



# Patient and Public Involvement Newsletter

March 2017



## Centre for Dementia Patient and Public Involvement

Our group for people with dementia and their family members or carers aims to help the research within **Centre for Dementia**. The group meets monthly to hear news from research projects, and also to learn about the processes of dementia research. Academic researchers also attend, to learn about how to work better with people with dementia. We hope that everyone gets something out of the meetings, including friendship and support that comes with a peer group. Specifically, we will ask your input to shape the way that research money is spent and the research is done. The meetings will also help people with dementia and their carers to link up with the individual research projects where there are more chances to get involved.

Meetings are on the **first Wednesday** of the month at the **Institute for Mental Health**, Triumph Road, Nottingham NG7 2TU. We have coffee and tea from 10.00am, for a 10.30am start. We expect to finish at 11.30am.

Please let us know if you can come, so that we can order catering.

If you have any questions or need **support** in order to participate, just let us know, and we will try to accommodate you: Neil



Chadborn (Neil.Chadborn@nottingham.ac.uk) or Jill Charlton (0115 82 30417). If no one is in the office, please leave a message on Jill's answerphone.

## PPI Activity in Projects

Researchers call upon members of the public to comment on all stages of their research to make sure that the questions being asked are relevant and sensitive to people's needs, and also to capture what issues are important.

Over the last seven months we have had a large variety of talks. We have aimed to cover different aspects of the process of research. For example :

- Laurie described a completed project where PPI had been involved in developing dementia-friendly GP practices.
- We have had PhD students presenting their projects on arts and reminiscence, including using technology such as iPads or tablets to prompt memories.
- At the other 'end of the spectrum' we have had a presentation by Maria of the laboratory investigations of 'genetic switches' that may link exercise with prevention of dementia.
- Finally we have had talks by Claudio, Jen and Rebekah about how PPI members can be involved in conducting the research itself as 'co-researchers' alongside academic researchers. If you would like further information about any of the presentations, please get in touch.



## **Coming up!**

**Café Connect, Drinking cultures in later life: An exploratory Study**

**Nottingham Contemporary, March 23rd and 24th, 10:00am-5:00pm**

We'd like to invite people over the age of 65 who are part of a social group (e.g. special interest group, hobbies, sports) to come and share your thoughts and opinions about the role of alcohol in the social lives of older people.



The small discussion group (5-7 people) would be held at lunchtime (1-2pm) at Nottingham Contemporary Art Gallery in the city centre. We can offer you a £2.50 voucher to be spent at the Café bar as a thank you for your time.

For more information and to register, please email [katy.jones@nottingham.ac.uk](mailto:katy.jones@nottingham.ac.uk).

## **Centre for Dementia seminar series**

**Rehabilitation for Outdoor Activities and Mobility in Care Homes: the ROAM study**

**Amanda King presents on 13th April 2017, 11:30am-12:30pm**

Care home residents should be supported to participate in meaningful activities in their preferred places, including outdoor spaces. Although outdoor engagement in greenspace is believed to be beneficial, the majority of residents stay indoors. Using a realist approach, this study is investigating what helps and gets in the way of residents' garden use. Data has been collected in 3 care homes in the East Midlands and analysis is currently in progress. Amanda will present an overview of the study and share some preliminary findings.

## Music in Care

**Farai Pfende, John Osbourne and JoCo Learning & Development  
present on 11th May 2017, 11:30am-12:30pm**



This Seminar is an introduction to the UK based **‘Music in Care’** programme which promotes the use of personalized music in therapeutic ways, in a range of care settings. This seminar will focus specifically on the **‘Soundtrack to My Life’** the first

program that was developed which explains the value of personalized music in dementia care highlighting important research evidence. Farai and John will discuss the outcomes the "Soundtrack to My Life" book enables people living with dementia to achieve. They will also talk about the accompanying training, designed to develop knowledge, competence and confidence of frontline staff and family carers in musical practice. Using a Care Home case study, they will share the positive outcomes the training program is having on meeting the challenges of living with dementia using this person centred approach to music.

