



**Universität  
Zürich** <sup>UZH</sup>

Center for Gerontology

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# **Participatively Developed Guidelines for Good Aging Research at the Center for Gerontology**

Version 2.0

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## 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<sup>1</sup> and to use them in further research, providing a citation is given.

### 1. *Position Paper (→ to download)*

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*

**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 modules 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.

<sup>1</sup> <http://www.zfg.uzh.ch/de/ueber.html>

# 1 Background

## **Current Situation**

It is important to answer the question of what constitutes good research into aging in order to efficiently conduct projects that meet high quality standards. Forward-looking, binding guidelines and criteria can only be formulated credibly if all persons involved in aging research are considered. With this in mind, in early 2014 the University of Zurich's Center for Gerontology formed a working group consisting of older people, researchers, and those who assess research projects, such as professors (cf. list of contributors on page 12). The aim of this partnership project was to draft joint guidelines for good aging research that can be used to evaluate the quality of research projects.

## **Approach**

Over a two-year period, the members of the group held regular meetings at which they examined the quality of research in gerontology in great detail. They initially looked into the existing criteria that are used to evaluate research projects, such as those applied by the Swiss National Science Foundation. They then gathered their own thoughts and ideas, which they discussed and systematized for the different stages of the research process. The group members reviewed this initial version of the Guidelines (V1.0) by reading through a variety of research proposals and discussing them in relation to their own principles. This process resulted in the present Version (V2.0).

## **Outcome**

The fact that the working group succeeded in working together to draft guidelines shows that participatory collaboration in research can work, and that it is possible to reach a consensus between older people and researchers about what constitutes good research into aging. The group members regard V2.0 of the Guidelines as a working paper intended to encourage a high quality of participatory gerontological research. It is planned that the Guidelines will be reviewed and updated on the basis of experience with their application.

## 2 Guidelines<sup>2</sup>

### 2.1 Aspects Applicable to the Entire Research Process

#### 2.1.1 Participation

- 2.1.1.1 All interested parties are able to inform themselves about the opportunity to become involved in participatory research projects.
- 2.1.1.2 The participating stakeholders together determine the collaborative framework.
- 2.1.1.3 The individuals participating in the project determine for themselves the form and scope of their contribution to the research project.
- 2.1.1.4 The participating stakeholders treat each other as equals and foster a culture of respect and appreciation.
- 2.1.1.5 The participating stakeholders recognize each other's individual experience and competence, and the others' capacity to learn and to acquire new skills.
- 2.1.1.6 The participating stakeholders make key research-related and strategic decisions together.
- 2.1.1.7 The participating stakeholders have the subject-specific knowledge and decision-making competence that their particular function requires to conduct the research project.
- 2.1.1.8 In the interests of optimum collaboration, preparatory training is offered that the participating stakeholders can attend as necessary.

#### 2.1.2 Economy

- 2.1.2.1 Costs and benefits are balanced at all stages of research.
- 2.1.2.2 Opportunities are taken to keep all stakeholders' costs down (e.g. by using the latest communication technologies).

#### 2.1.3 Ethics

- 2.1.3.1 Ethical guidelines are observed throughout the research process.

<sup>2</sup> Words that are underlined are explained in the glossary which begins on page 13.

## 2.2 Defining the Research Question

### 2.2.1 Participation

2.2.1.1 The research question and objectives are defined together by the stakeholders.

### 2.2.2 Knowledge Gains

2.2.2.1 The research question is aimed at generating new knowledge.

2.2.2.2 The research project should be innovative, and it must involve a substantial risk that the outcome will not be as expected.

2.2.2.3 The research question is aimed at generating starting points for new research questions.

2.2.2.4 The research question is designed to facilitate progress on key social problems.

2.2.2.5 The research question is designed to highlight potentially important factors in quality of life in the life stage of mature adulthood, along with ways of optimizing them.

2.2.2.6 The research question is formulated to make statements about the factors which affect aging individuals in as many situations as possible.

### 2.2.3 Resource Focus

2.2.3.1 The research questions results in a resource-based view on age, i.e. it focuses on the individual's possibilities and strengths.

