

# Engaging innovative and inclusive partnerships to inform dementia research: the Dementia Care Community

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## Summary

- The PriDem programme of research aims to develop and test **primary** care led post diagnostic support for people with **dementia** and their families.
- We have established a Dementia Care Community (DCC) to support and shape the research programme. The DCC integrates public, patient and professional perspectives.
- The DCC seeks to be flexible in how people are involved, using a range of approaches to enable involvement.
- We will explore the impact of the DCC on the research process and outcomes, and participants' experiences of the DCC.

## What is the Dementia Care Community?

The DCC brings together people with dementia, their family members, and a wide range of professionals involved in care and support throughout the illness, including those working in health and social care and voluntary organisations. The aim of the DCC is to ensure the PriDem programme is embedded in real life experiences and contexts.

The importance of actively involving patients and public in research is now well-established. Commonly this takes the form of a patient and public involvement (PPI) panel or advisory group. The DCC represents an innovative approach to involvement by engaging a wider range of stakeholders in the same group, including those who use dementia services and those involved in their delivery, to inform and shape the work of PriDem.



Initial meeting of the DCC



## Working with the DCC

The DCC will inform the research throughout the programme, for example, by

- Helping to identify post diagnostic support services
- Advising on how best to gather the views of people with dementia, families and professionals
- Co-creating user friendly ways of sharing the outputs of the research

At an initial meeting, DCC members were invited to discuss their experiences of post diagnostic support. Collective ideas for how the DCC should work, including preferred ways of communicating and training needs, were also discussed.

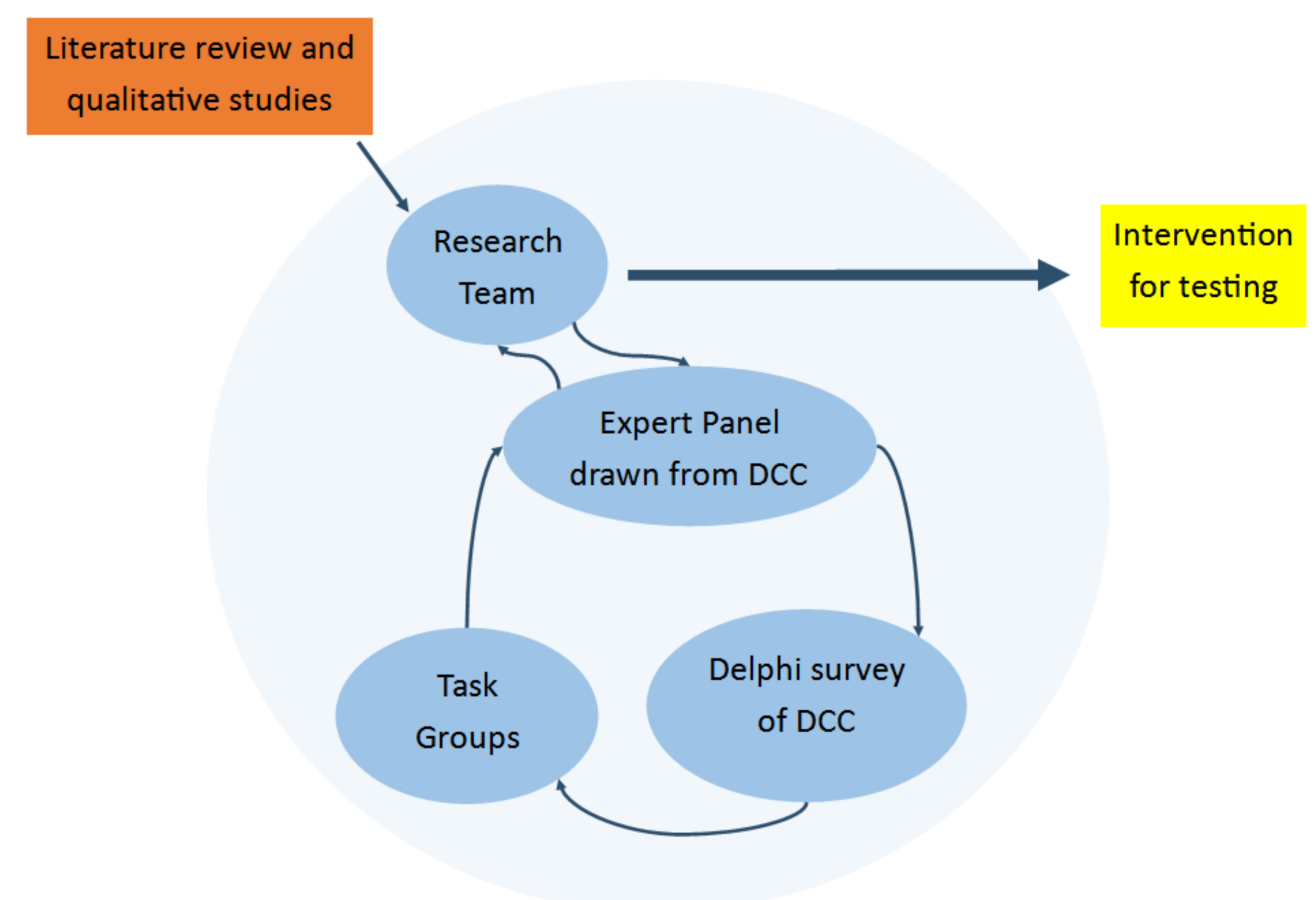
Feedback from people with dementia, family members and professionals who attended this meeting was very positive:

*"Enjoyed meeting people from a wider range of backgrounds...sharing information and stories"*

*"Good to talk about dementia services, what is out there and what could be improved"*

*"Thank you for a great event...really pleased to be involved in this work."*

The DCC will also play an important role in the intervention development phase of the research, as illustrated below:



DCC involvement in the intervention development phase of PriDem

## Key benefits and challenges

- There is great potential for positive synergy and innovative ideas from bringing together the perspectives of people who use, and those involved in the delivery of, post diagnostic dementia services.
- We are at an early stage of working with the DCC. Time is needed to establish how the research team and DCC members can best work together to inform and shape the work of PriDem.
- Maintaining the momentum of the DCC through the peaks and troughs of the research as it progresses will be an ongoing challenge.

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