

Daisy Chain..... Connecting YOU!

Volunteer



Patient & Public Involvement PPI

The VOICE...

Why is the voice so important?

*'Our senses combined make us whole,
however if we lose one the other must work a little harder!'*

Pauline M Mountain MBE

17/01/17

• This Editions Editor



Pauline Mountain MBE

I feel we embark on an unknown journey into involvement through a need and/or a desire to engage change, being driven by an innate passion to protect ourselves or our loved ones....

So does this begin a cycle?

'Training'.....is this about guidance or coaching to enable a depth of understanding of the system to effect such a change at the beginning of a cycle, which in the case of research becomes a 'dual' educator, each hearing the others VOICE of reason and rationale.

I believe this is where we could embrace and harness such passion without stifling and professionalising each voice.

When true partnerships are formed..... they listen, converse and

capture to combine all aspects and elements to create a balance where a suitably trusted outcome for all is sort, for further development, within the PPI cycle.....

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PMM

Why does this research matter?



What is the Cognitive Daisy research project?

The cognitive daisy is a tool kit that has been created to help staff working in care homes to support people living with dementia. In this research, staff in care homes will be given training about the changes in thinking and learning that people can experience when they have dementia. Staff will then be taught to use a special questionnaire that helps them to make sense of their residents' unique pattern of strengths and difficulties and how these might affect that persons day to day life. This pattern of a resident's strength and difficulties is displayed as a daisy with petals that show what someone might need help with. This is a quick way to help staff understanding what support a person might need.

This study will be working with 10 care homes in Lincolnshire Half of them will use the daisy tool kit and half will not have access to it. The researchers will be looking at what changes using the daisy tool kit can bring about and asking staff, relatives and care home residents what it was like to use it. Trying it like this in a small number of care homes will help the researchers learn more about whether the tool kit could be used in more care homes.

Potential benefits for Staff, Patients & their family carers!

Most people living in care homes experiences changes in their memory and thinking (known as changes in cognition). Understanding how these problems affects each person and how care staff can best support them is an important part of person centred care. However knowledge and understanding about cognitive changes varies amongst care home staff. We hope that this tool kit will help staff to understand people's needs and provide support in a way that suits each persons unique needs.

Who has funded it?

The research has been funded by the National Institute for Health Research (NIHR). The researchers involved in the projected work in different Universities including Lincoln, Hull and Leeds Beckett.

Plain English Summary

This was one of the first assignment for Emma and I when we were recruited to ensure our Public & Funders were clear in this statement, that it explained what the study was about, understandable to all, research language can be confusing at times with different terminology and jargon.

Up to 80% of older people living in care homes have problems with brain function, such as memory problems of reasoning or understanding, caused by conditions like dementia. Appreciating how these problems affect each person and how care staff can best support them forms an important part of good person-centered care. Knowledge about cognitive problems varies among care home staff, which may not always be taken into account when planning and delivering care.

The Cognitive Daisy (GOG-D) is a package we developed to help staff to assess and plan care around each individual cognition. It includes

- 1) staff training on cognition and using the COG-D;
- 2) a cognition assessment (looking at senses, understanding, communication, remembering and attention);
- 3) a 'Cognitive Daisy' that visually summarises cognitive strengths and difficulties using coloured petals, personalised in each resident's care plan (see www.cognitivedaisy.co.uk);
- 4) a 'Petal-By-Petal' Guide of possible approaches to supporting different cognitive difficulties for use in care planning.

In our COG-D development and evaluation work care home staff said they found it useful for delivery of person-centered care and care home residents were happy to complete the assessments.

We also need to understand how COG-D benefits the individual resident (e.g. for their quality of life, behaviour), we do this in two ways;

- A large study - known as a randomised controlled trial.
- a feasibility randomised controlled trial

Before we can do this in a large study, we need to check that our approach to the research will work and gather information to help us design the trial.

We also need more data on and how the COG-D package is implemented in a care home setting, including what helps and hinders its use. To do this we will carry out what is called a feasibility randomised controlled trial. We will recruit 100 residents in up to 10 care homes. Half of the homes will be assigned at random to continue with usual care and half to use the COG-D package, which will be led by a researcher and supported by staff. We will collect data on residents and staff before we randomise homes and 6- and 9-months after randomisation to look for any change. We will record COG-D use and interview staff, relatives and residents in the COG-D care homes about their experiences and any challenges of using it.

We will apply for more funding to carry out a larger trial if the COG-D lead to show change, based on what we find. Findings will be reported in research journals and at conferences. Care home staff have been involved in the design and development of the COG-D and a Patient and Public Involvement Group (PPI) made of up people affected by dementia and care home staff will provide input throughout the trial.

Welcome to our PPI group

Our PPI members are Emma, Pauline, Lyndsey and Jean

We are a group of people with 'lived experience & interest' in dementia, as family carers, care home staff and managers who all have experience of residential care for people living with dementia.

As members, we will work with the researchers to help shape the research from a '*lived experience*' perspective in true and honest representation of the millions living with the challenges that everyday life presents, while seeing your loved one change almost daily, to someone you can no longer communicate with. This is our chance to represent and influence many of you in what we do and how we do it.

The group enables the voices of people with many different perspectives and experiences to be heard and involved in making decisions about this research.

We want our research to be relevant and focus on what really matters to many people. With your help, our research can provide evidence to help improve services, treatment and care of the future.

We would like to provide opportunities throughout the study to hear your 'voice' too, so please keep in contact if you would like to 'feed-in' to our collective voice.

Meetings for Cog Daisy PPI Group

We as a PPI group are in contact on a regular basis via email, we have representation at the Steering Group and hold virtual PPI meetings throughout the duration of the study, the beginning & middle being the busier part , by March 2024 we'll be consolidating & reviewing

We would also love to hear from your own experience,

Carer & Family feedback.....to include any hints & tips you feel may be helpful to others that we could post on our website and maybe even in future newsletters, with your permission.

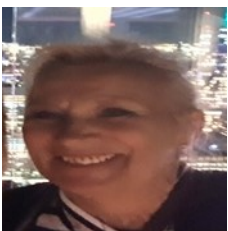
If you have any questions please get in touch. Or if you would like talk more about what you have read or discuss things further without making any commitment to become involved then please contact:



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If there are particular items of information or topics for discussion you wish to have included in future newsletters contact either Emma or Pauline as above.

Website :- Twitter :- Instagram:-