2.2.3.2 Where resources are concerned, gains and stability are considered to the same extent as losses and deficits.

### 2.2.4 Practical Relevance

2.2.4.1 The research question is based both on the current status of research and on practice.

2.2.4.2 The research question is aimed at recording day-to-day behaviors and experiences. Whenever possible, research is conducted in real-life settings, and not in the laboratory.

2.2.4.3 The research question is designed so that the findings will be applicable in practice.

### 2.2.5 Biographical Relevance

2.2.5.1 Gerontology is a part of lifespan research. It pinpoints models for quality of life that are applicable to the latter life stages being studied, but it also includes earlier life stages.

**2.2.6 Target Group**

2.2.6.1 The research question is geared to both the individual and at the collective. Its aim is to generate findings that are relevant to both individuals and to certain groups of individuals, as well as to society as a whole.

**2.2.7 Sustainability**

2.2.7.1 The research question is designed to achieve lasting change. This change should be verifiable.

**2.2.8 Wording of the Research Question**

2.2.8.1 The wording of the research question must make the importance of the issue clear.

2.2.8.2 The wording must be understandable for all stakeholder groups. For example, it must focus on the key points, be coherent, and must not contain any technical terms that are not defined.

**2.3 Determining Methodology****2.3.1 Participation**

2.3.1.1 The stakeholders decide together on the selection of methods.

**2.3.2 Suitability of the Form of Study**

2.3.2.1 The form of study that is used must enable the research question to be answered.

2.3.2.2 The form of study that is used must permit statements to be made about individuals.

2.3.2.3 The study methods that are used must consider the physical and cognitive resources of the research subjects.

**2.3.3 Suitability of Measuring Instruments**

2.3.3.1 The measuring instruments that are used must enable the research question to be answered.

2.3.3.2 The measuring instruments that are used must permit statements to be made about individuals.

**2.3.4 Effort**

2.3.4.1 The effort put into answering the research question permits it to be answered. Less effort would make it impossible to answer, while more effort would not generate any knowledge gain.

### **2.3.5 Quality Criteria for Measuring Instruments**

- 2.3.5.1 Steps are taken to ensure that the results are independent of the person using the measuring instrument in question (objectivity).
- 2.3.5.2 The measuring instruments that are used deliver the same results under the same conditions of use (reliability).
- 2.3.5.3 The measuring instruments that are used are suitable for measuring what is to be measured (construct validity).
- 2.3.5.4 Steps are taken to ensure that potential confounding variables are monitored so that alternative explanations of how the results have been gained can be ruled out as far as is possible (internal validity).
- 2.3.5.5 Steps are taken to ensure that the results can be generalized for other (groups of) individuals, points in time, and situations (external or ecological validity).

## **2.4 Data Collection**

### **2.4.1 Participation**

- 2.4.1.1 Stakeholders are involved in data collection, for example in planning data collection, recruiting study participants, and conducting surveys among participants.

### **2.4.2 Use of Existing Data**

- 2.4.2.1 Existing data are used before new data are collected. This also includes data that have not been collected primarily for research purposes.

### **2.4.3 Investigator**

- 2.4.3.1 The investigator has the skills required for data collection.
- 2.4.3.2 The investigator treats the study participants with respect.
- 2.4.3.3 During data collection, consideration is given to the individual needs and abilities of the participating individuals.
- 2.4.3.4 The investigator ensures that the study participants understand exactly what they are being asked to do.
- 2.4.3.5 The investigator goes through the data collection process themselves so that they can experience and evaluate the role of the study participants for themselves.

### **2.4.4 Study Participants**

- 2.4.4.1 Study participants are briefed about the objective and purpose of the research, and are able to understand both these and the reasons behind them.
- 2.4.4.2 Participants may gain or learn something from participating.

**2.4.5 Data Access**

- 2.4.5.1 Data are available at all times to individuals from whom it originates.
- 2.4.5.2 Newly collected data are anonymized and made available to other researchers and interested parties so that it can be used for further analysis.

