



ROADMAP

The involvement of the European Working Group of People with Dementia in the outcomes work of ROADMAP

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www.roadmap-alzheimer.org

- *Aims and objectives of the consultation*
- *Presentation of the EWGPWD*
- *Preparation of the consultation*
- *Carrying out the consultation*



Aim: Ensure active involvement of people with dementia in design, analysis & interpretation of activities

Objectives:

- a) Receive **feedback** on a **survey** - with emphasis on the design, content & layout

- b) Gain insights based on **personal experience** of:
 1. why specific outcomes might or might not have been prioritised in the survey and why **prioritised outcomes** might matter most.
 2. how prioritised outcomes can be translated into a definition of **'meaningful delay'** in disease progression in AD across the spectrum.

1 st Day	
10:40-10:45	Welcome to the ROADMAP consultation
10:45-10:55	Introduction to key concepts
10:55-11:15	Introduction to the ROADMAP project
11:15-11:30	Questions and answers
11:30-12:40	Group discussion about disease progression
12:40-14:00	Lunch at the hotel
14:00-15:00	Group discussion about meaningful delay and treatment
15:00-15:15	Coffee/tea break
15:15-16:30	Focus group discussion on topic of real world evidence of disease
16:30-17:00	Joint session (feedback about the day and main conclusions)

2 nd Day	
09.00-10.30	Feedback on the survey and areas covered with a focus on the identification of gaps
10.30-10.50	Coffee/tea break
10.50-11.30	Discussion about the question regarding long life versus quality of life in the survey
11.30-12.30	Feedback about the day's activities and the project in general
12.30-12.45	Close of the meeting

Two groups;

- EWGPWD members
- group of the supporters

Launched in 2012

People with dementia are nominated
by national Alzheimer associations

2016-2018: 12 members

Group operates with its own Chair,
Vice-Chair

The Chair of the group is AE
board member



What is your perspective about being involved in research?

What are from your point of view the benefits of involving the EWGPWD in projects like ROADMAP?

What are key messages you'd like to tell researchers?

Preparation of documents in advance for:

- Moderators (Schedules, Information about EWGPWD and supporters)
- Members of the EWGPWD
- Their supporters

Documents:

- Introduction to the project and moderators
- Key concepts (Clinical trial, Outcome, real-world research approaches, data platform)
- Icebreaker
- Main questions (disease progression, staging of AD & dementia, “meaningful delay” in disease progression)

Materials:

- Print outs; Schedules, Preliminary outcome list, Surveys
- Sticky dots
- Digital recorders
- Yellow and red cards
- Name stickers and place names for tables
- Flip charts

- Clear introduction to the topic of interest, written without jargon giving a detailed lay explanation of the issue
- Being concise about what is wanted from the group and from their involvement in the project
- Providing these details in writing in advance (at least a couple of weeks)
- Written information in an accessible format (we followed the Dementia Engagement and Empowerment Project (DEEP) [guidelines](#))

■ Presentations on key concepts & project





■ Using an ice-breaker

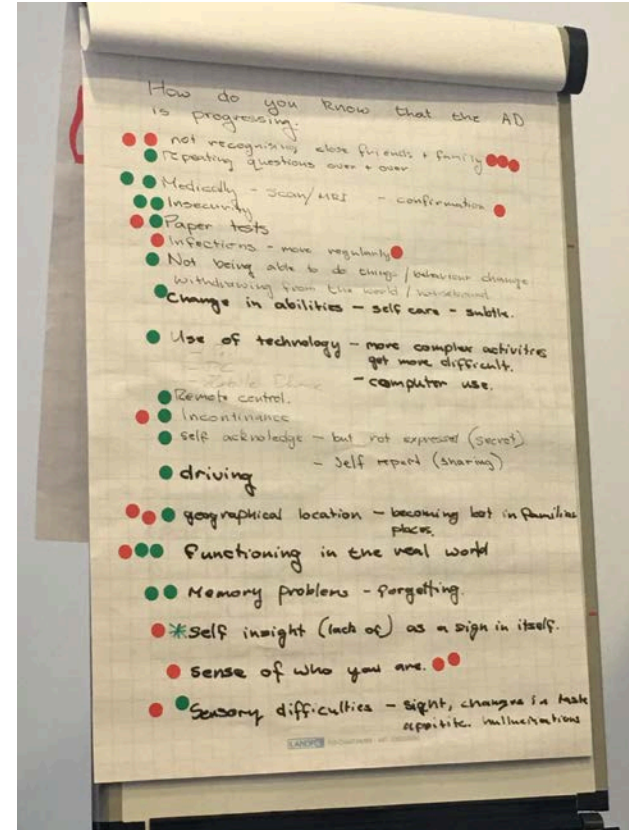
Introduce the following ice-breaker activity to get the ball rolling (10 minutes)

So here's the activity: I'd like you to imagine you are in a lift and are carrying a bag from a dementia conference with "dementia" written on it. Someone gets in the lift, sees your bag, and says, "Oh dementia! My mother has just been diagnosed with dementia but I'm not sure really what it is". You haven't got much time to go into detail. What would you say (in a nutshell) to give them a good general understanding of what it is?

