NIHR Applied Research Collaboration East of England





Stevenage Dementia Involvement Group

Summary Report

2023

NIHR Applied Research Collaboration East of England

University of Hertfordshire



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About us



Stevenage Dementia Involvement Group provides opportunities for people with experience of dementia to have influence on research and the planning of new services.

We launched in 2020 and we meet monthly to discuss particular topics relating to living with dementia or health and social care services in Stevenage.

At each session we invite a guest to visit the group and discuss their work. We then have a conversation around that topic and share our experiences.

Our highlights



Contributed to the development of a Dementia Friendly Activity brochure that is being shared by Stevenage Borough Council

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Input into the development of a Dementia Urgent Care Plan that NHS England launched in February 2023



Projects we have helped with our feedback

Inspired the set up of a new walking group in Stevenage

Collaborated

with Hertfordshire Partnership NHS Foundation Trust Memory Clinic to improve dementia services



Member of the Stevenage Dementia Sub Group that is working towards making Stevenage a Dementia Friendly Community



2023

WHAT WE SAID

I am so pleased to be given the opportunity to be involved with the group and know that my thoughts and feelings are being listened to and hopeful that this may lead to positive change

Ann, Group member

What we said Dementia Friendly Stevenage

We said:

- Awareness of dementia is key in places that people living with dementia regularly visit (e.g. shops, doctors, bus station.)
- Signage needs to be clear and accessible.
- Dementia friendly is inclusive to all.
- Benches around Stevenage Town to be accessible (e.g. back support)
- Education about dementia to start early (primary school)

An important topic area we have discussed is how to make Stevenage a more dementia friendly place to live.



- Researchers from the University of Hertfordshire visited us to talk about their project on dementia friendly activity in Stevenage and our feedback contributed to their <u>Dementia Friendly booklet.</u>
- We shared our experiences of living in Stevenage and what would help to make the area more dementia friendly with Stevenage Borough Council.
- We are now part of the Dementia Sub Group that is working towards making Stevenage a more dementia friendly place to live

"The group provided valuable feedback about the design of the [dementia friendly booklet], other activities they were aware of that we had not included and ways in which we could promote the resource"

Dr Becki Hadley, University of Hertfordshire

What we said Dementia Friendly Healthcare

We said:

- Communication between different health services in Stevenage is really important
- More information about support is required not only at first diagnosis but throughout the dementia journey
- Extra support from staff at hospitals where the needs of people living with dementia are understood makes all the difference

We have welcomed a number of guests with topics around healthcare.



- Researchers from the University of Hertfordshire visited us to discuss sharing dementia diagnosis and making hospitals dementia friendly.
- NHS England asked for our feedback on a new dementia urgent care form that is going to be rolled out next year.
- Staff from local NHS Trust organisations visited to discuss how to improve their dementia services.

"What a lovely group! The group identified how the form presented could be simplified and the suggestions have all been incorporated. They were constructive and supportive and a really fab bunch."

Colin Royle, NHS England

What we said Technology and Dementia

We said:

- Lots of people we know still **do not go online** or use their phone regularly
- Fluctuations in ability should be considered
- Support can be given to help people use technology
- Technology can enable people to do things they wouldn't usually be able to do
- Technology should be simple and accessible to all

Technology and dementia is an area that research is increasing in. A number of guests visited to speak with us about this.



- A researcher from University of East Anglia visited to discuss a new study on Global Positioning System (GPS) location devices for people with dementia.
- University of Hertfordshire researchers wanted feedback on two different studies: virtual wards for people with dementia and social wellbeing and technology.

"Feedback from the group will be used to inform our future work package which will look to explore both facilitating factors of tech adoption and barriers to this"

Dr Alison Tingle, University of Hertfordshire

LOOKING AHEAD



We are developing relationships with the local memory clinic psychology services with a hope that they direct people to our group to help more people get involved

NICOLE JONES, CO-FOUNDER OF STEVENAGE DEMENTIA INVOLVEMENT GROUP

What's next?

- We continue to get involved with both Stevenage and Hertfordshire's Dementia Friendly Community initiative.
- We have set up another group that will work with care home residents.
- We would like to take part in Mystery Shopping exercises and help improve local services and facilities by providing constructive feedback.
- We are developing relationships with the local memory clinic psychology services with a hope that they direct people recently diagnosed with dementia to our group to help more people get involved.

Find out more and get involved:



arc-eoe.nihr.ac.uk/stevenage-dementiainvolvement-group



ARCOffice@cpft.nhs.uk



@ARC_EoE



Thank you

Thank you to all our group members and all the guests that visited.

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 Jones (nicole.jones@cpft.nhs.uk) or visit our website https://arc-eoe.nihr.ac.uk/stevenage-dementiainvolvement-group.













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Get in touch with

The Stevenage Dementia Involvement Group For more information, visit our website or scan the QR code: arc-eoe.nihr.ac.uk/stevenagedementia-involvement-group



ARCOffice@cpft.nhs.uk



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