**2.5 Data Analysis****2.5.1 Participation**

- 2.5.1.1 The method used to analyze the data is determined in a participatory process.

**2.6 Data Interpretation****2.6.1 Participation**

- 2.6.1.1 The different ways of interpreting the data, and their relevance, are determined by the stakeholders, each having an equal say.
- 2.6.1.2 The data are interpreted together by the stakeholders.

**2.6.2 Relevance**

- 2.6.2.1 The findings of research are deemed relevant if they permit new and scientifically well-founded statements to be made about factors that produce the result desired by individual older people in a wide variety of situations.
- 2.6.2.2 The findings are placed in a broader gerontological context.

**2.6.3 Transparency**

- 2.6.3.1 The different ways in which the data can be interpreted must be stated openly.
- 2.6.3.2 The way in which the data have been interpreted must be transparent.
- 2.6.3.3 When interpretation of the data allows for several explanations having the same explanatory value, preference is given to the explanation that rests on the fewest assumptions.
- 2.6.3.4 The research question is answered.

## **2.7 Publication**

### **2.7.1 Participation**

2.7.1.1 The publication strategy is determined by all stakeholders together.

2.7.1.2 All stakeholders are involved to the same degree in publishing the results and the data.

### **2.7.2 Presentation**

2.7.2.1 Steps are taken to ensure comprehensibility. The way in which the findings and data are documented corresponds to the standard comprehensibility criteria, for example, a focus on the key points, coherence, no technical terms, and generally understandable vocabulary. Otherwise, individuals are given the additional information they need to understand the presentation.

### **2.7.3 Communications**

2.7.3.1 Steps are taken to promote the transfer of knowledge from the academic world to the general public.

2.7.3.2 Exchange about current research is encouraged among experts and among the general public.

2.7.3.3 The findings are included in teaching and continuing education curricula.

## **2.8 Implementation**

### **2.8.1 Participation**

2.8.1.1 All stakeholders are involved in drafting the strategy for implementing the findings.

2.8.1.2 The individual stakeholders (or stakeholder groups) help to ensure that the findings are implemented within their own sphere of influence.

### **2.8.2 Application**

2.8.2.1 The strategy developed jointly by the stakeholders is implemented.

### **2.8.3 Practical Benefit**

2.8.3.1 The new findings are put into practice.

2.8.3.2 The new findings have a proven benefit in practice.

### **2.8.4 Documentation**

2.8.4.1 Comprehensive documentation has been produced about the implementation.

### 3 Contributors

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## 4 Glossary<sup>3</sup>

### **Analysis**

Analysis is a systematic examination in which the subject is broken down into its constituent parts, which are then organized, studied, and evaluated. Empirical research employs a variety of analytical methods to determine the statistical coefficients of variables.

### **Data collection**

To be able to make statements on a given set of circumstances, data that describes those circumstances must be collected. The aim of data collection is thus, on the one hand, to arrive at hypotheses, laws, and theories and, on the other, to test them continually[1]. The methods used for empirical data collection serve to describe or replicate as precisely as possible those sections of reality which are interesting in a study context. Quantitative or qualitative methods may be used to do this[2].

### **Ethical guidelines**

There are a number of guidelines on compliance with ethical principles in academic research. These relate to both ethical standards within the academic sector and to the implications that research activities have for society. One example is the "Guidelines for Research Integrity" published by the ETH Zurich.<sup>4</sup>

### **Gerontology**

Gerontology is research into aging. It is an interdisciplinary and multidisciplinary field of research that deals with how to describe and explain the changes in structures and processes that occur throughout the human lifespan, and which determine human experiences and behaviors – as well as how they differ between individuals – into very old age[3].

### **Competence**

As part of a research project, all of those involved are required to have the competence (expertise) they need to contribute effectively. The *study manager* selects and instructs the test manager and monitors and supports the conduct of the project. The *test manager* is familiar with the methods that will be used (measuring instruments, procedures, etc.). They are able to deal with the study participants and to resolve any data collection problems which occur. *Stakeholders* participate in the conduct and implementation of the research project. This means that they have capabilities and knowledge that they have gained from personal and professional experience (competence in the subject matter) as well as the ability to make research-related as well as strategic decisions which take all of the relevant factors into account (decision-making competence).

