

FIGHTING DEMENTIA WITH A 'VOLUNTEER ARMY'

Northamptonshire Healthcare NHS Foundation Trust (NHFT) Innovation and Research Team are currently working with Voluntary Impact Northamptonshire (VIN) to create an army of volunteers to spread awareness of Join Dementia Research around the Trust and county. This initiative has created a social movement of engagement.

How did this initiative start?

NHFT is a community, mental health trust that covers a county population of around 700,000 people, with a significant ageing population. NHFT has also been engaged in delivering National Institute of Health Research (NIHR) portfolio research for over 10 years. They have a particular interest in dementia research, led by the clinical lead for dementia research, Dr Paul Koranteng. Paul has been recognised nationally by the NIHR as a leading clinician for commercial dementia research and by the Clinical Research Network East Midlands for leadership in dementia research.

Paul highlighted that "Everyone should be involved in dementia research when the opportunity arises, patients and carers may benefit directly from the research intervention or from the additional support of regular contact with research staff. Participating in research inspires hope and altruism."

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Paul Koranteng

*Consultant Old Age Psychiatrist,
Northamptonshire Healthcare NHS
Foundation Trust (NHFT)*



Northamptonshire Healthcare NHS Foundation Trust
Join Dementia Research and
I am Research 'roaming' campaigns

"For health professionals it may provide a mechanism for keeping up-to-date with recent developments in the subject area and the research outcomes may affect evidence based practice and NHS policy," he added.

NHFT has also been working with VIN to develop opportunities for volunteering within the Trust. Mandy Woolf, Volunteering Development Officer from VIN is located within NHFT to support the development of this initiative. In December 2017, Sue Palmer-Hill, Head of Innovation and Research at NHFT, was approached by Mandy and asked to host a volunteer with an interest in research. Since the Innovation and Research team had not had a volunteer before, they were presented with the interesting challenge of what the volunteer would undertake.

Mandy shared that she was "delighted when Sue Palmer-Hill accepted the challenge of involving volunteers in to her department. [Sue] was very enthusiastic and immediately could see the benefits and had a vision of the 'volunteer army'. This has been a great opportunity particularly for students looking to gain experience in this field. Since our first contact we have engaged 7 volunteers into this team. My role is to provide assurance that the appropriate checks and training are completed for the volunteers before they start and to give support and guidance to staff in managing volunteers."

Given their strong commitment to dementia research, a Join Dementia Research information kiosk had been supplied to NHFT in October 2017. However, some challenges with getting the technology to work, potential damage if left unattended in a public environment, and limited staff capacity meant that the kiosk was not being used to any real advantage.

Having volunteers presented an opportunity to have 'more boots on the ground' to spread the word about Join Dementia Research. This was appealing as it was something that everyone, be they patient, carer, member of the public, or health care professional alike could engage in. The ambition was to start a social movement of awareness of Join Dementia Research, first in the Trust, but then also out and about in the county.

A Volunteer Army is born

A brief project plan was developed and a volunteer role description was written. The initiative has been supported by the NIHR Clinical Research Network East Midlands with a small amount of Innovation funding to cover volunteer travel and out of pocket expenses and a small amount of coordination support. Volunteers were then recruited and underwent comprehensive safeguarding checks and completed mandatory training for the Trust, prior to commencing their roles.

The volunteers were immersed within the Research Delivery Team at NHFT to develop their understanding and gain mentorship support. Training on how the stand worked was delivered by Gozeder Aspe Juaristi, the Dementia Challenge Project Manager at NIHR Clinical Research Network East Midlands. The NHFT Research Delivery Team staff and volunteer were equipped with JDR t-shirts and 'I am research' stickers that could be awarded to people who signed up. The army was ready to go!



Hannah Clayson and Ken Agwegwe are part of the 'Volunteer Army' at NHFT

Initiative impact

So far, the overwhelming experience of this initiative has been very positive. Compared to the other Join Dementia Research information kiosks in current use, the kiosk used by NHFT and the volunteer army have generated the highest number of sign-ups into the Join Dementia Research service. A further bonus of this initiative is that it has raised a lot of awareness about clinical research as a whole and the work that the NHFT team does in particular.

Feedback from the volunteers has also been very rewarding. All the volunteers found the experience very beneficial and they have all registered on the Join Dementia Research service.

In addition, many research staff have also engaged with Join Dementia Research and are now participating in research studies themselves, including participating in the SeaQuest game!

John Adcock, a Clinical Research Support Assistant, at NHFT highlighted that "Join Dementia Research opens the door for people with dementia and healthy volunteers to participate in dementia research, and hopefully find a cure for dementia. Through joining Join Dementia Research, I have accessed a number of clinical trials, including the PROTECT study run by Kings College, London. Taking part was fun and competitive, as my wife also signed up to this study through Join Dementia Research."

"The 'Volunteer Army' is about starting a social movement, where members of the public are communicating the importance and value of clinical research to the people of the county."

Sue Palmer-Hill

Head of Innovation and Research,
NHFT



Sue Palmer Hill, Head of Innovation and Research at NHFT, with the 'roaming' Join Dementia Research information kiosk

Lessons learnt along the way

Moving the Join Dementia Research information kiosk is not without its problems! Since the kiosk is tall and weighted at the bottom, it is not built for easy portability. However, the team innovatively used a pair of suitcase wheels to aid the movement of the kiosk around sites. They also now know that it neatly fits in the back of a Ford Fiesta with the seats down or in an Audi TT with the roof down!

Once in location a power source and strong WiFi connection are a must, although this might mean that you need to stand in a corner where the plug points are located. Leaflets about Join Dementia Research are also handy to pass on information to people who do not want to use the internet.

Inducement also works. The Alzheimer's cupcake day and the NHS 70th birthday presented great opportunity for cakes, sign ups at these events were good!

Next steps

The NHFT Research team and volunteer army are currently planning on returning back to Berrywood, St Mary's, and Danetre Hospitals. In the future, they are also planning to visit Isebrook (Wellingborough) and Corby Community Hospitals. The NHFT research team are also reaching out to GP surgeries and local dementia support groups to check whether they would be willing to host the kiosk for a day or half a day.

"We, as a trust, are passionate about the importance of offering research opportunities to our patients and service users. We know that research active organisations have better patient outcomes and high standards of care. Our challenge is getting this message out across a large countywide community healthcare trust. We only have a small Clinical Research Delivery Team, so we needed reinforcements, more boots on the ground," shared Sue. "When we were approached with the opportunity of hosting volunteers, this seemed like the perfect answer. The 'Volunteer Army' is about starting a social movement, where members of the public communicating the importance and value of clinical research to the people of the county. Join Dementia Research and the information kiosk provide the perfect vehicle to support this," she concluded.

Top Tips

- Having volunteers staffing the Join Dementia Research kiosks drives engagement and registration.
- Do not underestimate the time taken to find suitable venues and arrange visits. The transport of the kiosk (and volunteers) to each venue must also be considered.
- The Join Dementia Research website is useful for getting other, up-to-date, promotional material, such as white Join Dementia Research t-shirts, which create further impact.
- The location of the stand at the site is an important consideration – e.g. close to a power source and away from windows/glare.
- Join Dementia Research registration forms can be used for those who are happy to get involved with research but do not want to register their details on the kiosk.
- Be proactive when staffing the stand; seek out potential 'sign-ups', rather than waiting for them to approach you. Use 'I am research' stickers to identify those to whom you have already spoken.
- Remind people that they will need to follow the link to the website to complete their registration on Join Dementia Research before they can be notified about potential studies in which they can choose to participate.

For more information visit:
nhs.joindementiaresearch.nihr.ac.uk