ensure ➤



► meetings are interactive. Approaches used include questions for discussion, templates to populate, role play and a sorting activity which is illustrated (right) and described in box 2 (below).

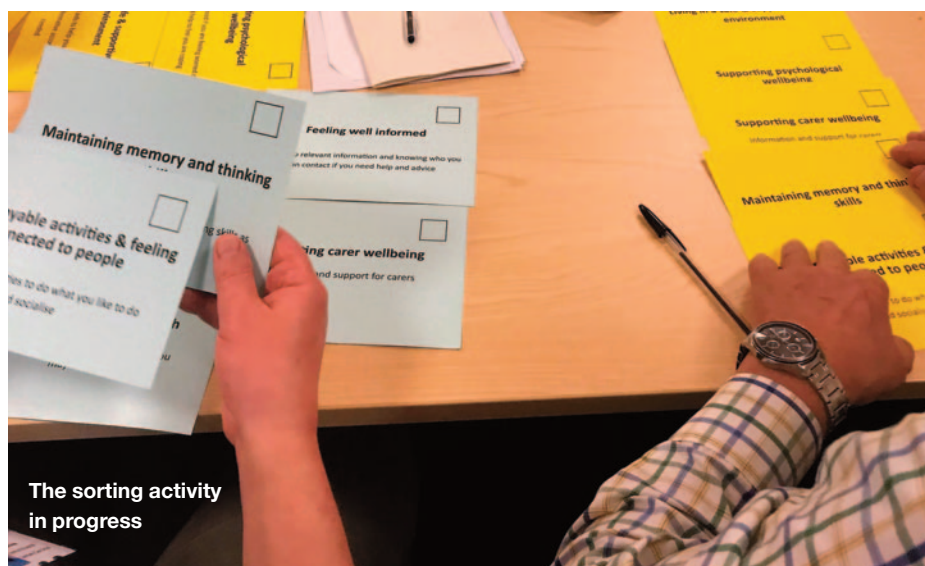
When the pandemic came we surveyed the DCC to ask about continuing their involvement remotely and most have opted to do so. Some lacked confidence with virtual meeting platforms like Zoom, so we offered one-to-one support to help them develop the necessary skills. We also started a bi-monthly newsletter to stay in touch with the group, update them on the programme, highlight a particular service, event or other project of interest and outline upcoming topics and events.

Virtual meetings focused on discussion have been kept small (up to six contributors) to help everyone have their say. This has necessitated rotating who is invited to attend and keeping everyone informed about these smaller discussions with summaries in our newsletter. Timely feedback from the research team enables participants to see how their comments and feedback are exerting an influence. Researchers follow timelines informed by recent research (Mathie *et al* 2018) and guidance (CLAHRC East of England 2018)..

**Box 1: In the words of DCC contributors**

“Thoughtful efforts have been made to foster the positive atmosphere within the group; in addition to the inclusion of time for socialising and formulation of ground rules, the research team have really gone much further and fostered a genuinely warm, friendly, and open feeling. There is a strong sense of sharing experiences to hopefully help improve things for the future” (carer).

“Group meetings have been facilitated through an atmosphere of warmth, respect and support for views and opinions, along with sensitivity to the experiences of carers and people with dementia on various topics. Humour, laughter, and openness have been present throughout, and the forging of meaningful relationships and connections is evident through DCC involvement over time. There’s also a sense of togetherness through a common desire, ambition, and commitment to improve the quality of post diagnostic support for people living with and affected by dementia” (professional).



The DCC has so far advised on 11 topics related to different phases of our research into post-diagnostic dementia support, including recruitment, data collection, and making sense of initial findings. Frequency of DCC involvement has been guided by the needs of the research and has evolved over time and in response to circumstances. So far, group meetings have predominantly been attended by carers and professionals, and people living with dementia have mainly been involved through home visits and visits to existing groups.

In time, we will evaluate the outcomes and impact of the DCC on PriDem. There will be two strands: an internal evaluation towards the end of the project co-produced with the DCC and a linked PhD study by Ester Bellavia focused on improving current PPI practice in dementia research.

**Discussion**

The DCC is an asset to the PriDem programme, bringing a breadth of views and perspectives that have influenced important aspects of the research and ensured it stays grounded in real experiences of dementia. This has occurred despite the challenges of the pandemic; most of our contributors having stayed with us since it all began in 2018. The question is, how do we maintain this level of engagement?

First, the DCC was designed, planned, and resourced well. Having a lead facilitator has been integral to building and maintaining meaningful relationships with everyone and establishing ways of working with the researchers. Regularly keeping in touch through the newsletter, among other things, has helped us stay connected.

Time to socialise in meetings has been

**Box 2: Example involvement activity**

**Background:**

Post-diagnostic dementia support can cover a wide range of services and interventions; the research team looked to the DCC for views on what a new intervention should focus on.

