



August 2012

Newsletter No. 53

# Brain Waves



## A monthly newsletter from Innovations in Dementia CIC

The aim of these newsletters is to keep people with dementia and their allies informed about the work of Innovations in Dementia Community Interest Company.

### Dementia Without Walls

Find out about the next phase of the Joseph Rowntree Foundation's work around dementia on page 2.



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## Dementia Without Walls

The Joseph Rowntree Foundation (JRF) has got a new programme of work called Dementia Without Walls. The aim of this programme is to investigate ways in which the UK can become a good place for people with dementia to live, and to live well.

JRF want to make sure that people with dementia are

- more understood,
- more heard,
- more included,
- more connected and
- more supported.



You can find out more from the JRF website

Go to: <http://www.jrf.org.uk/work/workarea/dementia-without-walls>

As part of this work, JRF have decided to provide additional and continuing support to **DEEP** - the Dementia Engagement and Empowerment Project - over the next three years. The first phase of DEEP (in 2011-12), investigated the different groups of people with dementia across the UK. It brought people with dementia together to start a discussion about building a 'collective voice' of people with dementia as well as promoting the work of existing groups at both local and national levels.

The next phase of DEEP will provide support to existing and new groups of people with dementia. The project will be led by Innovations in Dementia in partnership with the Mental Health Foundation and supported by the Alzheimer's Society. The project will be developed in collaboration with people with dementia, and will include opportunities for sharing resources and ideas, building the capacity of groups and setting up networking opportunities between groups. In this way, we hope to support groups of people with dementia to have a stronger collective voice to influence the world around them.

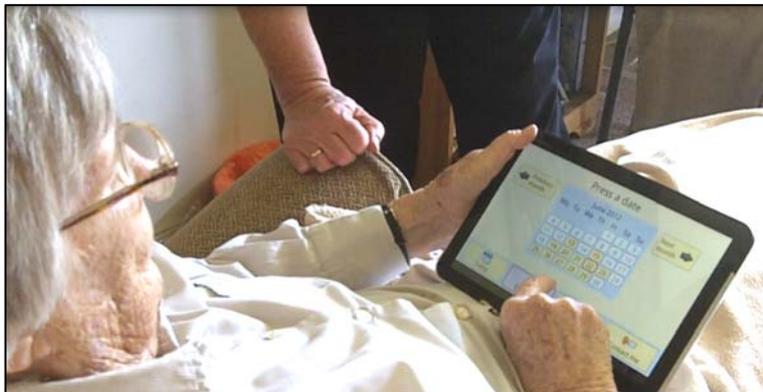
This work will not formally start until 24<sup>th</sup> October. This is when the findings from the first phase of DEEP will be launched.

In the meantime, if you want to find out more please contact Rachael Litherland, email [rachael@myid.org.uk](mailto:rachael@myid.org.uk) or telephone 01392 420076.

## User testing of technology for people with dementia

We believe that people with dementia should be involved in the design and testing of products and services that are designed for them.

At the end of September, Nada will be attending the official conference of the Ambient Assisted Living programme that supported the Mylife project that we have talked about in previous newsletters. This big European conference will talk about technical innovations to help older people age well.



Nada will be giving a talk about the ethics of involving people with dementia in field trials of the Mylife system.

Listening to the views of people with memory problems were an integral and major part of the project.

Projects which do not involve potential users risk delivering technology which people cannot understand, with the result that they do not use it.

Working with people with dementia demands an inclusive and ethical approach to field trials.

We think there is often reluctance on the part of researchers to engage directly with people with dementia. This might be caused partly by the stigma associated with dementia. But researchers might also be uncertain about how to go about involving people with dementia, and have concerns about the amount of time and costs involved in setting up a consultation process.

People with memory problems may find it hard to express their views - due to other symptoms of early dementia such as language difficulties, but also because they are often not used to being consulted.

We have been involved in many product testing projects including testing a shower design. We use a variety of methods to enable people with dementia to express their views in ways that suit them.

We are still learning about ways of listening to people with dementia - but we know good design must include everyone.

## Your opportunity to influence the NICE draft quality standard on dementia

The National Institute for Health and Clinical Excellence (NICE) is field testing the pilot social care quality standard on supporting people to live well with dementia.

The standard is made up of 13 concise and measurable statements that outline the high-quality care that is required.

People with dementia and their carers are encouraged to contribute their views in this on-line questionnaire, designed by Dementia UK. It would be great if you could circulate the link to your own networks of people with dementia and carers. This is a golden opportunity to influence future standards on dementia.

The survey is here:

<https://www.surveymonkey.com/s/Questionnaireforpeoplewithdementiaandfamilycarers>

It should take about 15 - 20 minutes to complete.

**Please note:**

**only family carers and people with dementia are invited to take part.**

The deadline is 16<sup>th</sup> September 2012 at midnight.



**Innovations  
in Dementia**

Innovations in Dementia is run by three directors – Rachael, Steve and Nada. We are a Community Interest Company. This means that any profit we make is put back into the organisation.

We do not offer services for people with dementia.

Instead we work with other organisations to make sure that people with dementia can continue to take part in their communities and have active lives.

Please share your ideas, experiences and positive stories with us.

### **Contact us**

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