



Young Dementia
Network

Welcome to Research Priori-teas

Why should I
get involved?



www.youngdementiauk.org/webinars

Introduction to panellists

Professor Jacqueline Parkes

Lead of the Dementia Research and Innovation Centre
University of Northampton

Dr Mary O'Malley

Lecturer in Ageing and Dementia
University of West London

Dr Wendy Mitchell

Living with young onset dementia, best-selling author and blogger

Frank Arrojo

Family member and Alzheimer's Society Research Network volunteer

Objectives

- **To identify what people with young onset dementia should be the top research priority**
- **To inform people with dementia and family members how they can get involved in research if they want to**

Interactive Presentation 1 - Jackie

- **What is Research?**
- **Who should get involved in research?**
- **Why should I get involved in research?**

Interactive Presentation 1 - Jackie

What is Research?



Interactive Presentation 1 - Jackie

What is Research?

Research is a careful and detailed study into a specific problem, concern, or issue using scientific and systematic processes

Interactive Presentation 1 - Jackie

Who should get involved in research?



Suggestions



[This Photo](#) by Unknown Author is licensed under [CC BY-NC-ND](#)

Interactive Presentation 1 - Jackie

Why should I get involved in research?

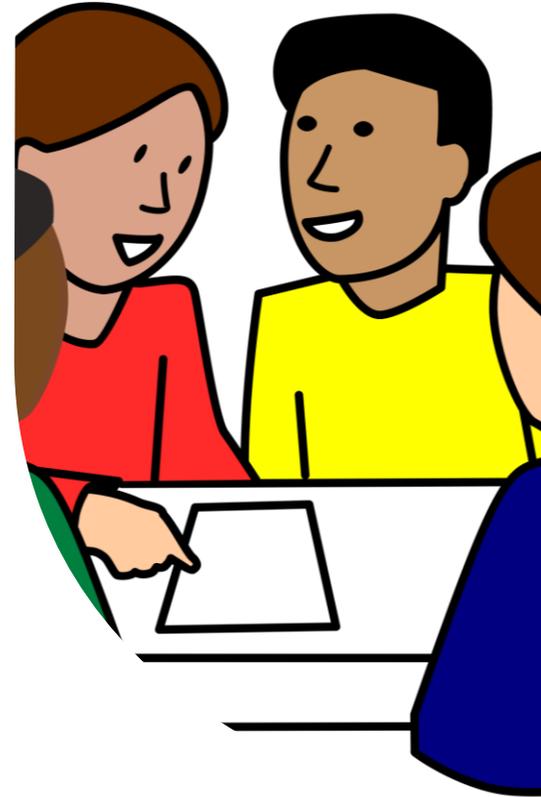


[This Photo](#) by Unknown Author is licensed under [CC BY](#)

Interactive Presentation 1 - Jackie

Why should I get involved in research?

1. **Make the research process relevant, transparent and accessible**
2. **Morally and ethically right to empowering and therapeutic**
3. **Provides a 'real world' perspective**
4. **Helps in recruitment, interviewing and dissemination**
5. **Improved communication with providers**
6. **Health care funding organisations require active engagement**



Interactive Presentation 1 - Jackie

The five **We** statements

People with dementia want a society where they are able to say -

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part



Q & A Session 1 - Mary

What research should we do that would be of interest to you?

What research is most important for younger people with dementia?



Wendy Mitchell

Author of Sunday Times best seller
'Somebody I Used to Know'
Published in the UK by Bloomsbury

Now proud and humbled to be DrDr
from Hull and Bradford Universities

Please feel free to read my blog
www.whichmeamitoday.wordpress.com



or follow me on Twitter
[@WendyPMitchell](https://twitter.com/WendyPMitchell)

Presentation 2 - Wendy

- **What does research mean to me?**
- **How have I been involved in research projects?**
- **Why would I encourage other people with dementia to get involved in research?**



