PATIENTS IN RESEARCH



#### Introduction

To follow are a series of template letters all of which are addressed to General Practitioners. These letters are examples of the various approaches taken by DeNDRoN to highlight and promote patient participation in research.

# 1. Letter One - Demographics

This letter was designed to be send to GP Surgeries with a backdrop of the list size including a significant number of people with Dementia (based on QOF information), and draws attention to the local research network.

## 2. Letter Two - Study Results

This letter was designed to be send to GP Surgeries who's patients has participated in a previous study. It support improved sharing of research outcomes, and uses the opportunity to further promote participation.

### 3. Letter Three - Media

To tie in the announcements and publicity around the Prime Ministers Challenge on Dementia, this letter highlights the local contribution being made to delivery, and introduces the concept of GP's promotion of research participation to patients.

## 4. Letter Four - Recommendation

This is a general letter to GPs suggesting a meeting to discuss ways of forming partnerships to promote research. This could be used specifically for any follow-ups from expressions of interest or previous contacts.

As long-term conditions and other health problems continue to be increasingly managed in Primary Care the network has learnt to explore improving direct partnerships with GPs. Proposed changes in research permissions which allow GPs to act independent of PCT (as was) will also help to solidify these partnerships.

The letters provided can be adapted to other diseases and research areas. Letters should be short, concise and clear about what you are asking, they should also introduce follow-up and be used to open further dialogue.

TV2 - March 2013







Surgery Address

Thames Valley DeNDRoN Room 4401D, Level 4, John Radcliffe Hospital, Headington, Oxford, OX3 9DU

Date

Dear <insert name of dementia lead>

### Re: Dementia Research

I am writing to you because our research team is interested in finding ways to offer people living with dementia more ways to take part in research. QOF data shows that your practice has a large number of patients with a diagnosis of dementia.

DeNDRoN (Dementias and Neurodegenerative Disease Research Network) is a NHS-based research network that aims to improve the amount and quality of UK-based research in dementia. We work closely with the \_\_\_\_\_\_ Community Mental Health Team.

I would be grateful for the opportunity to meet with you to discuss how your practice can play a more prominent role in the rapidly developing field of dementia research. We realise that every practice will be able to support us in different ways. Other practices to date have worked with us by:

- Displaying posters in waiting rooms
- Making DeNDRoN leaflets available in the surgery
- DenDRoN staff giving a talk to GPs and other practice staff
- Engaging with the surgery's patient representation group
- Publishing articles in practice newsletter
- Displaying links/news items on practice website

I hope you find this of interest, and will discuss this with your colleagues. I will contact you by telephone in a couple of weeks to discuss how your practice can contribute.

Yours sincerely,

Claire Hall, Research Nurse Dr Rupert McShane, Research Director

Cc: (insert name), Practice Manager





Surgery Address

Thames Valley DeNDRoN Room 4401D, Level 4, John Radcliffe Hospital, Headington, Oxford, OX3 9DU

Date

Dear <insert name of GP>

Re: <Patient Name and d.o.b> - Dementia Research

This patient from your practice recently took part in DOMINO-AD research study (Donepezil and Memantine in Moderate to Severe Alzheimer's Disease). We are really excited that the results of the study have now been published in the New England Journal of Medicine. The main findings were:

- Evidence of clinical benefit of donepezil for severe AD
- Evidence of clinical benefit of memantine for severe AD
- There was a suggestion that combining donepezil and memantine is more effective than either drug alone. However, data from other studies would need to be considered to demonstrate a significant effect.

Please find the final paper enclosed, with an editorial article from the same issue. This study has been worthwhile and provides an important step towards policy change.

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Yours sincerely,

Claire Hall, Research Nurse

Dr Rupert McShane, Research Director

Cc: (insert name), Dementia Lead (insert name), Practice Manager





Thames Valley DeNDRoN Room 4401D, Level 4, John Radcliffe Hospital, Headington, Oxford, OX3 9DU

Surgery Address

Date

Dear <insert individual practice manager names>

Our NHS research team is interested in finding different ways to offer people living with dementia more ways to take part in research. A recent (June 2011) Ipsos MORI poll – commissioned by the Association of Medical Research Charities (AMRC) surveyed the general public and found that:

- 97% of the public think it's important for the NHS to support research into new treatments
- 72% would like to be offered opportunities to be involved in trials of new medicines or treatments if they suffered from a health condition that affects their day-to-day life

In recent years there has been a significant increase in the media coverage and public awareness of cognitive impairment and dementia. This has been strengthened by the recent governement funding annoucement. A large section of the Prime Minister's Dementia challenge (DoH 2012) was dedicated to 'better research' and stated that "We will work towards recruiting 10% of patients into clinical trials." This is something that we are keen to work towards, and we would really value the chance to work with you on achieving this

DeNDRoN (Dementias and Neurodegenerative Disease Research Network) is a NHS-based research network that aims to improve the amount and quality of UK-based research in dementia. Our dedicated multi-disciplinary research team helps to run high-quality, nationally important studies. DeNDRoN-supported research can offer access to new treatments and management of memory problems. Contact with the research team may offer additional support for patients and help them to learn more about their condition. Many participants feel they will be helping future generations.

I would be grateful for the opportunity to meet with you to discuss how your practice can play a more prominent role in the rapidly developing field of dementia research. We realise that every practice will be able to support us in different ways. Other practices to date have worked with us by:

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- Publishing articles in practice newsletter
- Displaying links/news items on practice website

I hope you find this of interest, and will discuss this with the doctors and practice staff. I will contact you by telephone in a couple of weeks to discuss how your practice can contribute.

Yours sincerely,

Claire Hall, Research Nurse





Surgery Address

Thames Valley DeNDRoN Room 4401D, Level 4, John Radcliffe Hospital, Headington, Oxford, OX3 9DU

Date

Dear <insert name of dementia lead>

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DeNDRoN (Dementias and Neurodegenerative Disease Research Network) is a NHS-based research network that aims to improve the amount and quality of UK-based research in dementia. We work closely with the \_\_\_\_\_\_ Community Mental Health Team, \_\_\_\_\_ recommended that we contacted your practice.

I would be grateful for the opportunity to meet with you to discuss how your practice can play a more prominent role in the rapidly developing field of dementia research. We realise that every practice will be able to support us in different ways. Other practices to date have worked with us by:

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Cc: (insert name), Practice Manager