<sup>3</sup> All terms explained in the Glossary are to be understood in a research context.

<sup>4</sup> <https://rechtssammlung.sp.ethz.ch/Dokumente/414en.pdf>

**Life stages**

Developmental psychology divides human life into different stages. The mature adulthood stage is typically divided into middle adulthood (age 35–65), old age (age 65–80), and extreme old age (age 80+) [4].

**Quality of life**

The literature contains an enormous variety of definitions of what constitutes quality of life. Very often, quality of life is equated with life satisfaction. As a general rule, however, quality of life is determined for each individual by a combination of separate factors.

**Lifespan**

Lifespan refers to the time from birth to death.

**Methods**

Methods are the various procedures in research that are used to gain knowledge or to apply that knowledge successfully in a particular context [1]. Methods cover the characterization of study design, a description of the instruments to be used and of the sample, a description of how the study will be conducted, and the approach to analyzing data. Methods must be described in such detail that other researchers who are interested in the same problem are able to replicate the study.

**Objectivity**

Objectivity describes the independence of the results produced by a measuring instrument from the conditions under which the measurement was taken. An instrument – such as one to capture the capacity of a person's memory – is objective if the results are not affected by the person conducting the test or interpreting the results.

**Participation**

Participatory aging research means actively involving those individuals who are affected by the research question (cf. stakeholder). Ideally, integration or collaboration will take place at all stages of the research process. In other words, it will begin with the choice of topic, cover the formulation of the research question, the development of methods, the collection of data, and its evaluation and interpretation, and will conclude with the publication and implementation of the study outcomes. This participatory type of research combines the experience and specialized knowledge of those affected by the research question with the empirical knowledge of the researchers. With this approach, the older population is thus regarded not just as the subject of the research (the test community), but as an active partner in the research. In the ideal case, this lends additional practical relevance to the research question, and means that the findings will also be implemented in practice.

**Reliability**

Reliability describes the consistent accuracy of the measuring instrument, in other words the degree of precision with which it can record the variable in which researchers are interested. Two studies conducted under the same conditions using the same measuring instrument must thus arrive at the same result. An instrument that is used to measure vision, for example, is deemed reliable if it produces the same results for the same person under the same conditions (such as time of day, available light, and physical constitution).

**Resources**

Resources refers to the skills, capabilities, and opportunities that a person has to help them cope with the tasks that they must perform in life. A distinction is made between different types of resource, such as physical, mental, social, and environment-related resources. Thus, resource focus means concentrating on a person's strengths and on activating and using them.

**Stakeholder**

Stakeholder describes a person or group who/which has a justified interest in the research question and in the research findings. These stakeholders must be defined for each project. In addition to the researchers themselves, in gerontological research these are generally the research subjects, i.e. older people (mostly over the age of 65) or their family members, and the practitioners who will actually apply the research findings. The term "participants" which is used in this document refers to all individuals working on a specific project. They thus constitute a subgroup within the overall group of stakeholders.

**Validity**

There are different types of validity. The present document refers to the construct, internal, and external forms. *Construct validity* describes the legitimacy of a measuring instrument, i.e. the degree to which the instrument measures what it is intended to measure or what it claims to measure. A measuring instrument, such as one used to record quality of life, is deemed valid if it actually does so, and does not capture the state of health of the subject. *Internal validity* exists if changes in dependent variables can be traced back to modifications in independent variables, or if the differences between pre-intervention and post-intervention data are genuinely attributable to that intervention. To achieve this, potential influences (confounding variables) must be monitored as effectively as possible. This can be achieved by collecting data on them or by distributing them at random among those taking part in the study. A high degree of *external* (or ecological) *validity* is said to exist where the findings of research are also true of other individuals, points in time, and situations. This can be ensured by having a representative sample (in terms of gender and age, for example), or by collecting data in real-life situations rather than under artificial laboratory conditions.

## 5 References

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