**Task:**

Using cards describing 7 broad areas of post-diagnostic support based on our research findings, the group were asked to rank the different areas according to priority.

**Conclusions:**

- All areas were considered important.
- Many areas were felt to be interdependent.
- Priorities will depend on factors including individual needs, personal circumstances, and stage of dementia.

**Impact:**

The group highlighted major challenges in prioritising different areas of post- diagnostic support, emphasising that all could be important depending on a range of factors that will influence the needs of each person living with dementia and their family.

important and our resources have allowed us to offer people choice about how they are involved. Without this flexibility, fewer people would have come forward, particularly those with dementia. Importantly, these resources have enabled a collaborative approach in which researchers and DCC stakeholders

are working together in an ongoing partnership (INVOLVE 2012).

Our skills, knowledge and experience as a facilitation team – co-authors Greta Brunskill, Laura Booi and Claire Bamford – have been another important factor. Greta has experience of engaging different patient populations in the NHS, Laura is experienced in facilitating diverse groups online, and Claire has led public involvement in several projects.

The team had to be flexible and creative to develop and implement new but accessible means of engagement in response to the Covid-19 lockdowns. Using video technologies for group conversations and sharing PowerPoint slides proved beneficial for remote engagement and collaboration in meetings. Support from the wider research team has enabled us to facilitate small group discussions and assist people on the rare occasions when they have become distressed.

Involving a mixed group of people living with dementia, carers and professionals has been very positive. The synergy between the different perspectives was unexpected and brought a wider range of factors into discussions than would have been the case if we had consulted stakeholder groups separately. We also hope that being inclusive communicates the equal value of all views to the research.

Unfortunately, we were unable to maintain links with the dementia café and activity groups as they paused when the pandemic struck, even though it had been the most successful approach to involving people with dementia. We continue to work with our networks to invite more people with lived experience to join us and we hope to re-establish regular contact to these groups as soon as possible.

While virtual meetings have proved their value, they have not been an option for all. Individual contact via the phone has partially solved the problem but the option of sitting together again in a group setting will be a positive step. When we asked the DCC about their preference for meeting in person or remotely in future, opinion was split, so a blended approach is the likely way forward.

### Implications for practice

We recognise that the work described here is part of a research programme that is well-resourced for involvement. However, we feel there is learning relevant to all types of study (see Box 3, above, for our key recommendations).

Education and training have been highlighted as an important aspect of supporting public involvement (NIHR

### Box 3: Tips for stakeholder involvement in dementia research

- Relationships are key - have a lead or main point of contact who maintains a relationship and keeps in touch with all contributors
- Be flexible and offer options for how people can be involved to help establish and maintain the involvement of all types of stakeholder
- Tailor approaches to needs of stakeholders
- Remote meetings can work with the provision of support to help people build confidence in using a virtual meeting platform
- Communicate the value of involvement as you go by giving timely feedback on how contributions are being used
- Keep contributors informed about progress to help stay connected.

2019, Shippee *et al* 2013). Yet DCC participants have consistently said they want to be told what they need to know when they need to know it, rather than receive structured training. We have responded accordingly, providing learning in small chunks relevant to the topic for discussion, and this experience has shown us that consultation about training and any other support needed is key.

Our next step will be to summarise the outcomes and impacts of the DCC on the whole project. We plan to explore the views of contributors and researchers on their experiences, perhaps using the UK standards for research involvement (NIHR 2019). While our involvement activity so far has focused on research design and delivery, we look forward to involving the DCC in developing routes for disseminating the research outcomes.

Our initiative has demonstrated reciprocal benefits for contributors and researchers. This success suggests that involvement must be planned, well-resourced and ongoing. We hope that our experiences encourage other researchers to involve public and professional stakeholders together, especially where research aims to improve the services they use and deliver.

More information on PriDem at <https://research.ncl.ac.uk/pridem>

More information on the DCC, including meeting summaries and newsletters, at <https://research.ncl.ac.uk/pridem/patientpublicinvolvement>

### Acknowledgements

We are extremely grateful to all the members of the PriDem DCC for their valuable insights and contributions to PriDem. We would also like to thank Angela Mattison for her administrative support, and Ester Bellavia (PhD student) for her photos of DCC activity. The PriDem study team is led by Professor Dame Louise Robinson at Newcastle University and also includes Louise Allan (University of Exeter), Sube Banerjee (University of Plymouth), Alistair Burns (NHS England and NHS Improvement), Sophie Dimitriadis (International Longevity Centre), Karen Harrison Denning (Dementia UK), Derek King (London School of Economics), Martin Knapp (London School of Economics), Doug Lewins (PPI co-applicant), Jill Manthorpe (King's College London), Greta Rait (University College London), Kate Walters (University College London), Jane Wilcock (University College London) and Raphael Wittenberg (London School of Economics). This work was supported by funding from Alzheimer's Society Centre of Excellence grant number 331. ■

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