

National Research Programme Portrait (NRP 67)   
**End of Life**

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Wildhainweg 3

Postfach 8232

CH-3001 Bern

Editorial staff

advocacy ag

Design

Driven GmbH, Zurich

Photos

Hanspeter Hofmann, Basel

**NRP 67**

National Research Programme Portrait (NRP 67) 

## **End of Life**



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## How do we want to die?

Advancements in medicine and increasing affluence have led to a higher life expectancy, and most people in Switzerland now die in old age. One side effect of the many medical options open to us is that decisions have to be made, and that these decisively influence the last phase of life. Being confronted with the death and dying of family members today, or thinking about our own ideas concerning the end of life, is less frequently about fighting approaching death as it is about how to make dying "good" or least bearable.

As a consequence, how we are cared for at the end of life has changed substantially in recent years, as have our ideas about a "good dying". To understand these changes better, it is important to learn more about dying in Switzerland: What kind of care do persons receive at the end of life? How are decisions made today, and who makes them? What new challenges emerge for end of life in today's medicine, which makes almost anything possible? When is a person "allowed" to die nowadays? – These are central questions in the National Research Programme 67 (NRP 67), "End of Life".

The aim of this research programme is to generate guidance and actionable ideas in an area that has recently become a topic of public interest and debate. The main goal is to learn more about end-of-life care in Switzerland and to develop research-based information as a basis for optimizing medical practice and facilitating policy-making processes.

The research projects conducted under NRP 67 address diverse key topics, including: the costs of end-of-life care, the role of living wills, the development of palliative care, the practice of suicide assistance, persons with dementia at the end of life, and family caregivers in the balance between work and support for the dying. Connected with these topics are individual but also economic, medical, legal, and not least policy decisions, which are the focus of one of the main research areas within the programme.

This research will succeed only if it meets the highest scientific criteria, crosses disciplinary and national boundaries, and works in a target-oriented manner. The results will help us to find appropriate social and political answers to the question of how we want to die.



**Markus Zimmermann-Acklin**  
President of the NRP 67  
Steering Committee



**Jürg Steiger**  
Delegate of the National  
Research Council of the SNSF

# A better understanding of the end of life

**Within the NRP 67, 33 research projects study end-of-life issues in Switzerland. A particular research focus is placed on the care of dying persons and the decisions that are made at the end of life. Legal regulations and ethical guidelines are also examined, as are concepts and representations of a “good dying”.**

Often a taboo subject in past decades, death has recently become a topic of increasing public interest and debate. Many people and institutions today are involved with issues such as living wills, access to palliative care, assisted suicide, caring for dying family members, and treatment decisions at the end of life. Discussion on these topics is guided by differing ideas and ideals, such as ideas on what a “good dying” could be.

The NRP 67, commissioned by the Federal Council in 2010, aims to contribute to a better understanding of changes and newly emerging needs in the context of death and dying. The Federal Council approved CHF 15 million in funding for the conduct of the programme.

The research findings will identify gaps or problems in the provision of care and provide affected persons and care professionals with a useful basis for decision-making. Proposals will be developed for the adaptation of legal regulations, and ethical implications will be reflected upon. Another aim is to acquire a better understanding of social changes in perceptions of the end of life. With all of these objectives, the goal of the NRP 67 is to build up and strengthen scientific research competencies in Switzerland in the end-of-life field.

## Four main research areas

The 33 research projects within the NRP 67 study various aspects of the end of life from different disciplinary perspectives. Projects are grouped into four research modules. As at present very little is known about provision of care at the end of life and about end-of-life decision-making, the programme is focusing mainly on the first two of the following four research modules:

- “Dying processes and the provision of care”: investigates current provision of care in Switzerland and develops specific measures to improve care.

- “Decisions, motives, and attitudes”: throws light on, assesses, and redesigns current practices and decisions at the end of life.
- “Regulation and action proposals”: examines existing legal frameworks, regulations, and ethical guidelines as regards their applicability and suitability for real-world practice today.
- “Cultural concepts and social ideals”: studies how factors such as spirituality, alternative religious beliefs, and cultural backgrounds contribute to shaping ideas of a good dying.

Detailed descriptions of each research project can be found in the chapter on research in the four modules starting on page 11. In most of the projects, researchers are not only working together in different disciplines; projects also include collaborations between institutions at different locations, as well as between research institutions and practice institutions (see figure).

## Knowledge transfer: From research to practice

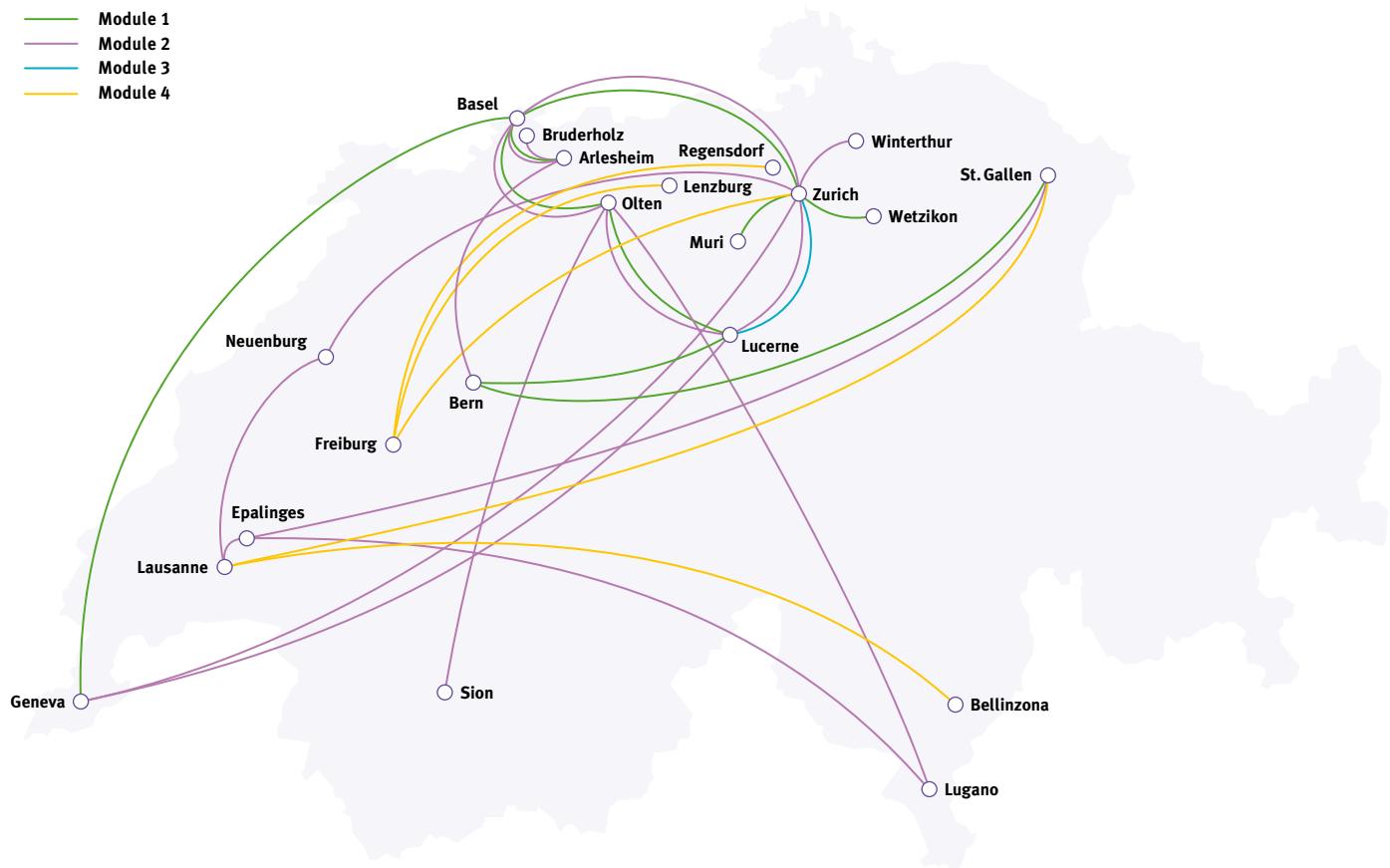
The purpose of national research programmes is to produce high-quality research findings relevant to important policy issues but also to make findings from this research available to interested audiences and discuss it with them.

