Patient Engagement: learnings from a European public-private research project

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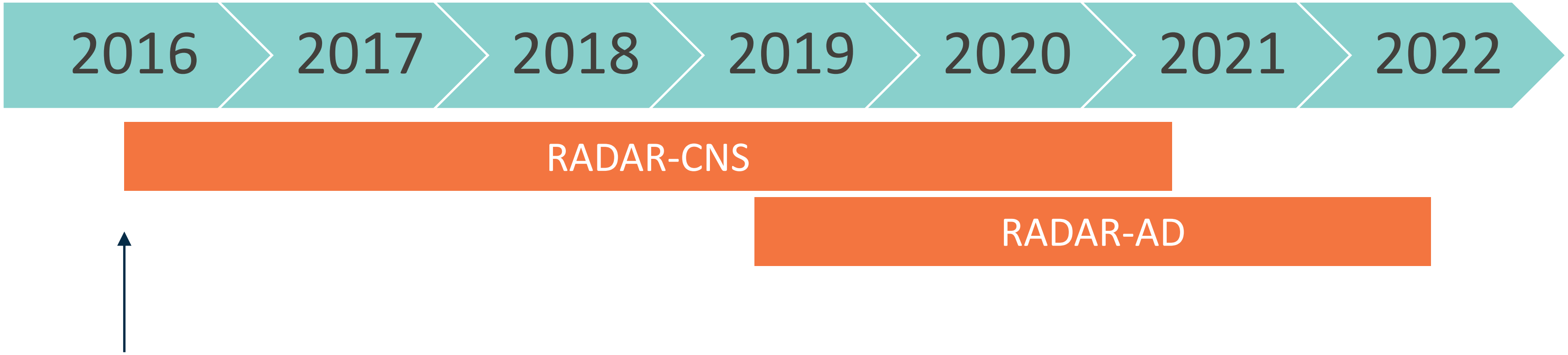
RADAR-AD is part of the RADAR ‘family’



RADAR-CNS

… started April 2016.

… RADAR stands for…**Remote Assessment (of) Disease** *And Relapse*

RADAR-CNS: Multiple Sclerosis, Epilepsy and Depression.

… brings together expertise on clinical disorders, technical platforms and translational pathways.

… builds a technical platform (data), does user testing of devices and runs clinical trials to ‘pressure test’ how this works in reality.

We use technology to remotely monitor how people go about their daily life (‘function’)

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- Before people experience symptoms
- People with prodromal Mild Cognitive Impairment
- People with dementia

Can we measure disease progression remotely?

Funded by

innovative medicines initiative

European Commission

Partners

King's College London
Lygature
VU University Medical Centre
The Hyve
University of Oxford
Karolinska
CBG/MEB
Fraunhofer Institute
Alzheimer Europe
CERTH
Altoida AG
Janssen Pharmaceutica NV
Takeda
Novartis Pharma AG
Eli Lilly
Software AG

What is RADAR AD?

WP 1	WP 2	WP 3	WP 4	WP 5	WP 6	WP 7
Project Management	Assessment of functional domains	Patient Engagement, Regulatory, Ethics	Develop remote monitoring technology (RMT)	Clinical trial to test RMT	Communicati on	Ethics

Takeda
Alzheimer Europe
KING'S College LONDON
lygature

- Set up a Patient Advisory Board
  - International
  - Accompanies all stages of the projects

- Organize focus groups
  - National (3 countries)
  - To address specific questions
  - Separate groups with carers & people diagnosed with early AD

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

Define functional domains

What are functional changes that are important to people and their families ?

Device selection

Would people use devices? How (often) would they use them in daily life? What would make it easier to use them?

Identify barriers and facilitators for successful implementation

What needs to be considered for remote monitoring in the ‘real world’?

Clinical study

How do we minimize the burden for study participants? How do we ensure compliance and minimize drop-outs? How do we communicate in the best way?

Define regulatory path forward

Ethical concerns for users?

The Patient Advisory Board (PAB): organization and challenges

All members of the ‘European Working Group of People with Dementia’ - set up by Alzheimer Europe – were invited to join the PAB

- 13 people living with dementia (mostly Alzheimer’s dementia) and people who provide support/care to them (e.g. family members and friends)
- A group of 4 people with dementia & 4 supporters form the ‘core PAB’

✓ Existing group, international & experienced in EU projects (no language barrier), deep involvement with project

