

Involving People Living with Dementia in Research: Development of the Stevenage Dementia Involvement Group

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ARC East of England, Aging and Multi-morbidity Theme, ARC East of England Inclusive Involvement in Research for Practice Led Health and Social Care Theme
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About the 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. Each session the group discusses a particular topic relating to living with dementia or health and social care services in Stevenage. Stevenage Dementia Involvement Group asks for people's views to shape research as co-researchers or experts by experience rather than as research participants.

Set up of the group

- Set up took place over a period of 3 months in early 2020
- Local groups in the area were visited to promote the group and understand local priorities.
- Gatekeepers were asked to distribute flyers and to be a means of contact for people initially.

COVID-19

- Meetings have moved online
- Difficult to get people to engage when not face to face
- Had online meeting practice sessions for group members to gain confidence in participating
- "Hybrid model" of both physical and virtual meeting offered for the first meeting
- Thank you vouchers sent to participants after the meeting

Impact

"I am so pleased at being 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"

- ANNE, GROUP MEMBER

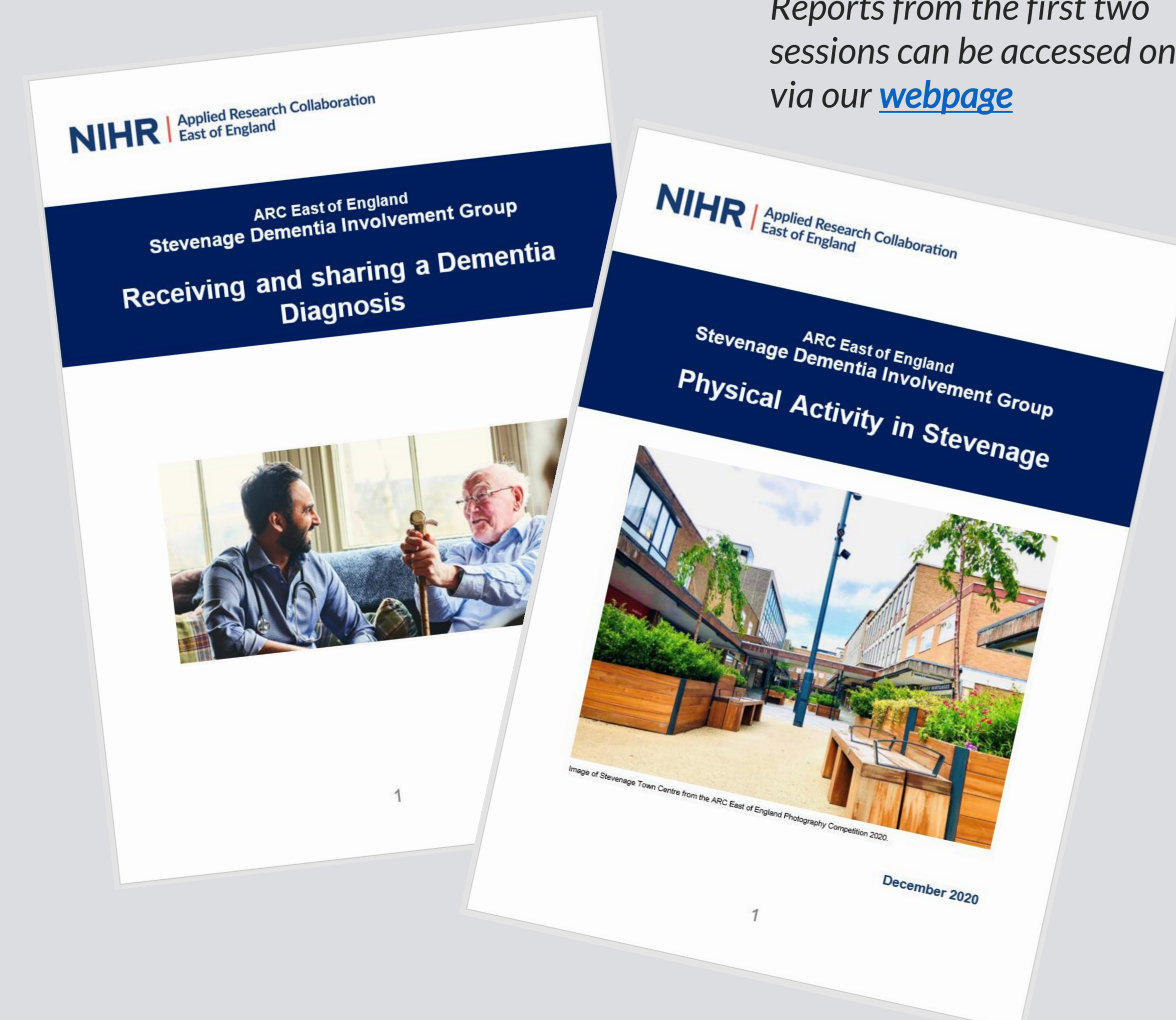
Since December 2020, the group of 5 members have met twice to discuss different topics. The first topic was about Physical Activity in Stevenage and the second topic was about Receiving and Sharing a Dementia Diagnosis. Both meetings took place virtually and a written report was produced afterwards with feedback from the group.

The group made recommendations in both sessions as to what they would like to see in Stevenage. This included: the set up of a dementia friendly walking group, more information about accessible transport, support in the middle and later stages of dementia and a "dementia hub" that provides a single point of support and information throughout the dementia journey.

Comments fed into a research ethics application and shaped survey and interview questions (more info about the Physical Activity Project can be accessed [here](#))



Photo shared with permission from group members



Reports from the first two sessions can be accessed online via our [webpage](#)

Acknowledgements

We would like to express our thanks to The Red Shed, Stevenage, in particular Su Harvey, whose support has been instrumental in the set up, recruitment and facilitation of this group. If you would like more information about The Red Shed then visit their website [here](#).

Thank you to all the group members who have attended the sessions so far and have been so enthusiastic about this new group and offered their feedback going forward.



Photo sourced from <http://www.theredshed.garden/services/>

Tips and Learning

DO

- Visit local groups to understand the priorities before setting up your group
- Access a "gatekeeper" that knows and is willing to contact interested people
- Make the advertising material accessible
- Allow time at the beginning and the end of the group to settle in and debrief
- Work together with the group to decide on the topics for the meeting so they stay relevant
- Let the group know any questions in advance
- Reimburse members for their time and travel
- Feedback to the group after the session about how their ideas have been taken forward
- Offer alternative methods to join the meeting (a hybrid model)
- Offer the use of a familiar community setting or person to access technology if people are not confident or need support
- Actively involve the person living with dementia by asking questions to them directly

DON'T

- Make the session too long: 1 hour is adequate
- Make the group too big: 4-8 people so that everybody gets time to speak
- Make a formal agenda with timings: the session should remain flexible

Contact Information

For more information about Stevenage Dementia Involvement Group please visit our [webpage](#) or contact Nicole Darlington on n.darlington@herts.ac.uk or ARCOoffice@cpft.nhs.uk

Disclaimer

This is a summary of research supported by the National Institute for Health Research (NIHR) Applied Research Collaboration East of England. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.