Knowledge transfer within the programme aims to bridge scientific reflection and fields of practice. Target audiences are mainly decision-makers in the health care system, in government, and in relevant professional groups. Wherever possible, NRP research knowledge should also have a direct impact on medical, nursing, social, psychological, and pastoral practice. The aim is to provide persons at the end of life and care professionals with better bases for decision-making and procedures, in hospitals, care facilities, or at home.

Research findings from the NRP 67 will not be able to directly solve contemporary problems in dealing

with the end of life. But they can be expected to direct increased attention to end of life issues among the public and in the target audiences. In this way, they should facilitate important discussions and enrich them with a scientific perspective.

### National Cooperation within the Four Research Modules of NRP 67



## Programme direction and timeline

### Steering Committee



**PD Dr Markus Zimmermann-Acklin**  
Department of Moral Theology and Ethics, University of Fribourg, (President)



**Prof. Luc Deliens**  
End-of-life Care Research Group, Vrije Universiteit Brussel, Belgium, Institute for Health and Care Research of Vrije Universiteit Medical Center and Vrije Universiteit Amsterdam, The Netherlands



**Prof. Stefan Felder**  
Wirtschaftswissenschaftliches Zentrum, University of Basel



**Prof. Michael Ewers**  
Health and Human Sciences, Institute of Health Sciences Education & Nursing Science, Charité Universitätsmedizin, Berlin, Germany



**PD Dr Sophie Pautex**  
USPC, service de premier recours, University Hospital of Geneva



**Prof. Arnaud Perrier**  
Service de médecine interne générale, Département de médecine interne, University Hospital of Geneva



**Prof. Ursula Streckeisen**  
Pädagogische Hochschule Bern, and Institute of Sociology, University of Bern



**Prof. Brigitte Tag**  
Chair of Criminal Law, Criminal Proceeding and Medical Law, University of Zurich

**February 2011**

First call for proposals:  
In Switzerland Applicants to NRP 67  
submit short pre-proposals

**January 2013**

The National Research Council approves  
an additional six research projects  
(second call for proposals)

**February 2010**

The Federal Council commissions the Swiss National Science Foundation to conduct the NRP 67

**March 2012**

The National Research Council approves  
27 research projects (first call for proposals)

**September 2012**

Start of research

**Programme Coordinator**



**Dr Stephanie Marie  
Schönholzer**  
Swiss National Science  
Foundation, Bern

**Delegate of Division IV of the  
National Research Council**



**Prof. Jürg Steiger**  
Clinic for Transplantation  
Immunology and Nephrology,  
University Hospital of Basel

**Responsable du transfert  
de connaissances**



**Mathis Brauchbar**  
advocacy ag, Zurich

**Délégué de  
l'administration fédérale**



**Herbert Brunold**  
Fachstelle Evaluation und  
Forschung, Federal Office of  
Public Health FOPH, Bern

**Summer 2017**  
End of research

**End of 2018**

End of the programme: Presentation of  
programme synthesis and final conference



## Dying processes and the provision of care

The research projects in this module examine the current state of services and provision of care in Switzerland. They investigate the institutions and end-of-life options actually available today. They also study how affected persons – dying persons, physicians, nurses, and family members – experience the care situation. In addition, some projects are developing specific proposals and measures with the aim to improve the quality of end-of-life care.

# Quality of end-of-Life care from the perspective of general practitioners and family members

Caring for persons at the end of life (palliative care) is a great challenge for everyone involved. This project examines palliative care from the perspective of general practitioners (primary care physicians) and family members of patients who have died. The goal is improvement of the quality of care at the end of life.

## Background

The majority of people die after a long illness not of cancer but of heart, lung or kidney diseases and chronic illnesses of the nervous system. General practitioners often play a central role in the care of persons at the end of life, as they have known the patients and their families for years. The physicians are expected to possess high competency in the area of palliative care. This goes far beyond treating symptoms of illness at the end of life. The tasks of palliative care include communicating appropriately in these situations, ensuring the patients and their families the necessary emotional support, aiding in decision-making and coordinating the different health services involved.

## Aim

General practitioners and family members of deceased patients in all three language regions of Switzerland will be surveyed through interviews and questionnaires. The aim is to gather information mainly on the quality of care of persons at the end of life. Special attention will be paid to the education and continuing education of future general practitioners and the quality of care structures up to now. The results of the study will contribute towards the drafting of specific suggestions for improving palliative care of persons at the end of life.

## Significance

This study aims to identify gaps in care and especially general practitioners' care of persons at the end of life and to draft suggestions for improvement. The study will contribute towards improving palliative care in Switzerland.

## Original title

Conditions and quality of end-of-life care in Switzerland – the role of GPs

Duration: 36 months

Funding: CHF 303.069

Project number: 139341

## Project leaders

- Dr Klaus Bally, Institute of Primary Care, University Hospital of Basel
- Prof. Bernice Simone Elger, Institute for Biomedical Ethics (IBMB), University of Basel
- Dr Heike Gudat Keller, Hospice In The Park, Hospital of Palliative Care, Arlesheim
- Dr Dagmar Haller-Hester, Unité de Médecine de Premier Recours, Faculté de Médecine, University of Geneva
- Prof. Brigitte Liebig, Institute for Research and Development of Collaborative Processes, School of Applied Psychology, University of Applied Sciences Northwestern Switzerland (FHNW)
- Prof. Thomas Rosemann, Institute of General Practice and Health Services Research, University Hospital of Zurich
- Prof. Peter Tschudi, Institute of Primary Care, University Hospital of Basel
- Prof. Elisabeth Zemp, Swiss Tropical and Public Health Institute, University of Basel

## Contact

Dr Klaus Bally  
St. Johanns-Parkweg 2  
4056 Basel  
Phone: +41 61 321 77 44  
E-mail: klaus.bally@unibas.ch

# Assisted suicide: developments over the last 30 years

As early as in 1918, the Swiss Federal Council commented that aiding suicide was not a crime if the reason was not selfish. Twenty-four years later, this decision was anchored in the Swiss penal code in Article 115; another 40 years later, the first organisations offering suicide assistance were founded.

## Background

In the last 10 years alone, the number of persons who died by assisted suicide (AS) tripled. This number is likely to continue to increase, but exact data on this development is lacking. To gain an understanding of AS, more information on factors and motives is needed. This knowledge is highly important for policy decisions.

## Aim

This study aims to produce an overview of the last 30 years, the period since the founding of the first organisations offering suicide assistance in Switzerland, to discover the dynamics of AS. Both regional differences and differences among the organisations offering suicide assistance in procedures, documentation and clients will be investigated. This will allow factors to be identified that have had an effect on the development of AS. In addition, clients will be studied regarding their reasons for AS, with the aim of drawing up preventive measures in the context of palliative care. The study will analyse retrospectively and statistically all documents archived in Swiss institutes for legal medicine. In addition, from the project start onwards, all new deaths will be captured using the questionnaire designed for the study.

## Significance

The results of the study will provide both an overview of the current state and a retrospective and prospective outlook on the development of AS in Switzerland and can be used as a basis for further debates and decision-making.

## Original title

Assisted suicide in Switzerland – a detailed national survey over the past 30 years

Duration: 36 months

Funding: CHF 230.493

Project number: 139240

## Project leaders

- Dr Christine Bartsch, Forensic Medicine & Imaging, Institute of Legal Medicine, University of Zurich
- PD Dr Thomas Reisch, University Hospital of Psychiatry, Bern

## Co-operating institutions

- Institute of applied Psychology, Department of medical Science, UMIT – Private University, Austria
- Institutes of Legal Medicine in Switzerland
- Clinic for Social and General Psychiatry, Zurich
- Institute of Community and Preventive Medicine, University of Zurich

## Contact

Dr Christine Bartsch

Institut für Rechtsmedizin Universität Zürich  
Abteilung Forensische Medizin und Bildgebung  
Winterthurerstrasse 190/52  
8057 Zürich

Phone: +41 44 635 56 06

E-mail: christine.bartsch@irm.uzh.ch

# Priceless? The value of health care at the end of life

**What do life-prolonging measures for the dying cost, and to what extent is our society willing to pay for them? To answer these and other questions, this research project will conduct an experiment on the Swiss population's willingness to pay for health care expenditures at the end of life.**

## Background

How many of the medical treatments at the end of life have little benefit? How much should life-prolonging measures be allowed to cost? And what do people in Switzerland think about the cost and value of life-prolonging measures? These are difficult questions that society must face, for up to one-fourth of all health care costs are incurred shortly before death. In addition, it can be expected that medical advances and more intensive treatments will continue to increase the costs in the last phase of life. Due to the aging population, there is a fear that health care expenditures will one day be no longer sustainable and that this could lead to health care rationing, which is a sensitive issue.

