

# European perspectives and experience in involving persons with dementia and dementia family caregivers as members of the research team

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#DementiaCareSummit

## Why should we involve people with dementia and caregivers?

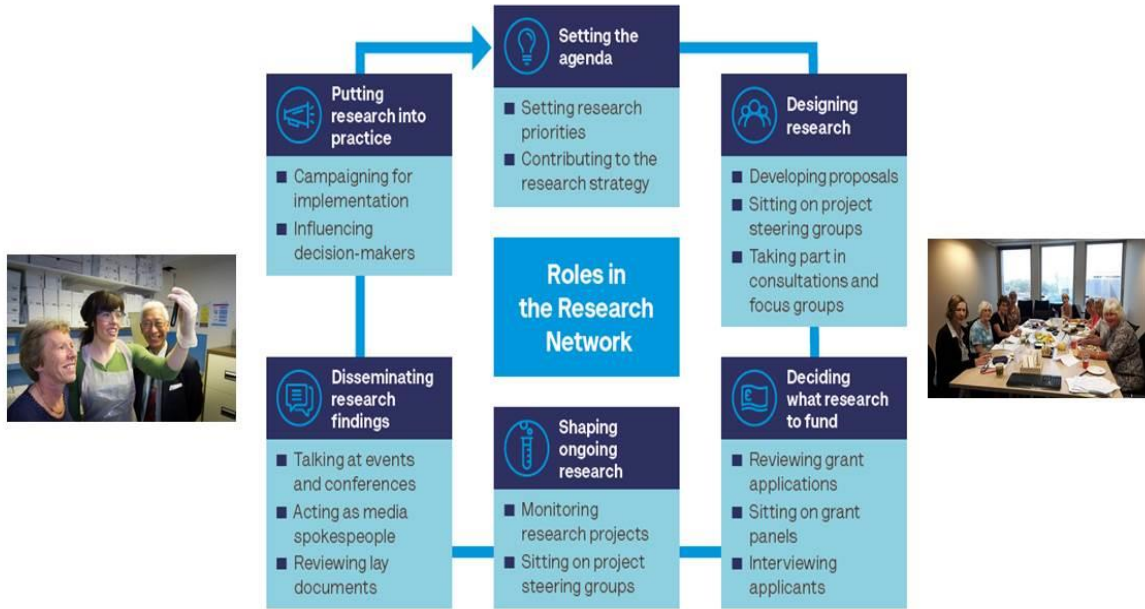
1. Because we should
2. Because it improves research



Gove et al, 2016, Aging and mental Health

Alzheimer's Society

# European perspectives

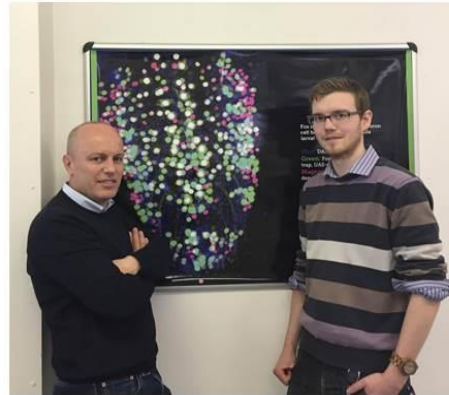


# Impact



**People with dementia and caregivers**  
*'Its my Sudoku'*

- Learn about dementia to cope better with their own experience
- contribute to something worthwhile
- Use existing skills
- Peer support and friendship



**Researchers**  
*'It takes me back to the point that we're engaging with society'*

- Motivation on the purpose of their research
- Focusing on impact
- Developing lay communication skills
- Learning how and why to involve people affected by dementia

# Impact



**Research**  
*'They make things accessible'*

- Changing methods to be more appropriate
- Solving ethical and recruitment challenges
- Impact on data collected
- More likely to produce useful outputs

**Society**  
*'People are surprised by what I can contribute'*

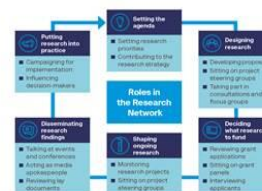
- Addressing stigma
- Elevating the voice of people with dementia
- Powerful dementia advocates
- Accountability and transparency of funding

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## Recommendation 1

### Strengthen PPI in at all stages of the research process

- National portal for the public to submit research questions and ideas – used for the development of commissioned calls.
- Funding made available for the establishment and maintenance of local, state and national PPI groups and networks, including self-run/ organised groups.
- Develop practices guide and materials such as guidance for ethics committees on including people affected by dementia as members of a study team.
- Research grant funding for the development of methodologically robust involvement practices
- Develop guidelines and processes for supporting involvement and participation of people affected by dementia in commercial clinical trials and research.





## Recommendation 2

### Inclusiveness is a core theme, not an afterthought

- Financially reimburse people for participating in research that does not involve contracts or impact on tax and benefits
- Embed inclusive ways of working i.e. tailored approaches to communication, support and training
- Develop methods for increasing involvement of people in later stages or with profound communication problems.
- Consider the perspective of those that professionally care; health care assistants, homecare workers etc, whose perspective is rarely heard.



## Recommendations 3

### Introduce 'nudges' that require and reward good practice

- Reporting on PPI in applications and project reports as routine
- Researchers include PPI involvement as part of journal articles or a separate papers
- Career incentives for including PPI – prizes, recognition, funding
- Embedded in graduate training – evolution of 'public communication' courses



GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

S Staniszewska,<sup>1</sup> J Brett,<sup>2</sup> I Simeria,<sup>3</sup> K Seers,<sup>1</sup> C Mockford,<sup>4</sup> S Goodlad,<sup>5</sup> D G Altman,<sup>6</sup> D Moher,<sup>7</sup> R Barber,<sup>8</sup> S Denegri,<sup>9</sup> A Entwistle,<sup>4</sup> P Littlejohns,<sup>10</sup> C Morris,<sup>11</sup> R Suleman,<sup>4</sup> V Thomas,<sup>12</sup> C Tysall<sup>4</sup>

## Recommendations 4

### Share and develop international best practice

- Develop common terminology (international consensus?)
  - Language is important to people affected by dementia
- International network for connecting those interested in PPI – working groups/ ISTAART? (National shared learning group on involvement in the UK)
- Regular sessions at international conferences



Thank you!

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[www.alzheimers.org.uk/researchnetwork](http://www.alzheimers.org.uk/researchnetwork)

