

# SENSE



Promoting health  
for eyes, ears  
and mind.

## Challenges and opportunities for patient involvement in dementia studies

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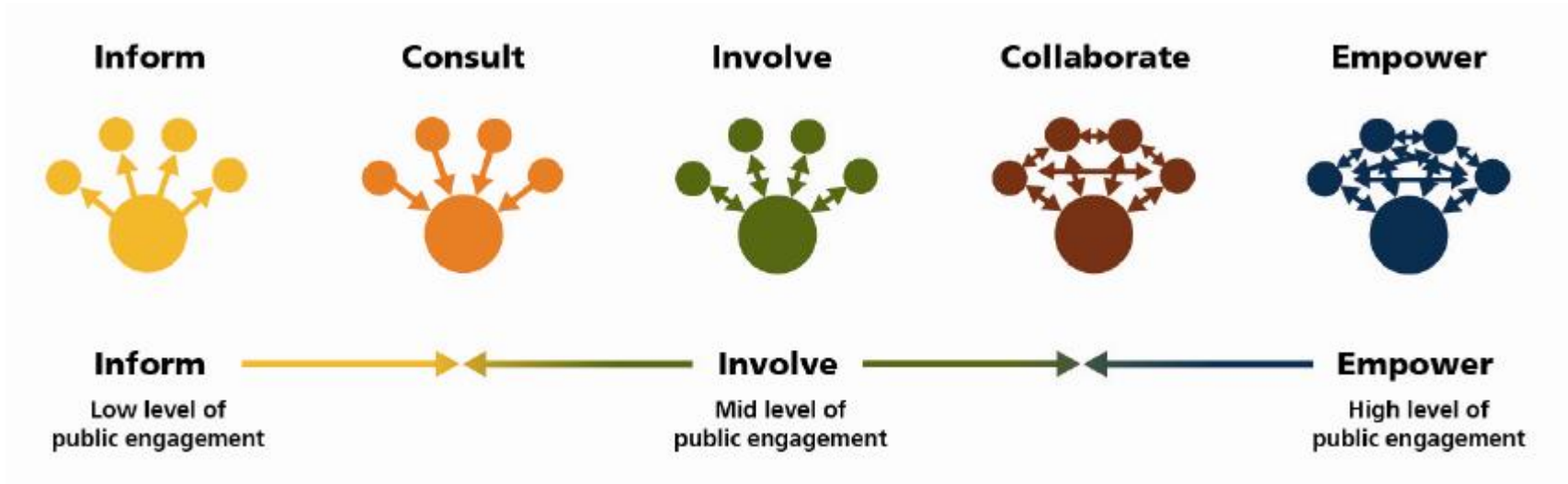


**Public Programmes**  
**People | Research | Dialogue**

at Central Manchester University Hospitals  
NHS Foundation Trust



# What is Patient and Public Involvement (PPI)?



Source: <http://www.bangthetable.com/>

## Patient and Public Voice:

“Public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

<http://www.invo.org.uk/>

# Why involve people with Dementia in research?

- Numbers of people with dementia
- Experience of living with dementia and sensory impairments
- Reality of living with dementia
- Valuing the unique insights of a person with dementia



“Promote mental well-being in older Europeans through engagement of the public and the full and **meaningful inclusion** of patients, participants and caregivers in every aspect of our research efforts”

“By fully involving people with dementia and sensory impairment and their caregivers in the different work packages within the SENSE-Cog programme and giving the concepts of empowerment, self-management, and participation full consideration”



## 3 Research User Groups (RUGs) – ‘lived experiences’

- Manchester
- Nice
- Nicosia

## Public advisors

## Expert reference group



## Trans EU Patient and Public Voice Steering Group




## Focus group: Flyer for Manchester RUG (MICRA)

- Recruit people with cognitive and sensory impairments,
- Wording, layout, presentation
- Message is clear.

## Action for Blind

- How information should be presented for older adult with vision problems.


**SENSE**  
Cog  Promoting health  
for eyes, ears  
and mind.

### Would you like to help shape research aiming to find the best ways of identifying and supporting older people with hearing, vision and memory problems?

**Are you:**

- Living with memory problems and/or hearing and/or vision problems?
- Caring for someone who is living with dementia and/or hearing and/or vision problems?

If yes, we are keen to hear from you to help us shape the SENSE-Cog research project.



**SENSE-Cog** is a five year European project, led by the University of Manchester. The project will investigate the impact of memory problems and hearing and vision problems. The SENSE-Cog project will also develop new tools that could improve quality of life for those affected by memory problems and hearing or vision problems.

**What does this mean for you?**


- Be part of a research user group in Manchester to help us shape the SENSE-Cog project.
- Act as a critical friend on our research. Advise and give feedback about our research via post, email or in person.
- Attend quarterly meetings (meetings will last 2 hours, with refreshments provided).
- Attend necessary training to support you in this role.
- You will be paid for your time and travel expenses.