## Aim

This project will conduct an experiment on the preferences of 1000 randomly selected persons. It will deliver information on whether society is in favour of defining a ceiling on health care expenditures shortly before death and on how high it might be. The participants will be presented with insurance models that differ in, for example, their exclusion of especially expensive medications for serious illnesses. Based on the participants' decisions, we will derive the willingness to pay for health care expenditures of predefined demographic groups and the Swiss population as a whole. In addition, the research team will examine the costs of over 70.000 deceased persons in their last year of life with regard to typical patterns of dying (such as costs connected with accidents, brief illnesses, chronic diseases) and then determine how the percentages of these patterns of dying have changed over time. This will provide an indication of whether medical care of the dying has increased in recent years or whether elderly people today are in a better state of health shortly before death. For assessing future health care expenditures, both of these findings are important factors.

## Significance

The results of this study will underpin the debate on the value and benefits of expensive health care measures at the very end of life. They might also be used in compiling guidelines to help the prevention of hidden rationing.

### Original title

Do high health care expenditures at end of life reflect preferences of the Swiss population?

Duration: 36 months

Funding: CHF 255.848

Project number: 145096

### Project leaders

- Prof. Konstantin Beck, CSS Institute for Empirical Health Economics, Lucerne
- Dr Harry Telser, Polynomics, Olten
- Dr Viktor von Wyl, CSS Institute for Empirical Health Economics, Lucerne

### Contact

Prof. Konstantin Beck  
CSS Institut für empirische Gesundheitsökonomie  
Tribschenthalstrasse 21  
6002 Luzern  
Phone: +41 58 277 11 11  
E-mail: konstantin.beck@css-institut.ch

# Regional differences in medical care at the end of life

This study examines regional patterns of utilising medical services by persons (now deceased) in the last 12 months of their lives. Regional differences indicate possible under- or oversupply of medical services in this phase of life.

## Background

Studies in many countries have shown that the extent of medical treatments in the last phase of life can vary considerably across regions. The different patterns of medical care not only reflect the effective needs of patients and their families but are also associated with different structure of supply – that is, different regional availability of hospitals, physicians, and nursing homes. This suggests that there may be inadequate provision of medical care to patients who are in a particularly sensitive phase of life.

## Aim

This study aims to document the regional variation of medical treatments at the end of life in Switzerland and to identify possible causes of different patterns of medical care. Hospitals service areas will be used as geographical units. This will allow a population-based documentation of regionally available resources (number of hospitals, medical professionals, medical equipment, etc., per 1000 residents) and their utilisation, independent of administrative or other predefined boundaries. Using data from the health insurance companies, the study will trace the patients' treatment paths for outpatient services, and care in hospitals, old peoples homes and nursing homes in the last 12 months of their lives. Regional differences in treatment intensity and the associated costs of individual patients will be determined and examined in connection with the regionally available medical services.

## Significance

The results will support an efficient and equitable access to the best available care for a population during the last twelve months of life.

## Original title

Regional and temporal variation in end of life care in Switzerland

Duration: 36 months

Funding: CHF 336.903

Project number: 139333

## Project leaders

- Prof. André Busato, Institute of Social and Preventive Medicine (ISPM), University of Bern (deceased in November 2013)
- Prof. Andreas E. Stuck, University Hospital of Bern
- Prof. Matthias Egger, Institute of Social and Preventive Medicine (ISPM), University of Bern
- Prof. David C. Goodman, The Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH, USA

## Contact

Prof. Matthias Egger

Universität Bern

Institut für Sozial- und Präventivmedizin (ISPM)

Finkenhubelweg 11

3012 Bern

Phone: +41 31 631 35 55

E-mail: egger@ispm.unibe.ch

# Active preparation for the end of life with patients with advanced cancer: A way to reduce stress and increase self-determination?

Talking about and clarifying questions about the end of life early on can have a positive effect on quality of life in the last phase of life. This randomized study will investigate the effect of a structured approach for clarifying open questions early on.

## Background

Persons with progressive cancer have a great many questions and often experience massive stress and strains. They have unanswered questions about the physical impairments that they can expect, what they can do about their own helplessness, and how and where they should spend the rest of their life. Persons with cancer want to know what medical treatments are available, what measures they can expect, what professional and private support will be needed and where their family members can get support.

## Aim

This study, called the SENS study, will investigate to what extent systematic discussion of these questions as soon as possible can lead to a discernible reduction of stress in patients and their family members. Parallel to the regular oncological treatment, in one or more consultations a palliative care team member will use a specific document to discuss important areas. The participants who will take part in this study will be chosen at random in the framework of a randomized study. During oncological consultations, one member of the palliative care team will discuss open questions and concerns using the document described above. The document is designed as a worksheet to be used over a longer period of time and is in the possession of the patient. Each month, the study participants receive a letter with a short questionnaire on their condition/state of health, especially regarding their quality of life. The data will be anonymized and prepared for analysis and evaluation.

## Significance

There is sound evidence in the research literature that discussions at an early stage and advance care planning have a favourable effect on coping with this difficult phase of life and ultimately has a positive effect on the person's life time remaining, mainly through stress reduction. We will examine the extent to which systematic, problem-oriented advance planning, together with tumour-specific treatment, facilitates and promotes partnership-like division of tasks between patient, family members and health care professionals. In addition, this can also help to reduce emergency measures, insufficient clarity and unnecessary costs.

## Original title

A structured early palliative care intervention for patients with advanced cancer – a randomized controlled trial with a nested qualitative study

Duration: 39 months

Funding: CHF 331.323

Project number: 145088

## Project leaders

- Dr Steffen Eychmüller, Center of Palliative Care, University Hospital of Bern
- Monica Fliedner, Center of Palliative Care, University Hospital of Bern

## Further institutional partners

- Oncology and Palliative Care Center, Canton Hospital of St. Gallen
- Medical Oncology, Canton Hospital of Lucerne

## Contact

Dr Steffen Eychmüller  
Palliativzentrum Inselspital  
Universitätsspital Bern  
SWAN Haus  
Freiburgstrasse 28  
CH-3010 Bern  
Phone: +41 31 632 50 40  
E-mail: steffen.eychmueller@insel.ch

# Dying at the beginning of life

Parents who learn that their unborn child has a terminal condition face an enormous challenge. This project aims to throw light on dealing with the death of the child from the perspective of the parents and health care professionals.

## Background

When parents receive a prenatal diagnosis of their child's terminal condition, they are usually confronted with the decision to terminate the pregnancy. With this decision, parents are said to experience "chosen losses" and "lost choices", which makes clear the inevitability of the loss of a desired child. After termination of the pregnancy, the parents commonly experience grief reactions but also mental and psychiatric disorders. Studies have shown that caring for parents guided by their needs can ease their burden and support them as they deal with the death of the child regardless of whether they choose to continue or terminate the pregnancy. This study is investigating what care and support services are available in Switzerland today and examining whether changes are needed to make this care and support need- and family-oriented.

## Aim

This project aims to throw light on having to deal with the death of the child from the perspective of the parents and health care professionals. Based on the findings, recommendations will be made for the design of future interprofessional care and support services. For this purpose, a minimum of 30 parents and 30 health care professionals will be questioned.

## Significance

The results of this project will contribute towards a rethinking of current practice, based on the experiences of parents and health care professionals. On this basis, recommendations will be made for improving care by and cooperation among health care personnel. All in all, this should contribute towards the prevention of serious health consequences in the long term.

