



Patient and Public Involvement in the IMI research portfolio

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Topics to be covered



1. Importance of dementia research for people with dementia
2. What is Patient and Public Involvement (PPI)?
3. AE's work in PPI
4. Examples of PPI in IMI projects (in which AE is involved)
5. Conclusions

1. Importance of dementia research for people with dementia

- No cure yet so research is particularly important
- Timely diagnosis means more opportunity to be involved
- “Nothing about us without us” - People with dementia:
 - have a right to have a say in what and how publicly funded dementia research is undertaken (INVOLVE 2012),
 - can provide a unique perspective “from the inside” (Simpson and House 2002),
 - want to share experiential knowledge,
 - do not want tokenistic involvement.

2. What is Patient and Public Involvement (PPI)?

- actively and meaningfully contributing towards the research process rather than being a research participant,
- creating a true partnership between people with dementia, researchers, policy makers and other members of society,
- moving away from hierarchical approaches to the acquisition of knowledge (towards an exchange of different kinds of expertise that are equally valued).

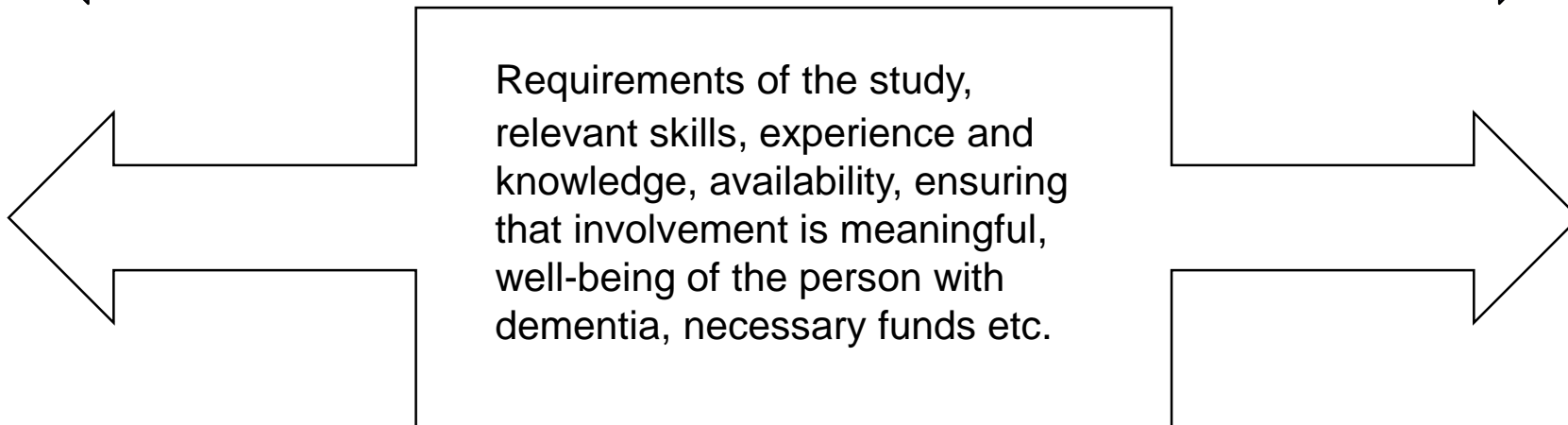
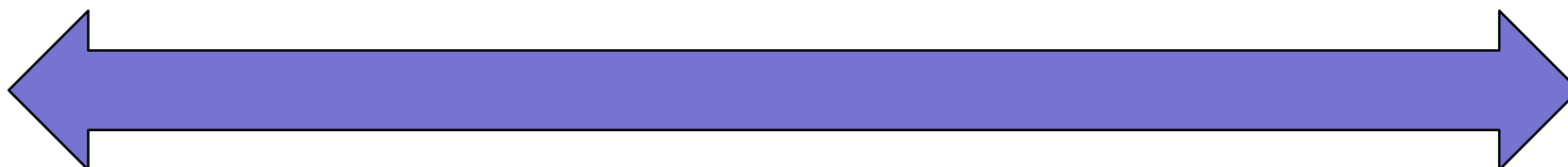
Different ways of involvement



Involvement in particular task

Full involvement as a member of the research team

Involvement at several or every stage of the research process





There are still many challenges to address ...

who to involve? how? when? value?