**Interested?**


Please contact the Patient and Public Voice co-ordinator Kerin Bayliss on 0161 276 3368 or email [Kerin.Bayliss@cmft.nhs.uk](mailto:Kerin.Bayliss@cmft.nhs.uk) or [Jahanara.Miah@manchester.ac.uk](mailto:Jahanara.Miah@manchester.ac.uk) with your name and contact details by **Friday 17th June 2016**

Want to find out more? Visit our website [www.sense-cog.eu](http://www.sense-cog.eu)

(SENSE-Cog has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 668648.)

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1824  
The University of Manchester

 Manchester  
Academic Health  
Science Centre

# Manchester Research user group (RUG)

RUG member	Status	Involvement
1	Carer & hearing problems	Full
2	Memory problems & Parkinson's	Full
3	Carer	Full
4	Dementia & hearing	Full
5	Early onset dementia, hearing & sight problems.	Full
6	Carer	Full
7	Some visual & hearing impairments	Full
8	Therapist working with older people with memory loss.	Telephone/ letter
9	Alzheimer's with hearing difficulties.	Not involved
10	Carer	Full
11	Memory problems	Full

- **Local Level - RUG**
- **Public advisors**
  
- **Strategic Level**
  - **Trans EU PPV Steering group**
  - **Ethical Advisory Board**





- Communication – telephone & letter – Plain English
- Taxi pick up and drop off points.
- ‘Buddying’ up of dyads and individual RUG members with a member of the SENSE-Cog staff.
- 30 minutes ‘Meet and Greet’ session before the involvement task.
- 1 hour 30mins – Involvement task
- 30 minutes ‘Debrief’
- **Feedback – Meaningful**

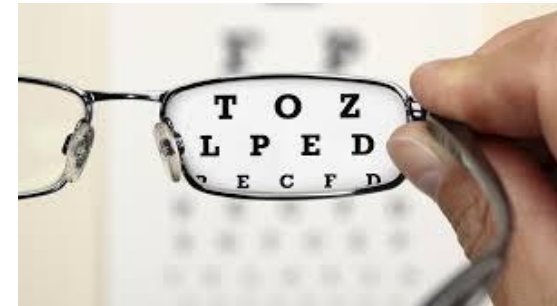


## 3 components:

- Hearing
- Vision
- Cognition
- Feedback Provision

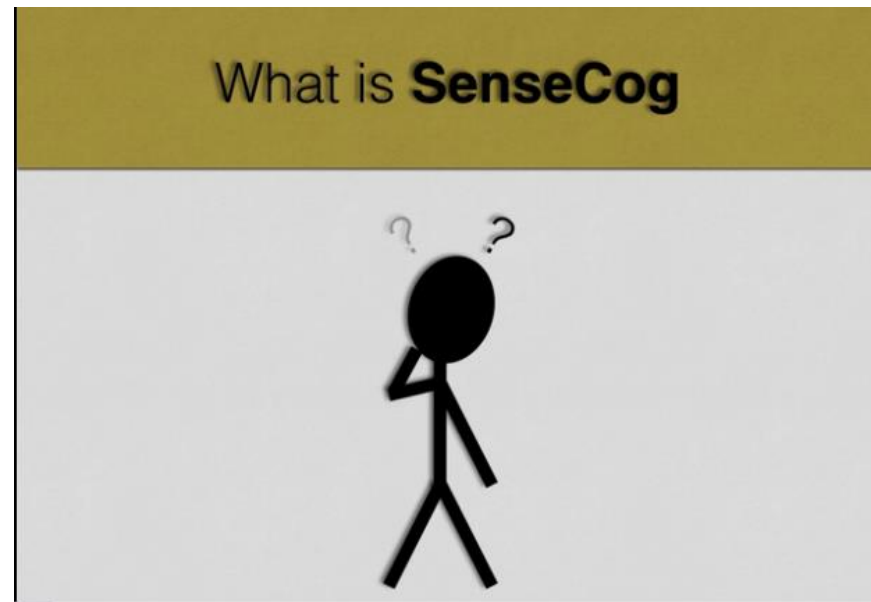
## Individual sound proof rooms

- Instructions - Length- Clarity
- Interface
- Usability
- Design



## Patient Information Sheet

<https://www.dropbox.com/s/fmt4swiewpd3vav/SenseCog%20v2.m4v?dl=0>



## Opportunities

- Researchers to become aware of the people behind the data
- Expertise by experience of the person
- Enhanced knowledge about dementia and sensory impairments
- Value to older people with dementia

## Challenges

- Managing behaviour of the condition
- Managing different impairments & needs





## **The Sea is an Edge and Ending**

produced and directed by Lavinia Greenlaw

<http://www.fvu.co.uk/projects/the-sea-is-an-edge-and-an-ending-1>

**For more information:**

<http://www.sense-cog.eu/>

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