### Original title

Dying at life's beginning

Duration: 24 months

Funding: CHF 119.551

Project number: 139359

### Project leader

- Prof. Valerie Fleming, School of Health Professions, Zurich University of Applied Sciences, Winterthur

### Contact

Prof. Valerie Fleming  
Zürcher Hochschule für Angewandte Wissenschaften  
Departement Gesundheit  
Technikumstrasse 9  
CH-8400 Winterthur  
Phone: +41 58 934 64 64  
E-mail: flem@zhaw.ch

# Access to palliative care for patients with chronic obstructive pulmonary disease (COPD)

Chronic obstructive pulmonary disease (COPD) is a common and, despite existing treatment options, progressive lung disease. Patients with COPD often have only limited access to palliative care. The goal of this research project is to improve the quality of life of patients with COPD.

## Background

In many cases, the symptoms of advanced COPD (including shortness of breath, pain and depression) are insufficiently alleviated. In addition, often in connection with an infection, patients frequently suffer from respiratory decompensation; this may lead to invasive interventions as well as the admission to the emergency room or an intensive care unit. It may ultimately lead to the death of the patient.

## Aim

This study aims to show that early palliative care can reduce the number of necessary invasive interventions and improve the quality of life of patients with COPD. For this purpose, a group of patients receiving early, standardized palliative care will be compared to a group of patients receiving customary treatment only, without systematic intervention by palliative care experts.

## Significance

The results of this study should make it possible to efficiently use the medical resources, which are required for the appropriate care of patients with COPD. The goal is the best possible quality of life and better coordination of the measures taken, especially with regard to the area of acute care and the wishes of the patient.

## Original title

Introduction de soins palliatifs précoce chez des patients avec une maladie pulmonaire obstructive chronique

Duration: 36 months

Funding: CHF 211.726

Project number: 145086

## Project leaders

- Prof. Jean-Paul Janssens, Division of Pulmonary Diseases, University Hospitals of Geneva
- Dr François Herrmann, Department of Geriatrics, University Hospitals of Geneva
- Dr Catherine Weber, USPC, Department of Primary Care, University Hospitals of Geneva

## Contact

Professeur Jean-Paul Janssens  
Service de pneumologie  
Département des spécialités  
Hôpitaux Universitaires de Genève  
Rue Gabrielle-Perret-Gentil 4  
1211 Genève  
Phone: +41 22 372 95 48  
E-mail: jean-paul.janssens@hcuge.ch

# Pathways of end-of-life care of the elderly with multimorbidity

The risk of overprovision of medical care is high for elderly persons with co-occurrence of illnesses. This study examines the factors that influence elderly patients' pathways of care at the end of life through the hospitals and nursing homes in Switzerland.

## Background

Medical advances and the aging of the population in the last decades have resulted in more and more elderly persons with multiple, often chronic illnesses. This multimorbidity often leads to intensive medical care, frequently by several specialists. Sometimes neither the patients nor their family want the medical measures, and occasionally the measures are not medically advisable. In addition, unnecessary health costs are incurred.

## Aim

This study will investigate how much time elderly people at the end of life spend in hospitals and nursing homes, how intensive the medical care that they receive is, where they die, and what regional, cultural, social and economic factors determine their pathways through the medical institutions. The research team will utilise three Swiss databases: the Swiss National Cohort, the hospitals' medical statistics and the statistics recorded by social-medical institutions. This will make it possible to track the paths of individuals through the medical institutions during the last years of their lives and to examine the relationship between these pathways and regional, cultural and other factors.

## Significance

The results of this study can be an aid to adapting the health care system to the needs of the dying and their family members. In addition, the results can be useful in the debate on the sensible distribution of medical resources.

## Original title

Multimorbidity and pathways of inpatient care at the end of life: a national study in Switzerland

Duration: 36 months

Funding: CHF 305.954

Project number: 139331

## Project leaders

- Dr Vladimir Kaplan, District Hospital for Muri (Freiamt)
- Dr Mathias Bopp, Institute of Social and Preventive Medicine, University of Zurich

## Contact

Dr Vladimir Kaplan  
Kreisspital für das Freiamt Muri  
Spitalstrasse 144  
5630 Muri  
Phone: +41 56 675 11 11  
E-mail: vladimir.kaplan@spital-muri.ch

# Family caregivers in critical end-of-life situations

**When caring for persons at the end of life, critical situations may arise for family caregivers. This study examines how caregivers perceive these situations and how they deal with them. The aim is to develop measures to empower and support family caregivers in order to prevent stressful hospital admissions of dying persons.**

## Background

Many people would prefer to spend their last days at home. Family members, friends, and acquaintances are often committed to fulfilling this wish. Nevertheless, many people die in hospitals or homes, due to emergency hospital admissions shortly before they pass away. The deciding factors are mental and physical strain on the part of all involved, lack of knowledge about suffering and dying and on how to deal with typical symptoms, but also insufficient support from or even inappropriate reactions on the part of professionals in critical situations. Seeing their family members spending their last days in the intensive care unit is often stressful for family members. They feel guilty because they were not able to fulfil the dying person's wish to die at home.

## Aim

This study will examine critical situations at the end of life of persons who are being cared for at home. Family caregivers will be asked what kind of services and which conditions would be needed to avoid unnecessary hospital admissions. To investigate the effects of various conditions and cultural differences, the study will be conducted in the French- and German-speaking parts of two cantons, Valais and Fribourg. The research team will learn from the experience of specialists in various organisations. In addition, extensive interviews will be conducted with family caregivers and other people close to those at the end of life.

## Significance

The results will lead to the development of instruments and workshops that reinforce and support family caregivers and specialists in caring for dying persons. On the one hand, this will contribute to fulfilling the widespread wish to spend the last days at home. On the other hand, to know how to deal with critical situations will provide considerable relief for family members as well as for the health care system as a whole.

### Original title

Informal caregivers in critical end-of-life situations

Duration: 24 months

Funding: CHF 282.836

Project number: 139243

### Project leader

- Dr Beat Sottas, sottas formative works, Bourguillon

### Contact

Dr Beat Sottas

sottas formative works

Rue Max von Sachsen 36

1722 Bourguillon

Phone: +41 43 222 50 29

E-mail: [sottas@formative-works.ch](mailto:sottas@formative-works.ch)

# Communication Skills in End-of-Life Care

End-of-life care presents challenges to physicians and nurses in their communication skills. This study will develop a training programme with the goal to improve physicians' and nurses' communication skills when providing end-of-life care.

## Background

The quality of physicians' and nurses' communication with patients is determined not only by their medical competence but also by their psychological skills. Complex issues and emotionally-charged topics like dying and death should be discussed with the persons affected – who are often quite vulnerable with regard to their cognitive and emotional state – in a professional manner.

## Aim

This study will develop a training programme on communication at the end of life. The training programme will be based on an analysis of the training needs of physicians and nurses who care for dying patients. The most important issues regarding end of life, the associated psychological challenges, and required communication skills will be identified by means of group discussions (focus groups) with physicians and nurses. Based on this analysis, a specific training programme will then be designed, and its effectiveness will be tested in a pilot study.

## Significance

The training programme for "communication at the end of life" developed in this study aims to enable physicians and nurses to be more competent when facing patients whose death is foreseeable. Through self reflection, training in specific communication skills and insight with regard the clinician-patient relationship, clinicians should learn how to respond adequately to the needs of the patients.

### Original title

Communication skills in end-of-life care

Duration: 30 months

Funding: CHF 387.473

Project number: 139248

### Project leaders

- Prof. Friedrich Stiefel, Service of Liaison Psychiatry, University Hospital of Lausanne (CHUV)
- Prof. Pascal Singy, Service of Liaison Psychiatry, University Hospital of Lausanne (CHUV)

### Contact

Prof. Friedrich Stiefel  
Service de Psychiatrie de Liaison, CHUV  
Rue du Bugnon 44  
1011 Lausanne  
Phone: +41 21 314 10 84  
E-mail: [frederic.stiefel@chuv.ch](mailto:frederic.stiefel@chuv.ch)

# Palliative care for persons with intellectual disability

**Demographic changes in Switzerland have an effect on the care provided in residential facilities for persons with intellectual disability. Are the facilities prepared for this change? Can persons with intellectual disability living in residential facilities have self-determination at the end of life?**

## Background

More and more old persons are being cared for in residential facilities for persons with intellectual disability. Because incurable and chronic illnesses occur more often in old age, there is an increase in the care and support required. But to date there is no data available on palliative care of terminally ill or old and dying persons with intellectual disability living in residential facilities.