**To register your attendance at seminars or for further information  
please email:- [jill.charlton@nottingham.ac.uk](mailto:jill.charlton@nottingham.ac.uk)**

### Dementia in the curriculum

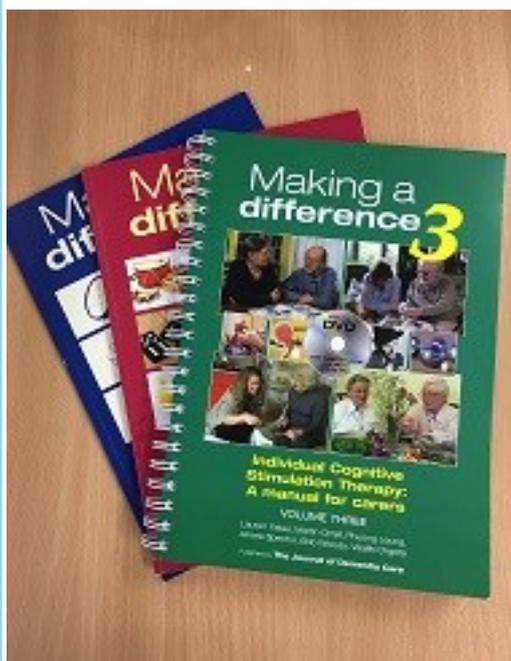
From 2019 onwards, medical students will participate in a ‘dementia-themed’ week as part of their studies. This aims to improve dementia awareness with a focus on public health, communication skills, behavioural sciences, anatomy and treatment. Anyone interested in finding out more can contact the module co-convenor, Georgina Jackson.

[Georgina.jackson@nottingham.ac.uk](mailto:Georgina.jackson@nottingham.ac.uk)

## We need you!

There are several opportunities for those wishing to become involved in research projects within the Centre for Dementia. If something interests you, get in touch with the project leader for more information.

### Developing a fun and stimulating application for people with dementia and their carers, by Harleen Rai



Harleen Rai is a PhD student who has attended a few of our PPI meetings. She would like a couple of PPI members to help her with her studies over the next few years:

“For my research I will be investigating whether a web application which can be used on computers and touch screen devices such iPads or smartphones could be used to stimulate memories, conversation, etc for people with dementia. This web application will be designed for and used by people with

dementia and their carers.

The therapy, which we will use on the computer/iPad/smartphone, is ‘Cognitive Stimulation Therapy’. This is an intervention developed by Martin Orrell, the director of IMH, and others over the last decade. We are now hoping to develop a web application and to do a feasibility test.

I would like a couple of PPI people to help give insights into the design of the web application, in the first phase and then testing (in a year’s time). It might involve 4-6 meetings a year and the work might include reading a few documents, having a go at some apps, and giving your thoughts and feedback. If you are interested and would like to have some more information, do not hesitate to contact me”

Harleen.rai@nottingham.ac.uk

## We need you!

### Making a research proposal and planning how to run the project, by Mohan Rathnaiah

“I am applying to Alzheimer's Society in March for a Phd fellowship. We are proposing to study the mechanism of benefit of exercise in memory improvement in elderly people with mild memory problems. We are planning to do MRI scans to measure for natural anti-oxidant in the brain. I am very keen to get the views of members of the PPI group about the development of our research proposal about measuring the anti-oxidant levels in the brain, before and after exercise therapy. If my application to Alzheimer society is successful, then I would be very keen for the active involvement of PPI group in the implementation of the project.”  
[mszmr1@nottingham.ac.uk](mailto:mszmr1@nottingham.ac.uk)

### Facebook Group Promoting Well-Being and Technology, by Dave Waldram

A volunteer member of MindTech's Involvement team ([www.mindtech.org.uk](http://www.mindtech.org.uk)) has created a Facebook group entitled Well-being Apps, Gadgets & Tech. The idea is that the posts are of interest to people of all ages and to include information that is



of use to older people including information about dementia. It is set-up such that anyone can post in the group. If you have any information relevant to the group please post it. The five Facebook tags for the group are well being, dementia, research, mental health and technology.

The group's website address is <https://www.facebook.com/groups/1025789210889092/>

## A Dementia-Friendly University

### **With your help we can become a (more) dementia-friendly University**

We all hope to live a long and healthy life yet one in four people aged over 80 experiences symptoms of progressive memory loss. As the older population increases in size, so do the numbers directly affected by one or more of the group of brain diseases known as dementia.

Fundraising in support of our world-leading research into earlier diagnosis and improved treatment for dementia has been tremendous with a staggering £359,142 raised last year through a host of Life Cycle 5 activities. That money is enabling us to use our Nobel Prize-winning MRI research to underpin ways of understanding better how dementia affects the brain.

Now The University of Nottingham is working to become a more dementia-friendly community. You can help by signing up to one or both of two initiatives. Find out more through this website <https://idea.nottingham.ac.uk/pledge>

### **What is a Dementia Friend and what do I have to do?**

The Alzheimer's Society provides basic information in an online video about dementia and registers people who have watched it as Dementia Friends. By viewing this short film you will gain understanding and be better able to act appropriately towards people with dementia in the university and in the wider community. You will be encouraged to tell your friends and family about the video and other resources available through The Alzheimer's Society.