These may be even more challenging in dementia research

- Existing stereotypes and beliefs that it is not possible/ valuable to involve people with dementia
- Researchers may not feel equipped to involve people with dementia in this way
- In some countries, diagnosis still not timely / people are not told their diagnosis
- Involving people at more advance stages is challenging
- Field is moving to earlier stages ... how should people with Alzheimer's disease prior to the dementia stage be involved?

3. Involvement of people with dementia in Alzheimer Europe's work



From 2000 (reliance on a few individual people) to today (EWGPWD set up in 2012, currently 13 members)

Peter Ashley



James McKillop



EWGPWD, AE Conference 2018

AE Position paper



Aging & Mental Health

Routledge
Taylor & Francis Group

ISSN: 1360-7863 (Print) 1364-6915 (Online) journal homepage: <http://www.tandfonline.com/ol/camh20>

Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement)

Dianne Gove , Ana Diaz-Ponce , Jean Georges , Esme Moniz-Cook, Gail Mountain, Rabih Chattat , Laila Øksnebjerg & The European Working Group of People with Dementia

- Determining, planning and involving people with dementia in the research process. Establishing and respecting roles and responsibilities
- Promoting and protecting their rights and well-being Providing any necessary training and support
- Managing information and input resulting from PPI
- Recognising and acknowledging their contribution
- Promoting an inclusive and collaborative approach to research

4. Examples of PPI in IMI projects where AE is involved



Also, on patient engagement ...





ROADMAP

<https://roadmap-alzheimer.org/>

PPI WORK IN ROADMAP



Involvement in WP2 (Outcome definition) and EXAG

- Consultation in Luxembourg (over 2 days)
- Involved people with dementia and carers (separate groups)
- Feedback on online survey to be used with people with dementia
- Discussions about understanding of outcome measures, prioritisation, challenges, etc.
- Similar discussions with other stakeholders
- The group had the chance to provide comments to the report.
- Final meeting to provide information on how input had been used and its impact.



“Working in an environment like this gives confidence back, gives value and a sense of purpose. The main thing is that the research you’re doing in ROADMAP actually gives us hope as well. (...) While the professionals work very hard to gain their expertise, we live with the illness. In this context there are things that the professionals maybe can’t find out on their own. So it’s great to work together (...).”

Chris Roberts, vice chair of the EWGPWD



The screenshot shows the ROADMAP website's news section. At the top, the ROADMAP logo is displayed with the tagline "Real world Outcomes across the AD spectrum for better care". Below the logo is a navigation menu with tabs for Project, Partners, Downloads, News (selected), Events, Background, and Links. Under the News tab, there is a sub-tab for Contact. The main content area features a news article titled "The value of being involved in research" dated 26 Sep 2017. The article text reads: "Today we talk with Chris Roberts and his wife Jayne about their involvement in the ROADMAP project. On 4 and 5 September they took part in a consultation with the projects' Outcomes Definition team. Chris joined the European Working Group of People with Dementia (EWGPWD) and was elected as Vice Chair in 2016. He". To the right of the text is a photograph of Chris Roberts and his wife Jayne standing outdoors in a rural setting.

<https://roadmap-alzheimer.org/news/after-diagnosis-research-gives-hope-interview-with-chris-roberts-and-his-wife-jayne/>