## Aim

This study aims to investigate the situation of adults with intellectual disability at the end of their lives who live in residential facilities for persons with disability. In Switzerland, care of persons at the end of life varies in quality. It is not known how well the residential facilities for persons with disability are prepared for the end of life of their residents. This study will survey residential facilities for persons with intellectual disability using a questionnaire on current possibilities for end-of-life care, on guidelines, and on adult residents' participation in decision-making. In addition, problem-centred, guided interviews will be conducted with care personnel, nurses, physicians and outpatient palliative care teams.

## Significance

The study will deliver important basic information for research, practice and policy. The data will make it possible to define factors that are useful for a self-determined course of the end of life of adults with intellectual disability. In addition, the study will aid planning of the required services in the area of palliative care. It will provide an overview of currently available services and the needs of adults with intellectual disability at the end of life.

## Original title

PALCAP Palliative care for people with intellectual disabilities

Duration: 36 months

Funding: CHF 194.546

Project number: 139324

## Project leaders

- Dr Monika T. Wicki, University of Applied Sciences of Special Needs Education (HfH), Zurich
- Judith Adler, University of Applied Sciences of Special Needs Education (HfH), Zurich

## Co-operating institutions

- Curaviva Schweiz –Federation of Care Homes and Institutions in Switzerland
- Dialog Ethik – interdisciplinary institute for ethics in the health care system
- Insos Schweiz – national interbranch association of the institutions for people with disabilities
- Institut Neumünster Zollikerberg
- Center for Gerontology, University of Zurich (ZFG)

## Contact

Dr Monika T. Wicki  
Interkantonale Hochschule für Heilpädagogik  
Schaffhauserstrasse 239  
Postfach 5850  
8050 Zürich  
Phone: +41 44 317 12 34  
E-mail: monika.wicki@hfh.ch

# How do persons with advanced dementia experience the end of life?

According to estimates, one in three or four Swiss persons will develop dementia in their lifetime. This study examines the end of life of persons with advanced dementia living in care facilities in the Zurich area.

## Background

Dementia is the third leading cause of death. The majority of persons with an advanced stage of dementia die in care facilities. Little is known about the last phase of life of persons with advanced dementia. The researchers will collect internationally comparable data on the health status, care and treatment situation, quality of life and quality of death of persons with advanced dementia.

## Aim

This study will examine residents at inpatient care facilities in the Zurich area for a period of three years. It will evaluate the medical files of approximately 1600 persons to identify factors in the course of care and treatment complications (such as behavioural problems, falls, serious concomitant diseases) and the mortality rate. In addition, the study will survey family members of 200 residents with advanced dementia and the staff members responsible for their care on the topics of quality of life and quality of and satisfaction with treatment. Here special attention will be devoted to the dying phase of the residents and their palliative care.

## Significance

The study will deliver important information on the course and especially the dying phase of dementia. This knowledge can help the persons affected, their family members, and also physicians and nursing staff to make certain decisions (such as for advance directives, or if there are complications, decisions on medical tests and hospital admissions). Further, the study will reveal how satisfied family members and nurses are with the care of persons with dementia. This will help facilities to improve the quality of their care services. The analysis of factors that contribute towards quality of life in dementia will yield important conclusions. Based on that, recommendations will be made, for family members for instance, regarding how quality of life can be better maintained into the stage of advanced dementia.

## Original title

The Zurich Life and Death with Advanced Dementia Study (ZULIDAD)

Duration: 48 months

Funding: CHF 476.072

Project number: 139363

## Project leaders

- Dr Henrike Wolf, Gerontopsychiatry Center Hegibach, University Hospital for Psychogeriatric Medicine, University of Zurich
- Prof. Mike Martin, Center for Gerontology, University of Zurich
- Dr Florian Riese, Gerontopsychiatric Centre Hegibach, University Hospital for Psychogeriatric Medicine, University of Zurich
- Dr Albert Wettstein, Center for Gerontology, University of Zurich
- Prof. Christoph Hock, Gerontopsychiatry Center Hegibach, University Hospital for Psychogeriatric Medicine, University of Zurich

## Co-operating institutions

- Municipal medical services of the city of Zurich
- Nursing home and centre of excellence Sonnweid, Wetzikon

## Contact

ZULIDAD

Dr Florian Riese

Psychiatrische Universitätsklinik Zürich

Gerontopsychiatrisches Zentrum Hegibach

Minervastrasse 145

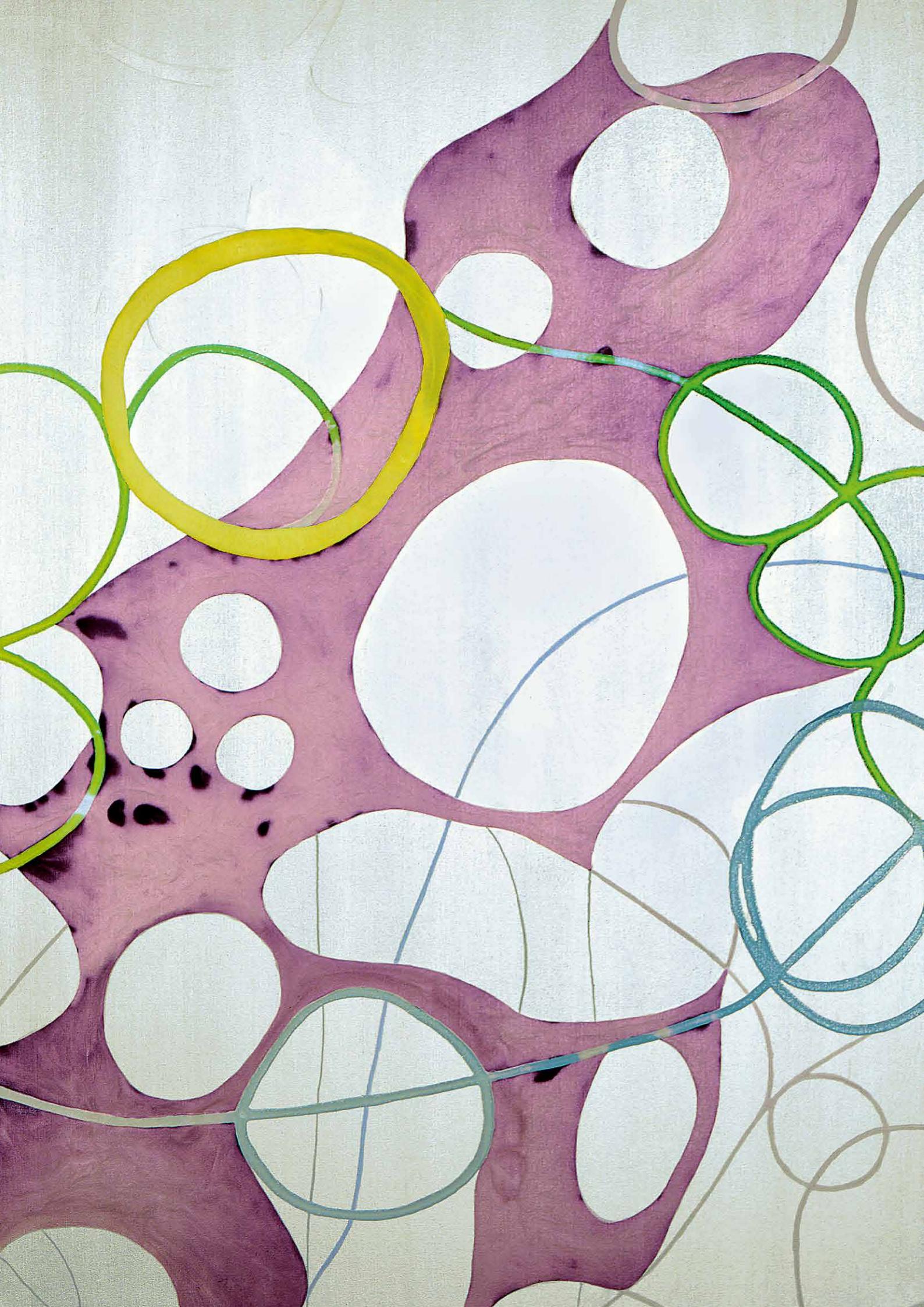
8032 Zürich

Phone: +41 44 389 14 15

E-mail: florian.rieze@bli.uzh.ch

## website

[www.zfg.uzh.ch/projekt/zulidad.html](http://www.zfg.uzh.ch/projekt/zulidad.html)



## Decisions, motives, and attitudes

The research projects in this module aim to contribute to a better understanding and assessment of current practices and decisions at the end of life with the goal of improving them. The main focus is on the situation in medical clinics and long-term care facilities; another goal is to improve our understanding of decision-making processes in care of the dying.