✗ Challenge to also include people with AD prior to the onset of dementia

Focus Groups: organization and challenges

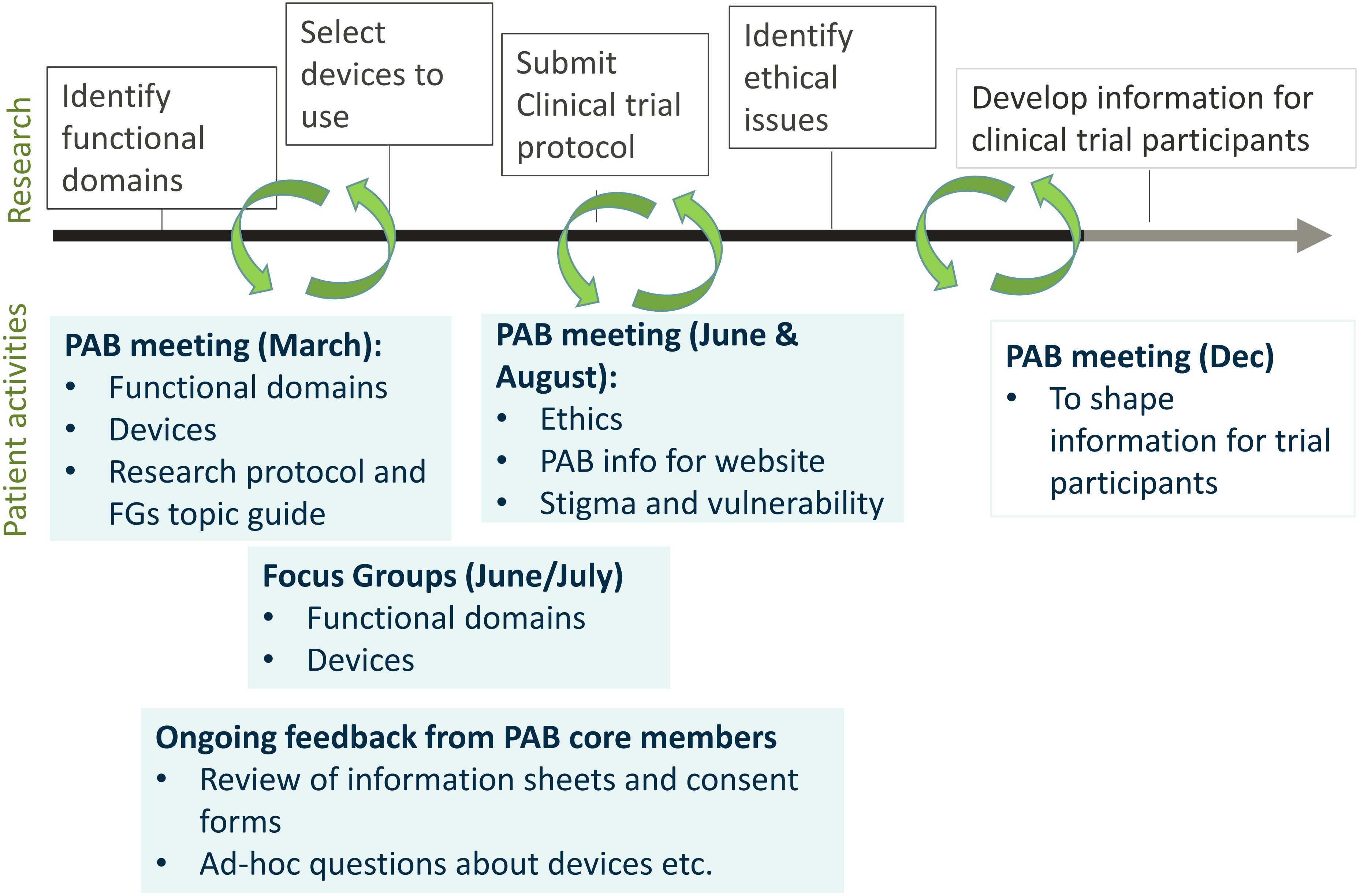
- 6 Focus groups
  - 12 people with Mild Cognitive Impairment and 7 people with mild AD dementia
  - 20 people who cared for loved ones with mild to severe AD dementia

- UK, Netherlands, Greece
  - Collaboration with local project partners and non-partners (e.g. Alzheimer Nederland, Alzheimer’s Society in the UK)

✓ Flexibility to select participants matching the project target group; national groups can help surface cultural differences

✗ Challenge to ‘find’ sufficient participants in short timeframe; no long-term relationship with the project

Patient input on project milestones



Research

Identify functional domains

Select devices to use

Submit Clinical trial protocol

Identify ethical issues

Develop information for clinical trial participants

Patient activities

PAB meeting (March):
- Functional domains
- Devices
- Research protocol and FGs topic guide

PAB meeting (June & August):
- Ethics
- PAB info for website
- Stigma and vulnerability

PAB meeting (Dec)
- To shape information for trial participants

Focus Groups (June/July)
- Functional domains
- Devices

Ongoing feedback from PAB core members
- Review of information sheets and consent forms
- Ad-hoc questions about devices etc.

Quotes from people involved

‘This is outstanding feedback, even at this stage. It has already helped influence our identification of the functional domains for RADAR-AD.’

Researcher at
King’s College London, UK

Member of the RADAR-AD
Patient Advisory Board

‘Using my experience of dementia and technology to assist in this project is very exciting, I think this research is very valuable and will make a huge difference for future diagnosis and care.’

Conclusion & learnings

- Input from patients & their families is valuable at **every stage of a project** (even for things not thought about upfront)
- Important to have an **open mind & open conversation** within the consortium to identify opportunities
- **Direct F2F interaction** of researchers with patient groups is extremely valuable
- Start with what you have & **build on it**
- ‘hard’ measurement of the impact of PE is difficult…

  … but once people experience the benefit, there may be no need for measuring the value

- **Just do it!**