

Towards active participation in ageing science: involving seniors in the analysis and interpretation of their own data

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Transfer of cognitive training gains in cognitively healthy aging: Mechanisms and Modulators – AgeGain
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Background and objectives

- Participatory research in ageing science helps to ensure that new findings can be transferred into practice in a sustainable way and that they have appreciable long-term effects on the target group¹
- Current multicentre study: transfer of cognitive training gains (AgeGain, BMBF grant no. 01GQ1425B)
 - Neuropsychological, neuroimaging and genetic examination before and after 12 sessions of computer-based cognitive training
 - As participants were curious about their results, we offered participatory workshops for them to gain further insight into the study and to analyse their own training data

Aims of the workshops

- Enhancing mutual understanding between researchers and participants
- Identifying research needs of participants
- Promoting scientific literacy
- Establishing a platform to involve senior citizens already in the planning phase of future studies

Methods

Participants

- Thirty-one participants from the AgeGain training group, 22 women
- Cognitively and physically healthy
- $M = 72$ years old (61-90 years), highly educated ($M = 16$ years)

Workshops

- Six workshops (4-7 participants), about 3 hours each (for agenda see table 1)

Table 1. Workshop agenda and active involvement of the participants.

Workshop Agenda	Participatory Involvement/Questionnaire (Q)
1. Greeting and introduction	Evaluation of study participation (Q), discussion
2. AgeGain: background information	Discussion
3. Analysis of training data	Calculation and comparison of training results (see figure 1)
4. Discussion of training data	e.g. effects of study participation on everyday life
5. Introduction to participatory research in ageing science	Involvement and participation in research (Q), discussion pros/cons
6. Prevention of dementia	Discussion
7. Science communication	Publication and communication of results (Q), discussion
8. Conclusion and outlook	Workshop evaluation (Q), participation in future research

Data acquisition and analysis

- Questionnaires with closed- and open-ended questions on different topics
- Discussion with guiding questions
- Quantitative data: descriptive analysis
- Qualitative data: content analysis

Results

- Core points of the gathered data:
 - “Would you like to work actively in a research project?” 74.2% Yes, 22.6% No
 - “What are your ideas for future research (in clinical dementia research/ ageing science)?” Ideas can be grouped as follows:
 - Dementia: early detection (8), aetiology (8), prevention (7), treatment (4), technical assistance (3), family caregivers (2)
 - Ageing science: new media and technology (5), healthy ageing (2), loneliness (2), other diseases (2), senior-friendly living, assistive suicide, participatory ageing research
 - “Would you like to participate in the publication and communication of research results?” 58.1% Yes, 35.5% No
 - “What chances and risks do you see in participatory research?” (see table 2)

Figure 1. Participants analysed their data from the cognitive training they received. They calculated their mean performance per week (left, for one working memory and two reaction time tasks) and compared their results with the mean performance of the whole training group (right, e.g. for the reaction time tasks) (one participant's original sheets).

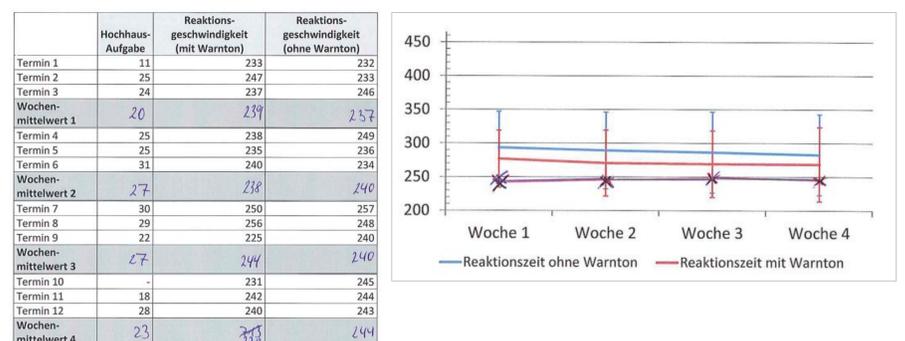
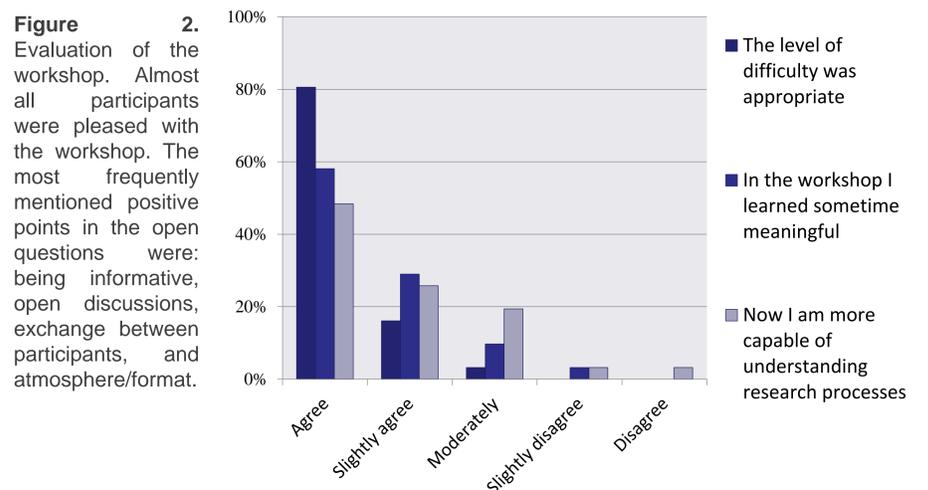


Table 2. Chances and risks of participatory ageing science.

Chances/Pros	Risks/Cons
Enables changes in perspective for both sides	Degradation of science
Seniors have enough time to participate in research projects	Lack of competence
Planning of studies according to needs and concerns of target group	Science is too specific and too difficult to understand in depth
Suggestions from citizens can be considered	Too much participation leads to chaos
Research topics: bottom-up decision making	Equal status not possible

Participants are willing to be more engaged in research, but clear structures are preferred
Participants suggest to be part of an advisory board in every phase of research, but decision-making authority should be kept on the side of scientists



Discussion and outlook

- The workshop was very well accepted (see figure 2)
- Seniors are valuable partners in applied ageing research and they see themselves as a good source of information
- Future plans
 - Setting up formats for science communication: newsletters and information events for the general public in cooperation with the Academy for Senior Citizens
 - Establishing a platform for participatory research at the department “Ageing of Individuals and Society”
 - Fostering the involvement of persons with cognitive impairments in research

Reference

[1] Eicher et al. (2017). Participatory Aging Research at the Center for Gerontology. University of Zurich, Center for Gerontology.