# End-of-life decisions for extremely preterm infants in Switzerland

For extremely premature infants life support decisions must often be made. What factors are considered in these decisions in Switzerland, and are there differences among the perinatal care centres?

## Background

Each year in Switzerland approximately 200 to 250 extremely preterm infants (less than 28 weeks gestation) are born. Many of these infants die in the delivery room (about 20 per cent) or later in the neonatal intensive care unit (about 25 per cent). In connection with these deaths, it has been discussed whether life-sustaining treatment is appropriate or whether palliative care in the delivery room would be preferable. Retrospective studies suggest that relevant factors for these decisions are weighted differently at the different perinatal care centres in Switzerland. Centre-specific characteristics probably have a considerable influence on the survival rates of extremely preterm infants.

## Aim

In this study the research team aims to analyse how end-of-life decisions for extremely preterm infants are made. For a study period of two years, all deaths of extremely preterm infants will be captured. In addition to demographic data – including identification of the perinatal care centre that cared for the infant – the patients' physiological stability and the extent of intensive care measures applied will be collected. The team will also gather information on how decisions to withhold intensive care measures or to discontinue measures were made and on what role the parents of the infant had in the decision.

## Significance

There are considerable centre-to-centre differences in survival rates of extremely preterm infants at Switzerland's nine perinatal care centres. It is important to gain a better understanding of these differences, so that quality improvement measures can be developed. Life support treatment decisions for extremely preterm infants must be based primarily on recognised ethical fundamental principles and, regarding prognostic considerations, must be as evidence-based as possible. In these decisions, the location (centre) where care is given should not play a significant role.

## Original title

End-of-life decision-making in extremely low birth weight infants in Switzerland

Duration: 36 months

Funding: CHF 232,297

Project number: 40740\_139303

## Project leaders

- Prof. Thomas M. Berger, Neonatal and Paediatric Intensive Care Unit, Children's Hospital of Lucerne
- Dr Ruth Baumann-Hölzle, Dialog Ethik Institute (interdisciplinary institute for ethics in health care), Zurich
- Prof. Jean-Claude Fauchère, Department of Neonatology, University Hospital Zurich
- Dr Matteo Fontana, Neonatal and Paediatric Intensive Care Unit, Children's Hospital of Lucerne
- Dr Riccardo Pfister, Neonatal and Paediatric Intensive Care Unit, Hôpital des Enfants, University Hospitals of Geneva (HUG)

## Contact

Prof. Thomas M. Berger

Kinderspital Luzern

Neonatologische und Pädiatrische Intensivstation

Spitalstrasse

6000 Luzern

Phone: +41 41 205 32 85

E-mail: thomas.berger@luks.ch

# **Supporting a dying relative: between working and end-of-life care**

**High expectations are placed on family members of persons in end of life situations: working and supporting a dying relative can lead to important tensions. This study seeks to understand the reality of caregivers' lives so that support measures can be drawn up.**

## **Background**

Terminally ill persons often receive support by their closest relatives. These informal caregiving family members (parents, children, spouses, friends) usually work at the same time, so that their burdens are heavy. How do they deal with the competing demands of working and supporting a dying relative? Do they want to, and can they, reprioritise the different tasks? What resources can they mobilise to support their dying relative adequately? This study wants to find answers to these questions and build a bridge between the world of caregiving and the world of employment.

## **Aim**

This study aims to contribute towards better integration of employed persons in supporting their dying relative. Its objective is to create a satisfactory situation at work for everyone involved (employer, employees, family member, care assistants). Using an anthropological research approach, approximately 20 life situations will be documented. The researchers will conduct observations and interviews with different persons involved to gain an understanding of the hurdles that employees must overcome in this situation.

## **Significance**

Employed family members should be relieved; at the same time this study will help decision-makers to improve support services for family members who are giving care to their dying relative. The results should help nursing staff to better understand the pressures of working and supporting a dying relative. The study will also collect data that can inform the coming policy debate on care leaves and alternative models. The legal framework conditions in Switzerland today are restrictive: family members caring for a sick child are granted only a three-day leave of absence.

## **Original title**

Working and supporting a dying relative:  
reconciling employment and palliative care in  
'end of life' situations

Duration: 36 months

Funding: CHF 324.902

Project number: 139246

## **Project leaders**

- Prof. Marc-Antoine Berthod, School of Social Work and Health (EESP), University of Applied Sciences and Arts Western Switzerland
- Dr Yannis Papadaniel, School of Social Work and Health (EESP), University of Applied Sciences and Arts Western Switzerland

## **Co-operating institutions**

- Raiffeisen bank
- Assistance and Prevention Centre for experts
- at the schools (CAPPES) in Neuchâtel
- Espace Pallium
- Valais Hospital (GNW)
- University Hospital of Lausanne (CHUV)
- Rive-Neuve Foundation
- Office for social insurances and in-care placements in the canton of Vaud

## **Contact**

Prof. Marc-Antoine Berthod  
Haute école de travail social et de la santé  
Chemin des Abeilles 14  
1010 Lausanne  
Phone: +41 21 651 62 43  
E-mail: marc-antoine.berthod@eesp.ch

# End-of-life decision-making in paediatric oncology

End-of-life decisions for minors are the result of complex considerations. They require a multi-layered medical, social, ethical and legal approach to consider the different points of view.

## Background

Until today, there has been a lack of studies on minors' rights to be heard and to have their wishes respected in healthcare. This study looks at children who were recently diagnosed with cancer or who are receiving cancer treatment. The opinions of these children, their parents and oncologists will be explored. The study participants are recruited at member clinics of the Swiss Paediatric Oncology Group (SPOG). A survey will be used to obtain a detailed picture of how end-of-life decisions for minors are currently made. Furthermore, interviews with oncologists, parents and the minors themselves will provide insights into the attitudes and reasons connected with these difficult decisions.

## Aim

The goal of this study is to examine the extent to which minors with cancer can be included in decision-making concerning treatments at the end-of-life. The information gained should depict the circumstances and conditions of these decision-making processes.

## Significance

The study aims at contributing to a better understanding of this complex issue and thus to a more informed decision-making concerning minors' autonomy. The findings will provide a basis for evaluating how and to what extent minors should be included in their treatment decisions. Study results could be used as guidelines by practicing physicians, researchers, bio-ethicists and policy makers. In addition, the study should contribute at both national and international levels to debates concerning autonomy of minors when it comes to health care decisions in general and difficult end-of-life decisions in particular.

## Original title

Attitudes and motives concerning end-of-life decisions: competency and autonomy of children and adolescents in paediatric oncology

Duration: 36 months

Funding: CHF 291.649

Project number: 139283

## Project leaders

- Prof. Bernice Elger, Institute of Biomedical Ethics, University of Basel
- Prof. Thomas Kühne, Department of Pediatric Oncology/Hematology, University Children's Hospital (UKBB) of Basel
- Prof. Felix Niggli, Division of Oncology, University Children's Hospital of Zurich

## Contact

Prof. Bernice Simone Elger

Universität Basel

Institut für Bio- und Medizinethik Basel (IBMB)

Missionsstrasse 24

4055 Basel

Phone: +41 61 260 11 21

E-mail: b.elger@unibas.ch

# Factors in intensive care unit admission decisions

Persons at the end of life are often admitted to intensive care units (ICUs). This study examines how physicians make the decision to admit or not admit a seriously ill hospitalized patient to the ICU.

