



# **Participatory Aging Research at the Center for Gerontology**

**Position Paper**

Status as at 26 January 2017

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· <http://www.zfg.uzh.ch/de/projekt/guetesiegel.html>

Citation: Center for Gerontology. (2017). *Participatory Aging Research at the Center for Gerontology. Position Paper*. Available from: <http://www.zfg.uzh.ch/de/Partizipative-Altersforschung.html>

## Document Context

A participatory approach to research means involving those individuals, or groups of individuals, who are connected with the topic of the research as equal partners in the research process from the outset. Thus, research projects can be described as participatory if these (groups of) individuals are viewed as active research partners and are granted genuine co-determination power.

The University of Zurich Center for Gerontology describes the importance and application of participatory research into aging in a number of documents to give the approach a stronger and more systematic foundation for the future. A summary of these is provided below in ascending order of detail. Once they have been completed, it will be possible to download the documents from the Center for Gerontology website and to use them in further research, providing a citation is given.

### 1. *Position Paper*

**This provides the strategic framework for all conceptual and structural work, as well for all participatory research projects at the Center for Gerontology. It describes the participatory approach to research into aging and sets out the criteria and principles by which the Center for Gerontology abides when conducting participatory aging research.**

### 2. *Guidelines for Good Aging Research (→ to [download](#))*

The Guidelines have been drawn up in a participatory process, i.e. jointly by research subjects and researchers alike. They cover a variety of aspects which those involved believe characterize good gerontological research projects. The Guidelines should be regarded first and foremost as a formal statement, but can also provide guidance for the initiation, conduct, and evaluation of aging research projects. They themselves are subject to an ongoing process of evaluation and will be revised regularly on the basis of continuing experience with their application.

### 3. *User Guide (in progress)*

This document describes the individual stages of participatory research projects, its prerequisites, decisions and specific execution. It is a working paper containing specific practical recommendations for researchers.

### 4. *Overview of Completed and Ongoing Projects at the Center for Gerontology (in progress)*

This document contains a list of all participatory research projects conducted to date at the Center for Gerontology, as well as an overview of efforts to establish a structural framework for participation in aging research.

### 5. *Worksheets (in progress)*

These are used as working guidelines and checklists for researchers, project managers, and moderators initiating and/or conducting a participatory project in aging research.

### 6. *Training modules (in progress)*

The training models are designed for those interested in contributing to a participatory project, or who plan to implement a research project using a participatory approach. The courses teach the basic principles of a variety of topics.

### 7. *Contact Point (→ to [website](#))*

The *Participation Office* is the first point of contact for those interested in participatory aging research, whether they are researchers, research subjects, or practitioners.

· <http://www.zfg.uzh.ch/de/ueber.html>

## 1 Introduction

Participation refers to community involvement in socially relevant issues, which include research into aging. In becoming part of the research process, participants at the Center for Gerontology contribute on their own terms to the project and have an effect on its outcome. By doing so, they help the circumstances of the target group not only to be understood and recorded more fully, but also to be stabilized and, where necessary, improved. In this way, participation in the Center for Gerontology's research helps to ensure that new findings can be transferred into practice in as sustainable a way as possible and thus have an appreciable, long-term effect on the target group in question.

To us, a participatory approach to research means involving the individuals and groups who are connected with the research topic into the research process. We define participatory research projects as those that integrate these (groups of) individuals right from the outset, that view them as active research partners, and that include them in decision-making. For each project, we identify the groups having an interest in the research topic, independent of any previous project. In our view, there are essentially three groups of stakeholders with a strong interest in aging research:

- 1) research subjects and/or their families
- 2) practitioners (e.g. carers, physicians, public service employees)
- 3) researchers

We regard researchers as having the same status as the other two groups. However, they do have a special role to play because of their extensive training and background in academic work.

In this Position Paper, we describe what we see as the key criteria in participatory research into aging. We set out the guidelines on which our day-to-day work is based, and we state our motivation for taking the participatory approach. The purpose of this paper is make our position clear and to guide systematic implementation at both the conceptual and the structural level.

## 2 Participatory Aging Research at the Center for Gerontology

At the University of Zurich Center for Gerontology, we are working on establishing a scientific foundation for aging with a good quality of life; we are developing, testing, and exploring individualized interventions to improve and to stabilize this quality of life. To do so, we engage in participatory processes – in other words processes that include the individuals who are the subject of the research.

### 2.1 Criteria for Participatory Research into Aging at the Center for Gerontology

All of our participatory projects fulfill the following criteria:

#### *Equal Partners*

Participation in research goes hand in hand with an attitude toward others that is based on equality and respect, and that focuses on enabling individuals to act independently. As researchers, we recognize the individual experiences and abilities of the research subjects, and we appreciate their capacity to learn and to acquire new skills. We expect participants to treat us in the same way. With this foundation, everyone involved is able to take independent responsibility for their own contribution and thus help to improve the social situation (of their reference group).