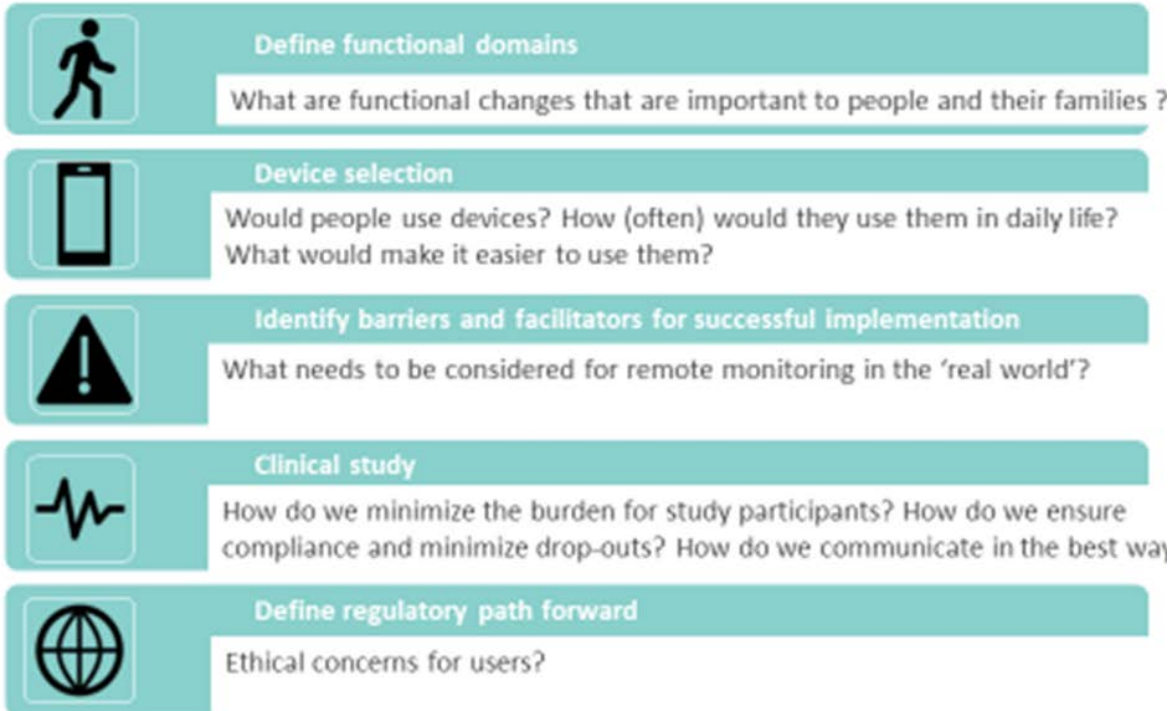
RADAR-AD

<https://www.radar-ad.org/>

PPI WORK IN RADAR-AD



Input of people with AD is essential at each step of the project



**Patient
Advisory Board
(PAB)**

**6 Focus Groups
(UK, Netherlands,
Greece)**

RADAR-AD PAB



Core PAB team

People with Dementia



Stefan
(Sweden)



Helen
(Ireland)



Chris
(UK)



Geert
(Belgium)

Supporters



Janni
(Sweden)



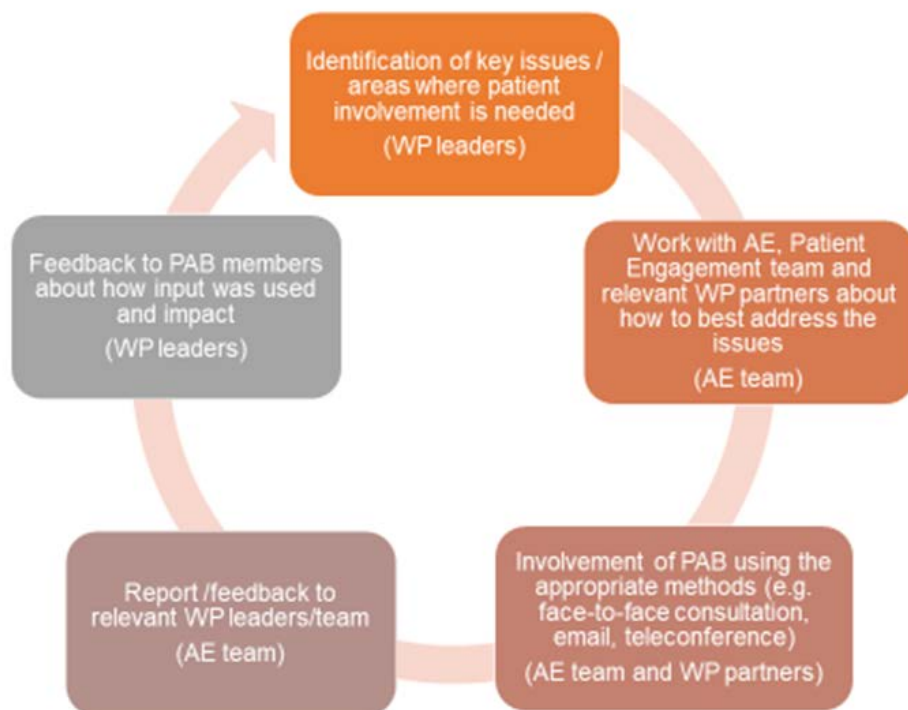
Jayne
(UK)