## Background

Intensive care is a special and costly medical service. A patient in the ICU is under a great deal of physical and emotional burden. The aim is to significantly increase survival rates and quality of life. At the same time, transfers to the ICU must be done with the patients' agreement. The patients are mainly frail and elderly persons and persons with serious illnesses and therefore poor prognoses. The decision-making process has to be fair. When the circumstances are assessed, all patients should be treated equitably.

## Aim

This study aims to find out what factors form the basis for physicians' decisions to transfer or not transfer a hospital patient to the ICU. Interviews with internists and intensive care physicians form one part of the study. In addition, decision criteria will be evaluated by questionnaire. The study aims to find out, for one, whether ICU physicians' assessments of the likelihood of death of patients planned to be transferred to the ICU are the same as ward physicians' assessments. For another, the aim is to uncover what factors these assessments are based on.

## Significance

The results of the study should contribute towards discovering possible improvements in admission of patients to the ICU and towards developing strategies for equitable distribution of these health care resources.

## Original title

Medical and non-medical factors that influence the decision to admit a seriously ill patient to intensive care

Duration: 36 months

Funding: CHF 233.271

Project number: 139304

## Project leaders

- Dr Monica Escher, Pain and Palliative Care Consultation, Division of Clinical Pharmacology and Toxicology, University Hospitals of Geneva
- Prof. Pierre Dayer, Division of Clinical Pharmacology and Toxicology, HUG
- Dr Patricia Hudelson, Department of Community Medicine and Primary Care, HUG
- Prof. Mathieu Nendaz, Department of Internal Medicine, HUG
- Prof. Thomas Perneger, Division of Clinical Epidemiology, HUG
- Prof. Bara Ricou, Intensive Care Unit, HUG

## Contact

Dr Monica Escher

Hôpitaux universitaires de Genève (HUG)

Équipe mobile douleur et soins palliatifs

Service de pharmacologie et toxicologie cliniques

Rue Gabrielle Perret-Gentil 4

1211 Genève 14

Phone: +41 22 382 99 32

E-mail: monica.escher@hcuge.ch

# Extremely preterm infants born at the limit of viability: factors in decision-making

**Extremely preterm infants run a high risk of severe impairment or death. Life support decisions are not always taken in the interest of the child. What factors play a role in the decision-making, and what differences are there between people involved and society at large?**

## Background

When a difficult medical decision must be made for an extremely preterm infant, physicians and parents tend to act not only in the interest of the child. Other factors, such as personal attitudes and values, also play an important role in decisions at the end of life. These in turn are influenced by age, professional experience, culture and religious attitudes.

## Aim

This study aims to examine attitudes and values that play a role in end-of-life decisions for preterm infants. It will focus on all physicians and nurses working in neonatal intensive care units in Switzerland. Of great interest is the effect on these health care providers of the long-lasting strain of working with seriously ill newborn infants, and of the ethical dilemmas that arise with difficult and wearing decision-making. In addition, this study will investigate attitudes and values concerning extremely preterm infants in parents and in society at large.

## Significance

This study will deliver important new information on how physicians' and nurses' personal attitudes and values have an influence on end-of-life decisions. In addition, the chronic stress of difficult medical and nursing situations at the end of life of extremely preterm infants will be described. This knowledge, together with the results of the survey of parents and the population, will make a broad and open discussion on this difficult decision-making possible. The findings will be valuable with regard to the care of extremely preterm infants but also for other intensive care disciplines.

## Original title

Attitudes and values among health care providers, parents and society regarding end-of-life decision-making in extremely preterm infants in Switzerland

Duration: 36 months

Funding: CHF 394.859

Project number: 139350

## Project leaders

- Prof. Jean-Claude Fauchère, Department of Neonatology, University Hospital of Zurich
- Prof. Hans Ulrich Bucher, Department of Neonatology, University Hospital of Zurich
- Prof. Thomas M. Berger, Neonatal and Paediatric Intensive Care Unit, Children's Hospital of Lucerne
- Dr Ruth Baumann-Hölzle, 'Dialog Ethik', Interdisciplinary institute for ethics in health care, Zurich

## Contact

Prof. Jean-Claude Fauchère  
Universitätsspital Zürich  
Klinik für Neonatologie  
Frauenklinikstrasse 10  
8091 Zürich  
Phone: +41 44 255 35 84  
E-mail: jean-claude.fauchere@usz.ch

# The wish to die in persons with serious illness

**It is normal for persons with advanced, incurable diseases to have thoughts about dying and also sometimes to experience a wish to die. This research project will highlight the patient's perspective and derive possible measures for appropriate care and support.**

## Background

The reasons behind a wish to die in persons with serious illness are mostly complex. The wish to die is closely connected with treatability and course of the illness, with the quality of life experienced, with the patients' own biographies, with their needs, attitudes and concerns, but it is also connected with the immediate environment and society. There has been little research on how persons with serious illness themselves view their wish to live and to die and what their reasons are. This is especially true for persons with incurable, non-cancer diseases.

## Aim

The aim is to survey 30 persons with incurable, advanced non-cancer diseases on their life situation and quality of life, their attitudes, concerns and needs. Based on their responses, conclusions will be drawn regarding the intentions behind, reasons for, meanings, and functions of the wish to die, how these change over the course of time and how they are weighed against each other. Close relatives and the health care professionals will be asked about the patient's situation and their own attitudes. Special attention will be focused on the effect of family members' and health care professionals' attitudes on patients' decisions. The study method follows an interpretive phenomenological approach and was developed in a previous study that investigated similar questions with persons suffering from cancer. The model for structured analysis of the wish to die developed in that study will be used in this NRP 67 study.

## Significance

The findings of this study should help us to better understand persons who in the face of near death are dealing with the realization that life is finite and with their own death. This will contribute towards an improved medical-ethical view and assessment of the wish to die as well as to better decision making, care and support of persons at the end of life.

## Original title

Palliative non-oncology patients' wish to die. The attitudes and concerns of patients with neurological diseases, organ failure or frailty about the end of life and dying

Duration: 36 months

Funding: CHF 267.663

Project number: 145089

## Project leaders

- Dr Heike Gudat Keller, Hospiz im Park, Hospital for Palliative Care, Arlesheim
- Prof. Christoph Rehmann-Sutter, Institute for Biomedical Ethics, University of Basel, and Institute for the History of Medicine and Science Studies (IMWGF), University of Lübeck
- Dr Kathrin Ohnsorge, Hospiz im Park, Hospital for Palliative Care, Arlesheim, and University of Padua

## Cooperation partners

- Prof. Guy Widdershoven, Department of Medical Humanities, VU University Medical Center, Amsterdam, The Netherlands
- Dr Rouven Porz, Ethics Unit, University Hospital of Bern
- Department of Acute Geriatrics, University Hospital of Basel (Prof. R. Kressig)
- Institute for Primary Care Medicine, University Hospital of Basel (Prof. P. Tschudi)
- University Clinic of Medicine, Canton Hospital of Bruderholz (Prof. J. Rutishauser)
- Department of Medical Oncology, St. Claraspital, Basel (Prof. Ch. Ludwig and PD Dr D. Köberle)
- REHAB Basel (PD Dr M. Hund-Georgiadis)

## Contact

Dr Heike Gudat Keller  
Hospiz im Park, Klinik für Palliative Care  
Stollenrain 12  
4144 Arlesheim  
Phone: +41 61 706 92 22  
E-mail: heike.gudat@hospizimpark.ch

# Medical end-of-life decisions: prevalence and trends in Switzerland

Advances in medicine have made it increasingly possible to extend the end of a person's life. Medical decisions that have a direct influence on how long the patient lives are becoming ever more frequent. This study examines the decision-making practice regarding the use of life prolonging procedures or withholding or withdrawing such procedures.

## Background

Medical care and life prolonging procedures at the end of life, as well as the patient's right to self-determination have been the subject of broad public and political discussions for years. In addition to ethical aspects, the question of financial viability is being raised more and more, particularly as medical progress increasingly enables prolonging terminal illness. Reliable information on medical end-of-life decision-making practice is scarce. It can be assumed that the decision-making is not only defined medically but is also influenced by cultural norms and the attitudes of patients, family members and treating physicians.

