



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Summary of meeting: European Medicines Agency and Alzheimer Europe (AE)

20 January 2026, 14:00 -15:00 CET

1. Introduction and tour de table

EMA's Head of Public and Stakeholder Engagement department welcomed the delegates of Alzheimer Europe (AE) and members of the CHMP to this meeting.

2. Topics for discussion

AE outlined the difficulties that people with dementia face in participating in EMA activities from interacting with multiple staff members to IT issues, through to trouble following complex discussions, maintaining concentration, and expressing themselves, especially given the highly structured and formal nature of the meetings.

CHMP members acknowledged the stress and complexity of EMA meetings for all participants and recognised the particular difficulties for people with dementia. They expressed appreciation for patient contributions and agreed on the importance of preparatory meetings and support.

2.1. Improving how meetings are conducted and how people with dementia are involved

- Chairs and rapporteurs are informed of participation of people with lived experience and any needs that they may have. Organisations are welcome to share any advice on how to better support their members.
- Dedicated times can be and have been incorporated for patient representatives to contribute to the discussion. Chairs now systematically ask the patients for input on more than one occasion.

2.2. Clarifying the role and conditions for involvement of people with dementia and AE

- Patient participation is required in scientific meetings and AE colleagues (who are not patients themselves) can also be nominated as experts in view of their experience. They must complete a declaration of interest as any other expert and can contribute to the discussion ensuring that they clarify their perspective is from an organisational point of view. They will also have a key role in supporting participating patients. The EMA will ensure that all present at the meeting are informed of the presence of members of AE and understand their role in specific meetings.

2.3. IT and administrative support

- EMA acknowledged ongoing IT and administrative challenges and described observed improvements that have been implemented as well as troubleshooting support offered by Stakeholder Engagement colleagues.
- The Stakeholder Engagement team supports and accompanies patients along their journey and is available for any questions and offers help at any point in time along the process.

2.4. Updates on competing interest policy and remuneration initiative

- EMA has presented the revised competing interest policy during meetings with all eligible organisations and the Patients and Consumers Working Party (PCWP) and shared a [quick guide](#) that was created for patients and healthcare professional organisations.
- The [remuneration call](#) was also introduced during previous meetings, and EMA is willing to meet with AE to present these topics in more detail to the organisation and its members.

3. Summary of discussion/next steps

AE proposed organising focus group discussions with the members of the European Working Group of People with Dementia to address broad questions of relevance to upcoming EMA discussions and meetings. They emphasised the need for joint preparation of such focus group discussions to ensure that the questions addressed are clear and relevant. These sessions would be facilitated by Alzheimer Europe, with EMA being welcome to attend and co-facilitate subject to their availability and interest.

EMA and CHMP committed to continue the review of patient engagement processes, including revising communication about the representativeness of patient input, exploring new engagement models such as focus groups or public hearings, and ensuring that lessons learned from AE's involvement inform broader EMA practices.

It was highlighted that the collaborative approach with AE could serve as a model for patient involvement in other therapeutic areas, aiming for earlier engagement and more representative input while recognising the need to adapt processes to different contexts.