

Alzheimer's Society Centre of Excellence at Newcastle University



PriDem Dementia Care Community

Summary of meeting on 5th March 2019

Update on the programme

Greta gave an update on progress with the programme.

- We have received 39 responses to the e-survey of commissioners of dementia services. These will help us to map post diagnostic dementia services available across the country.
- We are in the process of finalising a review of evidence about post diagnostic support in primary care. This has found a range of different ways of providing support from across the world including the UK, the Netherlands and Canada.
- We have identified services providing different models of post diagnostic support to people with dementia and their families. We are about to begin interviews with service managers and commissioners of these services.

PhD projects linked to PriDem

Ester Bellavia, Johanne Dow and Remco Tuijt each discussed their PhD projects with a small group of DCC members. Below is a summary of feedback from each of the group discussions.

Ester's project: Exploring and explaining the involvement of people with dementia and family carers in research

- People described a range of personal and professional reasons for getting involved in research, with some not having any experience of research before joining the DCC.
- Barriers to involvement in research were identified including time constraints, accessibility issues, and the terminology or language used.

Johanne's project: The role of the general practitioner (GP) in caring for people with dementia and their carers

- Carers and people with dementia described mixed experiences with their GP after a diagnosis, with most feeling there had been a lack of contact.
- Professionals described being keen to work with GPs, but felt there were several obstacles. These include GP knowledge about dementia services, and the lack of a time in a GP's working day when they can be contacted.

Remco Tuijt's project: Experiences of follow up care for people with dementia shortly after diagnosis

- Some challenges to joint working between professionals, people with dementia and their carers were highlighted. These include ensuring the needs of both the person with dementia and the carer(s) are understood, and the need to have some conversations all together and some separately.
- It was suggested that more regular reviews at the GP practice (for example with a GP or a specialist nurse) would improve care.

If you would like to add your views or make any further comments on any of these projects, this would be most welcome. The enclosed slide presentations give details about each PhD project and the key questions discussed, and a contact email address. If you would rather share your comments by telephone, please contact Greta Brunskill on 0191 2087963 who can share these with Ester, Johanne or Remco.

Plan for the Dementia Care Community

We discussed future plans for the DCC. We agreed

- To meet 3-4 times a year
- To try meeting at other, local venues, with car parking a key consideration. The newly opened Dementia Advice Centre at West Denton is a possible future venue.

- To add an information session on topics related to dementia to some meetings for people to join if they wish to.
- To keep in touch between meetings through a twice yearly newsletter, Twitter and the project website.

Next steps

- Writing a report on the findings of our commissioner survey
- Finalising the evidence review on post diagnostic support in primary care
- Completing telephone interviews with service managers and commissioners of dementia services

We would value your thoughts on this summary and any suggestions to improve it. Please share any comments with Greta Brunskill by email greta.brunskill@newcastle.ac.uk or telephone 0191 208 7963

You can now follow us on Twitter @ThePriDemProject

Our website is <https://research.ncl.ac.uk/pridem/>