

The Participatory Advisory Board for Dementia Research Rostock: Evaluation of Members' Motivation, Challenges, Facilitators, and Impact

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Background:
Participatory research refers to involving people with lived experience (PWLE) of a condition in the research process to make it more relevant and effective [1]. As part of our ongoing PART project [2], we aimed to establish a sustainable structure at the University Medical Center Rostock (UMR) to include underrepresented patient groups with neurodegenerative diseases.

Aim:
To describe the implementation of our participatory advisory board and share longitudinal findings from the ongoing process evaluation.

Methods: The qualitative interviews presented here contribute to an ongoing process evaluation, which additionally includes quantitative monitoring and meeting minutes (not presented).

Data collection

1. Guided interviews
Qualitative Monitoring
Using the WE-ENACT tool [3] we conducted a thematic analysis [4] (MAXQDA) of member **interviews** at 6, 12, and 18 months (T1 to T3)

Purpose
To optimize board collaboration, improve members' satisfaction and enhance quality of the board's work

2. Quantitative post-meeting surveys

3. Meeting minutes

Ethical approval:
Obtained from the Ethical Committee of the UMR (Registry number **A 2023-0007**).

Results 1: Patient Advisory Board Dementia (PART-Beirat Demenz)

- Founded in 2023, 19 participatory board meetings conducted to date
- 5 members (3 patients, 2 relatives), participation varied over time + 1 scientific coordinator (accompanying research)

Key Achievements & Milestones (Co-Creation)

- Development of board bylaws and evaluation questionnaires
- Redesign of the project flyer and website for improved accessibility
- Co-development of conference presentations and scientific posters.

Consultation for multiple projects:
→ Presentation → Participatory Statement → Project Impact Report

Project	Task
Living@home (DZNE): → aims to empower family caregivers and reduce caregiver burden	→ Review usability of an app prototype
Ministry of Social Affairs M-V: → Dementia Plan for Mecklenburg-Western Pomerania	→ Discuss everyday life needs and recommendation regarding the Dementia Plan

Website PART-Beirat

Results 2: Qualitative Process Evaluation

Participants (Advisory board members)	
Interviews	T1: n = 7 T2: n = 6 T3: n = 2 (between 13 and 52 minutes)
Expertise	4 patients 3 relatives
Gender	6 women 1 men
Age (years, T1)	Mean = 65.3 SD = 10.42 Range = 53 – 83
Ongoing evaluation:	2 board members reached T3 to date

Advisory Board Perspectives at Baseline (T1)

Motivation

- Valued the involvement of people with lived experience (PWLE) in research
- Support dementia research and gain latest information

Guided interviews

Expectation

- Respectful exchange between PWLE and medical professionals
- "Being able to do something"

Experienced facilitators

- PWLE became a genuine voice – no "fake" participation
- Appreciative and respectful communication culture

Experienced barriers

- Unclear personal roles within the advisory board
- Time constraints – balancing caregiving with board duties

Evolution of Members' Experiences: Longitudinal Trends from T1 to T3

→ From initial role uncertainty to self-directed scientific empowerment

T1: "I first have to see what it brings and what tasks I will have in there." (**Relative 2**)

T3: "Because among other things, for instance through the [PART-Beirat], I have gained a bit of background knowledge" (**Relative 2**)

→ From individual illness focus to a strategic research metaperspective

T1: "[...] my mother also got Alzheimer's and dementia and passed away two years ago, that's why I'm interested in this matter. Because you're also a bit afraid that you'll get it yourself." (**Relative 3**)

T3: "I am always in favor of networking etc., [...] This also came across in the workshop, that people work with each other, pass on the experience. What did you do there in your advisory board? What could be adopted?" (**Relative 3**)

Conclusion:

- Meaningful **participatory dementia research** is **feasible**, delivering substantial **value to academic projects** and **advisory board members** alike
- Direct collaborative **inclusion of PWLE** delivers concrete **academic value**, proving that **long-term advisory boards** significantly **refine both research materials and political guidelines**

- Personal **fate** inspires **initial commitment**, while a **respectful, empowering environment** enables proactive **scientific work**
- **Longitudinal participation** builds professional **confidence** and **self-efficacy**, which fosters a loop of **self-reinforcing motivation**.