A new initiative piloted in the West of England with local GP surgeries, has revealed a successful approach to recruiting volunteers to Join Dementia Research. A joint project between the NIHR Local Clinical Research Network (LCRN) and the Office of the NIHR National Director for Dementia Research, aimed to work alongside GPs in the region to identify and engage with patients via mailings to recruit for dementia research studies.

Adam Smith, Programme Manager for the Office of the NIHR National Director for Dementia Research, was keen to partner with this channel: “There are over 450,000 people living with dementia being cared for by their local doctor. Despite this however, they currently have one of the lowest number of referrals of all the channels that recruit to Join Dementia Research”.

“Once a patient has been diagnosed with dementia, their ongoing care and treatment will normally be provided by GPs in a community setting. We wanted to understand if writing to people via their GP would be a successful, cost effective way of attracting more volunteers to Join Dementia Research”, he explained.

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The Join Dementia Research Project Officer for the West of England LCRN, Charlie Procter, approached GP surgeries who have already shown commitment to supporting research via the local NIHR Research Site Initiative (RSI). The initiative’s purpose is to support the establishment and maintenance of infrastructure enabling primary care organisations to contribute to the delivery of the NIHR Clinical Research Network’s portfolio studies. Charlie identified ten surgeries that were keen to be involved with the pilot. Using a secure mailing system called Docmail, the surgeries were asked to upload details of their patients who were aged over 55 (or 65) and not terminally ill. The mailings were sent out over an 18-month period, with over 14,500 people receiving letters.

The letter to each patient outlined the reasons why they should sign up to Join Dementia Research, along with details on how to register via the charities’ helplines or the website. With some of the surgeries, half of the patients also received an application form (including a freepost...
address), to test if this was a preferred method of signing up.

It was important that all the results were carefully measured to be able to track the project's success. “All letters and sign-ups were tracked using unique registration numbers and URLs in addition to recording and monitoring by the helplines and Google Analytics. To allow cost and conversion rate comparison two of the GP surgeries wrote to only patients with dementia. This was a smaller number, but enabled sign-up percentage comparison and cost comparison. This was also seen as a necessary element, as people with dementia are harder to reach and more in demand”, explained Adam.

The results revealed that almost 10% of all the patients who received a letter contacted Join Dementia Research and over 5% then went on to register. However patients actually preferred to complete an application form and send it back (5.72% V 3.57%). Considering memory clinics have a registration for research rate of around 2% via leafleting, the direct mail approach has been a successful recruitment channel.

Charlie has been encouraged by the positive approach from GPs in the area, saying “Despite being busy and under pressure, the GPs we have approached to support this and other initiatives, have been extremely supportive. This could be due to our making it simple and delivering much of the work ourselves. The GPs were only tasked with uploading mailing lists; the rest was handled by us and Docmail. So, don’t be afraid to ask”. She added: “Despite being over 12 months on, we still get forms back from their mailings, so the return might happen over a longer period”.

Dr Antony Crockett, a GP from the Elm Tree surgery in Swindon, was part of the trial. He commented “The process was very simple and the response from patients and relatives was overwhelmingly positive. Lots of patients were very pleased to have the opportunity to possibly help research in the future and were very grateful that research was and will be carried out. Many patients also appreciated the critical importance of good research in managing and treating and perhaps even preventing or curing dementia in the future and were happy to sign up to Join Dementia Research as a result of receiving their letters”.

Adam is keen for regional plans being developed to promote Join Dementia Research to consider this approach, adopting this initiative in their area; and is pleased there are currently mailings being sent out from 4 GP practices in the Camden area of London. “We hope this case study and the associated data will encourage local areas to consider this method as part of their Join Dementia Research planning and achievement of the 2020 vision objectives. It does cost money, however it has proven to be one of the most cost effective and reliable ways we have found to engage patients”, he added.
Top Tips
• Start by approaching GPs who are part of the NIHR RSI scheme or those interested in dementia
• As GPs are very time-limited, send out a letter in advance telling them exactly what you require from them
• Make it simple for the surgeries, keep the work you are asking them to do to a minimum
• Remember to evaluate uptake and feedback success to GP Practices
• The letter you send out to patients needs to be engaging and informative – tell them about why Join Dementia Research is so important and why we need their help
• Consider who you are mailing - everyone over 55? Just people with a dementia diagnosis?
• Before any mailings are sent out, ensure the charity helplines have been informed so they can prepare for phone calls and application forms

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