#### *Equal Rights*

In our view, participatory research means that all participants have the same say in key research-related and strategic decisions. They are given the right to help determine how the project progresses. The "Participatory Aging Research Processes" document (cf. page 3) describes the form that participation in decision-making might take at different stages of the research.

### *Excellence*

Our participatory projects comply with our "Guidelines for Good Aging Research" (cf. page 3), which also cover participation and long-term effect.

### *Good Information*

To us, participation means all interested parties are able to inform themselves about the opportunity to become involved, thus giving them a sound basis for their decision. To support a decision on whether or not to participate in a project, at what point, to what extent, and how closely, we make it easy for interested persons to find relevant information that is straightforward and transparent.

## **2.2 Guidelines for Participatory Aging Research at the Center for Gerontology**

Taking the participatory approach, we develop instruments and methods that can be implemented systematically and that will also ensure that, in the future as today, we

### *Equal Partners*

- ... not only research about older people, but also with them.
- ... treat participants with respect and appreciation. In doing so, we help to foster a relationship of trust between the participants themselves, as well as between academics and practitioners.
- ... learn from the participants and, in return, give them full access to our academic knowledge.
- ... carefully establish in advance the expectations, experience, and expertise of anyone interested in participating in a project, thus creating a reference for the entire duration of the project.
- ... achieve maximum transparency when conducting participatory projects.

### *Equal Rights*

- ... balance subject and decision-making competence. This means being able to distinguish between an individual's capabilities and knowledge, as gained from personal and professional experience, and their ability to make research-related as well as strategic decisions that take all of the relevant factors into account.
- ... are able to determine the form that collaboration will take on an individual basis in consultation with the interested individual. This includes, for example, how they wish to be involved, how closely they wish to participate, the scope of their decision-making authority, agreements about payment, etc..
- ... are able to define decision-making power with the participants in accordance with the joint agreements which have been reached. In principle, every vote carries the same weight.

### *Excellence*

- ... are able to implement our "Guidelines for Good Gerontological Research" (cf. page 3) as effectively as possible.
- ... can ensure that our work has a long-term effect, meaning that our research findings are put into practice for as long as possible, thereby strengthening our relationship with our reference groups.
- ... are able to evaluate all of our participatory projects and continue to enhance our approaches and methods on the basis of our findings.

**Good Information**

... give interested individuals the best basis on which to decide on participation. We will do this by offering training on the basic principles of the participatory approach.

... can give interested individuals the basic knowledge that they need to be able to contribute satisfactorily to a participatory project. We will do this by offering training on the basic principles of academic work.

## 2.3 Reasons for Undertaking Participatory Aging Research at the Center for Gerontology

At the UZH Center for Gerontology, we take the participatory approach to research for the following reasons:

**Conviction:** Researching not only about, but with, older people is consistent with our belief system. At the same time, however, participation is a fundamental principle for which calls are growing from a variety of quarters – both within<sup>1,2</sup> and outside of<sup>3</sup> the academic sector and from the research subjects themselves<sup>6,7</sup>.

**Reciprocal learning:** By collaborating, we and all of the participants gain insights into the life and work of the others. This expands our knowledge and strengthens both our professional skills and social competence. By passing on what they have learned to their friends and families, all participants help to spread the new findings quickly and economically.

**Participation is a factor in quality of life:** The opportunity to play an active part in the life of society is an element in a high quality of life.<sup>8</sup> By participating in research, older people can become involved in a socially relevant and recognized field and thus contribute somewhat to improving the living conditions of the subject target group.

**Transferring research into practice:** The participatory approach results in a stronger base of local support for our research projects, thus lending them practical and everyday relevance. The new findings are put into practice via the reference groups. This practical application then has a multiplier effect which, in turn, promotes acceptance of the study results and broadens the impact of the research project.

**Innovation:** Research subjects and practitioners who participate in research projects ask different and critical questions, challenge common views and methods, and thus offer new perspectives. Adopting new perspectives leads us to asking new questions, potentially giving rise to new research projects that employ innovative methodologies.

**Economy:** By harnessing the knowledge of the research subjects and practitioners about real-life problems, our research into aging gains focus and efficiency. We firmly believe that participation pays off in the long run, even though in the short term it may involve more staff hours, more coordination, and higher costs.

**Practical expertise:** To date there have only been a few examples of participatory research into aging at the Center for Gerontology, such as the round table on dementia. This means there is a lack of established processes and structures at the operational level that would motivate researchers to take a participatory approach to their research projects. The materials developed on the basis of our experience create incentives to choose the participatory path.

### 3 References

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#### Further links

*White Paper on Citizen Science:*

<http://www.socientize.eu/?q=eu/content/white-paper-citizen-science>

*Ten Principles of Citizen Science:*

[http://ecsa.citizen-science.net/sites/default/files/ecsa\\_ten\\_principles\\_of\\_cs\\_german.pdf](http://ecsa.citizen-science.net/sites/default/files/ecsa_ten_principles_of_cs_german.pdf)

<http://www.zfg.uzh.ch/de/projekt/alt/rt-demenz.html>