

**ARC East of England
Stevenage Dementia Involvement Group**

Experience of Hospitals



November 2021

Stevenage Dementia Involvement Group

Stevenage Dementia Involvement Group aims to provide opportunities for people with experience of dementia to have their voice heard and to have influence on research and the planning of new services. In each session the group will discuss a particular topic relating to living with dementia or health and social care services in Stevenage.

Stevenage Dementia Involvement Group met face-to-face on 4th November 2021. In attendance were seven people with experience of living with or caring for somebody with dementia. Two people gave feedback after the group via email as they could not attend on the day.

Attending the group was Chloe Bennett (from the University of Hertfordshire) and Su Harvey from The Red Shed Project, Stevenage. Guest researchers from the *CONNECT* project were Mel Handley, Alex Young from the University of Hertfordshire and Rosemary Phillips, a PPI representative working with the University of Hertfordshire.

The topic of discussion **Experiences of Hospitals in Stevenage** was introduced by Mel Handley. Mel is working on the *CONNECT* project, which is about person-centred care in hospital.



Summary of discussions

The CONNECT project

Mel introduced the CONNECT project which is looking at how people with dementia are cared for by staff when they are admitted to hospital. The researchers are working in three locations, these are Stevenage, Leeds and Nottingham. In Stevenage, the team are looking at what happens at Lister Hospital. Mel explained that each of the 3 locations has a different approach to how staff work with people with dementia who may need additional support during their stay in hospital.

The group discussed how it is not possible for people with dementia to all stay on the same ward as they may all have different medical needs and conditions. Mel informed the group that in Stevenage a team of staff work across the hospital with people with dementia. This is different to how the other hospitals involved in the study have organised support.

Mel invited members of the group to join the co-design group for the project and explained that this would involve taking part in six local meetings. The group were given a leaflet explaining the project in more detail and six of the group put their names down as they might be interested in taking part in the co-design aspect of the CONNECT project.

Staff can have a big impact

Rosemary cared for her dad who with dementia and had visited him in hospital. She shared her positive experience during one of his admissions. One member of staff had lifted her spirits with their positive personality and in trusting her to walk with another patient whilst they cared for her dad.

The group discussed how individual staff can really impact a person's experience whilst in hospital and that experiences can differ greatly depending on ward. The group had mixed experiences. Some had good experiences, including staff going above and beyond to make sure loved ones can stay overnight at the hospital and reassuring family members

that their loved one is safe in the hospital. The group also had some bad experiences, including not being allowed to visit their loved one, not being informed of changes in their loved one's condition and long waits in A&E.

However, the group agreed that often staff are incredibly busy and when extra support is given it is well appreciated.

Extra support in hospitals

The group agreed that sometimes it can be difficult to find your way around a hospital and spoke about arrows on the floor that direct you to specific parts of the hospital, but not all felt that these were helpful.

The group also discussed that a lot of planning can sometimes be needed to attend appointments at the hospital, for example where to go and how to get to the part of the hospital they need to be in. Some of the group had experienced these appointments being changed last minute after lots planning.

Sometimes appointments must be made online and the group acknowledged that not everybody would be confident enough to do this.



The group also thought that allowances are not always made for people with dementia by healthcare professionals and that healthcare professionals could be more proactive in allowing for a person's memory and communication ability.

What could help?

The group acknowledged that some of these suggestions would be helpful for both people living with dementia and people without dementia.

- Volunteers in hospitals to guide people find their way around and provide reassurance.
- Extra staff or volunteers available to provide reassurance once somebody is in a ward.
- Extra training for staff to get a greater understanding of dementia and how best to care for someone with dementia.
- Allowances made by healthcare professionals for people's memory and communication abilities. For example, not having to give a detailed medical history to staff.
- An understanding that somebody may not be able to process all the information given to them in an appointment, especially when receiving difficult news.
- Multiple ways to make appointments, not just relying on online appointments.

Conclusion and next steps

This group provided people with experience of living with dementia the opportunity to share their opinions and experiences about visiting and staying in hospital in Stevenage. Members of the group have been invited to be involved with the CONNECT project if they would like to. For the researchers the session provided the opportunity to hear people's experiences in hospital and see if people were interested in more involvement with the project. This summary report has been read and approved by the group members who attended.

For more information about the CONNECT project visit:

<https://arc-ee.nihr.ac.uk/research-implementation/research-themes/ageing-and-multi-morbidity/connect-person-centered-hospital>

The next meeting will take place in December 2021 with the topic to be confirmed.

This group is organised by researchers from the University of Hertfordshire as part of the National Institute of Health Research Applied Research Collaboration (ARC) East of England. For more information, or if you are interested in joining or visiting the group, please contact Nicole Darlington, n.darlington@herts.ac.uk or visit <https://arc-ee.nihr.ac.uk/stevenage-dementia-involvement-group>.