**Take action  
on dementia**

## A Dementia-Friendly University

### **I'm a fit and healthy person so how can I help with the research?**

'Join Dementia Research' is a database of people who are interested in taking part in research relating to dementia; its causes, potential cures and everyday care. Individuals provide information about themselves, it is stored in a confidential database and only released to accredited researchers. People can then be contacted about studies for which they are eligible.

You do not have to be diagnosed with dementia to register with Join Dementia Research – some studies require healthy volunteers, as well as carers or relatives of people with dementia. By signing up you increase your chances of being asked to consider taking part in ethically-approved dementia research.

So far, we can confirm:

- 333 people from the University have signed up to become a Dementia Friend
- 167 people have signed up for Join Dementia Research
- 145 people have registered their interest in volunteering at the Dementia-Friendly University of Nottingham
- We have linked up with Department of Life Sciences who are carrying out laboratory science on the fundamentals of the disease
- Dementia friendly building audit – we recently met to discuss how we could encourage improvements to our buildings on the campus for people with dementia. This includes a checklist, but more importantly trying to see corridors, steps and toilets as someone with dementia might.



**Take action  
on dementia**

## Who's Who?



In this edition, we're catching up with Professor Martin Orrell.

### **What is your job title, and what does your role entail?**

I am Director of the Institute of Mental Health and I am also Head of the Division of Psychiatry and Applied Psychology for the University of Nottingham. As the Director, I ensure that the Institute runs smoothly and pursues pioneering education and research. The Division strives to provide excellent research and teaching programs related to mental health, as well as contributing to the BMedSci medical student training at the Medical School.

### **How long have you been interested in dementia?**

I began my PhD in 1988 having developed an interest in social psychiatry. I wanted to see how stressful experiences and social support can relate to dementia. I found that stressful life events was linked to low mood in dementia, and life events that disrupted daily living was linked to deterioration and hospital admissions.

### **What is your greatest achievement?**

I am a dad of two lovely daughters. And also I lead the development and evaluation of Cognitive Stimulation Therapy. This is a useful technique for people with dementia that is used in 25 countries across the world, which has therapeutic benefits but is also very popular and enjoyable. CST helps with cognition and quality of life, so this feels like a great achievement.

### **What is your favourite food?**

I really like nice chocolate!

### **What is your favourite hobby?**

I really enjoy singing and have done a lot of this over the years. I also participate in amateur musical theatre groups which is great fun.

### **How would you like to see the role of PPI grow over the coming years?**

I have been working to support PPI development at the Institute. PPI plays a crucial role in helping us understand the acceptability and practicalities of our research. We recently published a paper on involving people with dementia in research and training, so I'd be very keen to continue supporting the role of people with dementia in PPI. We've made great progress so far, and we'd like to engage with people along the whole research journey.

## Diary Dates

### **5th April 2017: Room A08, IMH**

Harleen has introduced her topic in a previous meeting, but she would like to spend more time letting people have a look at the individual Cognitive Stimulation Therapy (iCST) manual and discuss what they like or dislike. Then she would also like to hear more views on how this could be converted into a computer programme (app). Harleen will demonstrate these on the big screen.

**Neil Chadborn.** Learning about the research process and how Patient and Public Involvement can influence research studies

### **3rd May 2017: Room A08, IMH**

Tracy Marr. Neuroimaging tools to better understand how the brain is changing in the early stages of dementia.

2<sup>nd</sup> slot – to be decided – please send in suggestions if there are topics you would like covering.

### **7th June 2017: Room A06, IMH**

Tony Kelly and Justine Schneider. BOUGH study of home care (domiciliary) and commissioning.

2<sup>nd</sup> slot – to be decided – please send in suggestions if there are topics you would like covering.

### **5th July 2017: Room B27, IMH**

Both slots to be decided – please send in suggestions if there are topics you would like covering.

## Get in Touch!

Whether you're an academic, working in healthcare, or are a member of the public, if you're interested in hearing more about PPI at the Centre for Dementia please get in touch with Jill Charlton. We can then make sure that you receive this newsletter and updates about ongoing research at the Centre.

**Email:** [jill.charlton@nottingham.ac.uk](mailto:jill.charlton@nottingham.ac.uk)

**Telephone:** 0115 8230417



The **IDEA** website offers lots of information about dementia and can be found by following this link on the internet: [www.idea.nottingham.ac.uk](http://www.idea.nottingham.ac.uk). It includes free online training courses and the **Dementia Day-To-Day** blog, which is always on the lookout for more contributions from patients, members of the public, health care workers, and academics.

**Public Face** is an online bulletin about PPI. You can submit items for inclusion to [katie.swinburn@nottingham.ac.uk](mailto:katie.swinburn@nottingham.ac.uk), and find previous issues on the internet at [www.emahsn.org.uk/public-involvement/public-face-newsletter](http://www.emahsn.org.uk/public-involvement/public-face-newsletter).