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

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Why should we involve people with dementia and caregivers?

1. Because we should

2. Because it improves research

Alzheimer’s Society
European perspectives

- **Putting research into practice**
  - Campaigning for implementation
  - Influencing decision-makers

- **Setting the agenda**
  - Setting research priorities
  - Contributing to the research strategy

- **Roles in the Research Network**

- **Disseminating research findings**
  - Talking at events and conferences
  - Acting as media spokesperson
  - Reviewing lay documents

- **Shaping ongoing research**
  - Monitoring research projects
  - Sitting on project steering groups

- **Designing research**
  - Developing proposals
  - Sitting on project steering groups
  - Taking part in consultations and focus groups

- **Deciding what research to fund**
  - Reviewing grant applications
  - Sitting on grant panels
  - Interviewing applicants

Impact

- **People with dementia and caregivers**
  - "It's 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

**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,1 J Brett,1 I Simera,1 K Seers,1 C Mockford,1 S Goodlad,1 D G Atkin,2 D Moher,2
R Barber,1 S Dimeglio,1 A Entwistle,1 P Littlejohns,11 C Morris,11 R Suleman,4 V Thomas,11 C Eyass11

Patients Included
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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