Frank Arrojo

Former family carer

**Alzheimer's Society
Research Network Volunteer**

**Member of tide
(together in dementia everyday)**

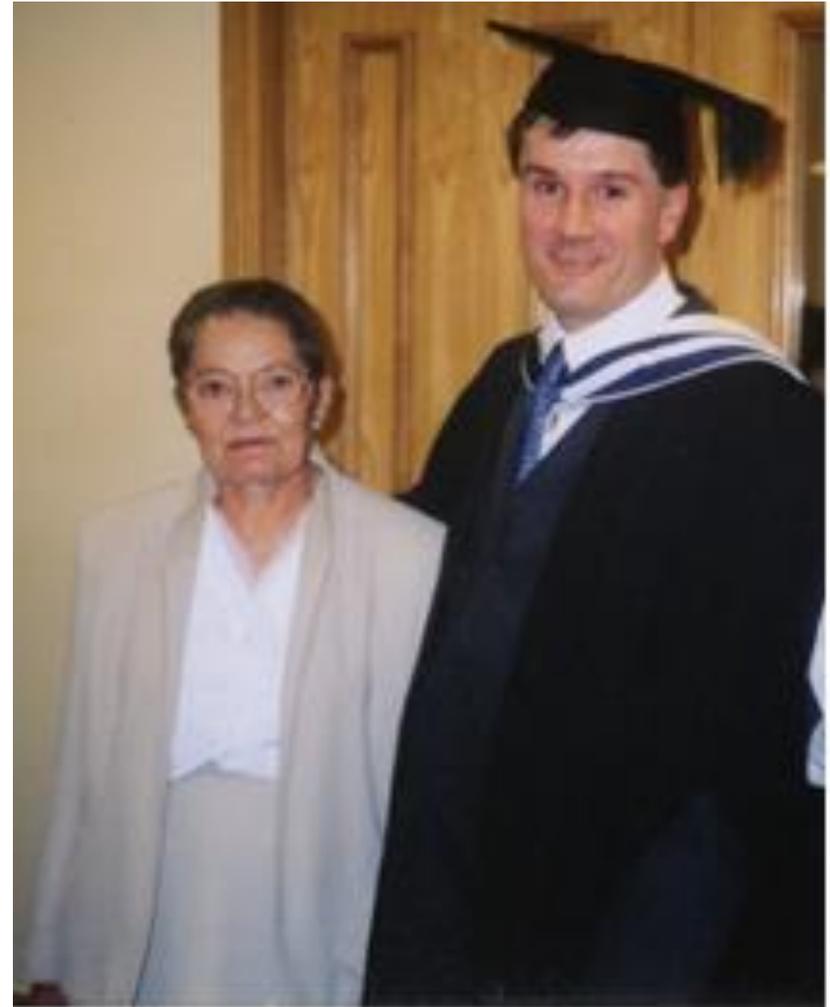
**Sudbury & Wembley Dementia Carers
Support Groups**

Presentation 3 - Frank

- **What does research mean to me?**
- **How have I been involved in research projects?**
- **Why would I encourage other carers to get involved in research?**

Presentation 3 – Frank

Why did I get involved?



Presentation 3 – Frank

Why am I still involved?



What does research mean to me?

It is like stepping onto a large bus going on a very long journey, with the final destination being



Having a positive impact on everyone's education and knowledge (incl. senior management and frontline staff) to change / improve / transform

- Attitudes and behaviours
- Customs and practices
- Procedures and systems
- Cultures of the team and the environment

How I have been involved in research projects

- Participated in research projects
- Assessed, reviewed and commented on applications for dementia research projects
- Member of Research Grant Panels, helping to make decisions on which research projects should be prioritised for funding
- Monitored research projects, incl. helping researchers by providing advice on the design and drafting of information sheets, writing case studies, and giving an insight into understanding potential participants and the need for sensitive and effective communication
- Helped with the development of potential research projects, including supporting potential researchers of the future such as junior and senior fellowship researchers
- Involved in the implementation and dissemination of research outputs.

Why would I encourage other carers to get involved in research?

- Your story, experiences and skills are just as relevant as everybody else's. The more personal stories (including the good stories just as much as the indifferent ones) researchers listen to, the better information and opportunity they have in which to produce evidence-based outputs.
- Hope for the future, and for society at large.
- May help you personally to find something you feel passionate about, including making use of the skills you have developed throughout your life.

Here is an
example



What to expect from us during a stay in hospital

We're signed up to the

DEMENTIA-FRIENDLY HOSPITAL CHARTER



As a signatory of the National Dementia Action Alliance's "Dementia-Friendly Hospital Charter" this hospital has made a commitment to people with dementia, their families and friends, in respect of what to expect during a stay in hospital. For people with dementia, their families and friends this hospital will:

- Ensure our staff and volunteers understand and are skilled in dementia care
- Actively involve patients, families and friends as essential partners in providing care and planning discharge from hospital
- Provide families and friends with flexible visiting times, including overnight stays where possible
- Respect patients' rights to make decisions themselves or decisions made on their behalf by families and friends (where patients lack "capacity" to do so)
- Provide assistance to patients with eating and drinking
- Use information that patients, families and friends have provided to us – making it visible and available to our staff – to help us know what is important for our patients' care
- Understand patients may have difficulty in expressing their needs, and assess and investigate any evidence of distress
- Provide access to dementia specialists to whom patients, families and friends can talk and provide feedback
- Minimise the number of times patients are moved during their stay in hospital
- Seek to ensure that the surroundings of where patients stay are as friendly, comforting and accessible as possible
- Support discussions about patients' personal preferences on future care, resuscitation needs and end-of-life care, where appropriate

If you require further clarification on any of these statements please see one of our members of staff. Download the Dementia Friendly Hospital Charter at:
www.nationaldementiaaction.org.uk/campaigns/dementia-friendly-hospital-charter/

Q & A Session 2 - Mary

What would be the top three priority topics?

- 1.
- 2.
- 3.

How can I get involved in research?

Closing Summary - Mary

The poster features a teal background with white text. At the top left is the University of West London logo and name. The main title is in large, bold white font. To the right, two overlapping circles contain the event type and date. Below the title is a short description and the Eventbrite URL.

UNIVERSITY OF WEST LONDON
The Career University

Engaging People Living with Young Onset Dementia in Research

Online Event

Thursday
28 January
2021
1pm - 4pm

An online information event about research engagement opportunities for people living with Young Onset Dementia

youngonsetdementia.eventbrite.co.uk

Why not join us on Thursday 28 January where we will share examples of how people affected by young onset dementia have engaged in research





**Young Dementia
Network**

Thank you for joining us



www.youngdementiauk.org/webinars