Nélide
(Portugal)

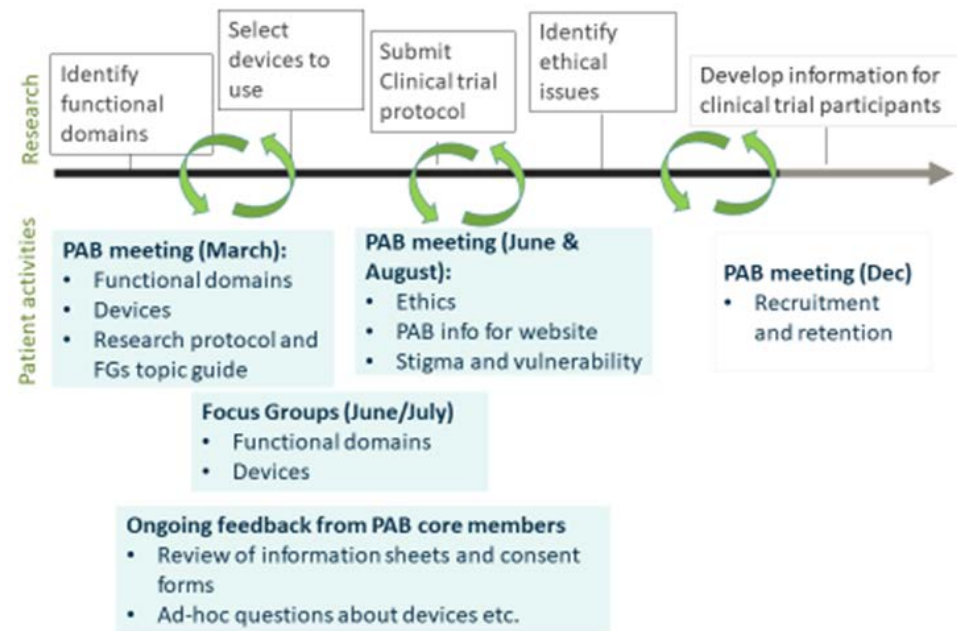


Ikuko
(Belgium)



Examples of PAB work from March to date:

- Understanding and prioritisation of functioning in early Alzheimer's dementia.
- Helping the Device Selection Team to understand benefits and barriers of existing devices and preferences to consider when selecting the devices.
- Feedback about the RADAR-AD focus groups.
- Feedback to the protocol of the RADAR-AD clinical trial
- Feedback to the participant & study partner information sheet and consent forms for trial
- Ethical issues to be considered in the context of RADAR-AD
- Input to the researchers about issues that could help them make decisions regarding device selection.
- Input about vulnerability and stigma in the context of RADAR-AD research.





EPAD

<http://ep-ad.org/>

PPI WORK IN EPAD



Aim of the Participant panel



- Provide feedback on good and bad elements of study experience and recommendations for improvements
- Ensure that participants are represented in decision making which may affect them
- Review documents related to the study aimed at participants
- Raise any other issues they feel we should take into account related to the EPAD study





PARADIGM

<https://imi-paradigm.eu/>

PARADIGM



- A Distinct Voice In the Patient Engagement Landscape

Patients
Active in
Research
And
Dialogues for
An
Improved
Generation of
Medicines

Mission

Contribute to a sustainable framework that enables meaningful patient engagement (PE) and demonstrates 'return on engagement' for all players



Research and
priority setting



Design of
clinical trials



Early dialogues with
regulators and HTA bodies



Objectives

Develop processes and tools for these three points in the medicine lifecycle
Develop a sustainability roadmap for patient engagement



PARADIGM



5. Conclusions



- There is increasing consensus that PPI in research is critical. PPI should be carefully planned, organised and monitored, and inclusive, meaningful and respectful of all people involved.
- PPI work is not «set in stone» - our own experience has evolved over the years, and we continue to improve and find new ways of involving people with dementia
- There is no recipe for PPI, different ways and methods depending on aims and purpose.
- There are currently initiatives (like PARADIGM) working on PPI to develop systematic, ethical and inclusive ways of involving «patients» and to better measure and understand its value and impact.



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