So that was helpful in helping us to understand broadly speaking what you feel it is important to know in order to understand what dementia is. We'd now like to move on to the first question which is about the progression of dementia.

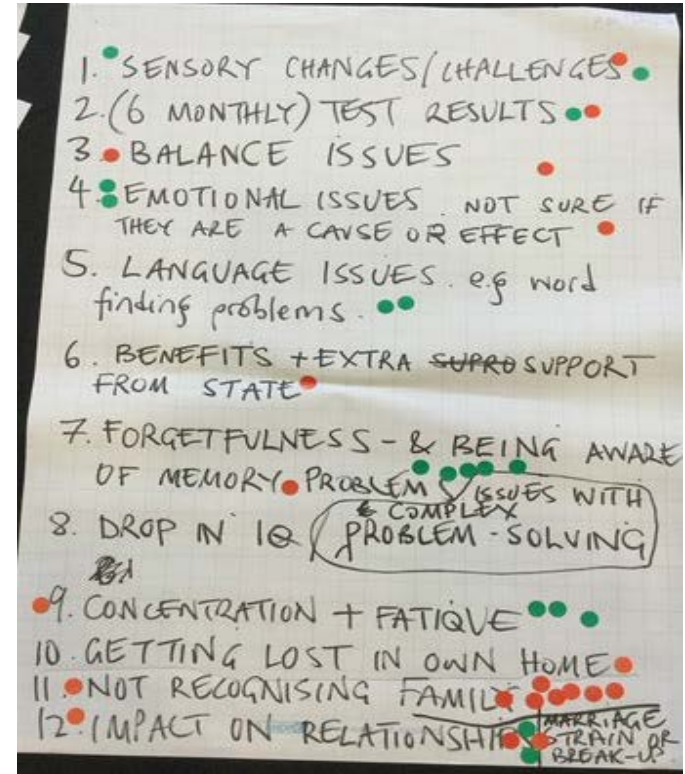
- How can you tell that someone's dementia is progressing/getting worse? (20 minutes)

(could be based on your own experience or based on your observations of other people you have encountered with dementia)

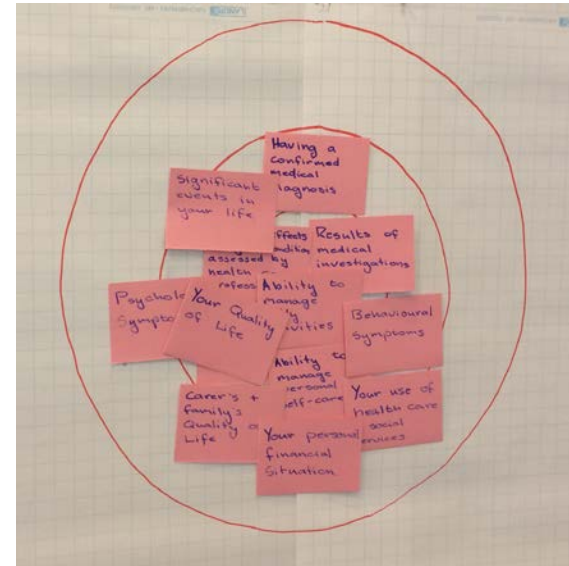


- **Green** sticky labels/dots to identify changes which might indicate:
 - a progression from a mild/early stage to a mid/moderate stage of dementia?

- **Red** sticky labels/dots to identify changes which might indicate:
 - a progression from a mid/moderate to a later/more advanced stage of dementia?



Activity (20 minutes): There are hundreds of different outcomes collected as part of real world evidence and we want to understand which ones are most important. We have drawn 3 concentric circles on the wall – like an archery target. Like in archery the centre circle is the most important. The outer circle is the least important. We grouped all the different outcomes into 13 types of outcomes.



- Explaining the topic of interest again and giving time to answer questions or explain the issue in further detail as required.
- Taking adequate breaks between each session.
- Atmosphere of trust and a positive environment.
- Ensuring people talk one at a time and avoiding talking over each other.
- Allowing time for the members to reflect on and add to the discussion when they are ready.

- Concluded with joint feedback session
- Future involvement for wider publication



- For more details contact:

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- Visit Alzheimer Europe's website:

www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia

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

<https://doi.org/10.1080/13607863.2017.1317334>

- Detailed information on the consultation and further work: D2.1-D2.5 <https://roadmap-alzheimer.org/downloads/deliverables/>





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Learn more about the project:
www-roadmap-alzheimer.org