## Aim

This study aims to deliver valid and up-to-date information on the type and prevalence of medical end-of-life decisions in Switzerland. Comparisons will be drawn between the different language regions of Switzerland and with other European countries. A comparison with the first study of this kind in Switzerland, conducted in 2002, will also provide insights on developments and trends. The starting point will be 9000 randomly sampled death certificates from the German-, French-, and Italian-speaking parts of Switzerland. For each death certificate, the issuing physician will be asked what medical procedures were used, for what reason, prior to the death of the patient, and how the decision-making processes went, and who was involved in the decision-making.

## Significance

This study will provide a reliable evidence base and landmark for medical practice, policy decisions, and development of guidelines, but also for public discussion. The results should lead to improved awareness of ethical aspects of medical end-of-life decisions and contribute towards improving the quality of life of persons with terminal illness.

## Original title

Medical end-of-life decisions: prevalence and trends in Switzerland

Duration: 36 months

Funding: CHF 360.991

Project number: 139309

## Project leaders

- Prof. Felix Gutzwiller, Institute of Social and Preventive Medicine, University of Zurich
- Dr Georg Bossard, Alterszentrum Oberi, Winterthur
- Dr Karin Faisst, Institute of Social and Preventive Medicine, University of Zurich
- Prof. Samia Hurst, Institute of Biomedical Ethics, University of Geneva
- Dr Christoph Junker, Health Section, Swiss Federal Statistical Office, Neuchâtel
- Prof. Milo Puhan, Institute of Social and Preventive Medicine, University of Zurich

## Co-operating institutions

- Federal Office for Statistics (BFS), Neuchâtel
- Swiss Academy of Medical Sciences, Basel
- End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Belgium
- Institute for biomedical ethics, University of Geneva

## Contact

Prof. Felix Gutzwiller  
Universität Zürich  
Institut für Sozial- und Präventivmedizin  
Hirschengraben 84  
8001 Zürich  
Phone: +41 44 634 46 10  
E-mail: felix.gutzwiller@ifspm.uzh.ch

# Cost at the end of life from an economic perspective

This project will develop a theory for assessment of the total utility social benefit of life-prolonging measures. The most important associated variables will be estimated empirically and compared with the costs incurred. The project will deliver an economic basis for the regulation of health care services at the end of life.

## Background

Industrialized countries are spending an increasing percentage of the national income on health. Approximately one-fourth of these health care costs are incurred in the last year of life. Based on traditional valuation methods, the very high costs appear to produce a very relatively low benefit in the form of additional lifetime (often only a few months) or better quality of life. This raises the question as to whether and how access to life-prolonging measures should be rationed.

## Aim

The central aim of this study is an economic analysis of medical care at the end of life. On the one hand, the project examines the theoretical valuation of life-prolonging medical interventions in cases with very high mortality risks, as traditional methods for assessing this mortality risk valuation are not appropriate. On the other hand, the project will define benefits that go beyond the actual prolonging of life, such as further development of drugs or the possibility to say goodbye to family and friends.

## Significance

The theory developed in this project will serve as a basis for empirical estimation of the most important direct and indirect benefits of life-prolonging measures, which can be compared with the costs. The study will use patient data (diagnosis, treatment and the associated flat rate) from Swiss hospitals and time series of medication prices. To capture benefits that cannot be measured directly, a survey will be conducted with patients, family members and healthy persons on their willingness to pay the cost of various interventions. The theoretical and empirical results of this study are of interest to health care policy makers, hospitals and health insurance providers but in the end for all members of society in their dual function role as payers of premiums and potential recipients of life-prolonging health care services.

## Original title

Ökonomische Bewertung von medizinischen Interventionen am Lebensende / The valuation of medical interventions at the end of life

Duration: 36 months

Funding: CHF 177.296

Project number: 145090

## Project leader

- Prof. Beat Hintermann, Faculty of business and economics, University of Basel

## Contact

Prof. Beat Hintermann  
Wirtschaftswissenschaftliche Fakultät  
der Uni Basel  
Peter Merian-Weg 6, 4002 Basel  
Phone: +41 61 267 33 39  
E-mail: b.hintermann@unibas.ch

# Advance care planning

For medical teams it is often difficult to take patients' wishes into consideration and to support patients' family members. To gain insight into these processes, this study will bring together and test the instruments of advanced care planning and decision aids.

## Background

In the last 20 years, it has been shown that it is ethically and legally important to make patients' living wills and advance directives more legally binding. The forthcoming new "adult protection law" will support this. However, this will not guarantee that treatments at the end of life will be adapted to the patients' wishes or that decision-making will be easier for patients, their families and the medical team.

## Aim

This study aims to work with national and international partners to develop best practice in planning for the end of life. For Switzerland this means first testing a programme for acute hospitals. As one part of the programme, physicians will receive further training in this area. For another, and similar to successful programmes in other countries, also other qualified health care staff (nurses, social workers, pastors) will be certified hold conversations and provide information. The programme will be tested by means of an intervention study. Participants will be competent patients that have a life expectancy of a few weeks or months and their closest relatives.

## Significance

Previous studies have shown that programmes with structured informational conversations by trained medical teams lead to an increase in the number of living wills and advance directives; decision uncertainty decreases, and patients' wishes are followed more frequently. In addition, after the patient's death, family members appear to be significantly less traumatised and depressed. With these programmes, there is also a drop in the number of invasive medical procedures and in the costs at the end of life, with no negative effect on mortality. The research team hopes that, by means of the further education programme and associated documentation as well as the sharing of information between hospital, rescue services and primary care physicians, practices can be significantly improved.

## Original title

Multiprofessional advance care planning and shared decision-making for end of life care  
MAPS Trial

Duration: 36 months

Funding: CHF 469.379

Project number: 740\_139255

## Project leaders

- Dr Tanja Krones, Clinical Ethics, University Hospital of Zurich, University of Zurich
- Prof. Nikola Biller-Andorno, Institute of Biomedical Ethics, University of Zurich
- Dr Kathrin Zaugg, Radiation Oncology Unit, Department of Medical Radiology, University Hospital of Zurich
- Prof. Rebecca Spirig, Centre of Clinical Nursing Science, University Hospital of Zurich

## Co-operating institutions

- Various departments of the University Hospital of Zurich
- Institute for family medicine
- Emergency/rescue of Zurich
- Lighthouse hospice, Zurich
- Institute Neumünster
- Swiss Red Cross
- Harvard University
- Programme "Beizeiten Begleiten"
- Ottawa Health Research Institute
- ACPEL Society

## Contact

Dr Tanja Krones  
Universität Zürich  
Leitende Ärztin Klinische Ethik  
Universitätsspital  
Gloriastrasse 3  
DERM C 18  
8091 Zürich  
Phone: +41 44 255 34 70  
E-mail: tanja.krones@usz.ch

# **Decision-making practice at the end of life. The case of general practice**

**Decision-making in the primary care of terminally ill and dying persons is a complex situation. This study will develop recommendations for education and training and for improving the structures of outpatient palliative care.**

## **Background**

Primary care physicians (general practitioners) play an important role in the support of terminally ill or dying patients. Together with patients, family members and nursing staff, they have to make decisions when it comes to admission to hospital or hospice, symptom relief or withdrawing treatment. Today we still know little about the prerequisites and challenges of decision-making on palliative care in general practice settings.

## **Aim**

The study aims to investigate decision-making at the end of life, taking into consideration the primary care physician-patient relationship, communication with family members and co-operation with nursing staff, family members and hospitals. In addition, it will examine how important legal regulations, different supply structures across the cantons, patient advance directives and normative notions of "good dying" are for decisions at the end of life. In addition to analysis of the framework conditions of primary care at the end of life at the cantonal and national levels, the research team will interview health policy actors, patient organisations and representative primary care physicians and nursing staff. Further, primary care physicians, nursing staff and family members of dying persons from the German-, French-, and Italian-speaking parts of Switzerland will be surveyed in group discussions on the conditions and processes of decision-making at the end of life. The analysis of the interviews will uncover central factors and indicators for successful decision-making on palliative care in general practice settings.

## **Significance**

The results of the study will contribute towards improving palliative care in general practice settings in Switzerland by identifying the necessary competencies on the part of primary care physicians for optimal decision-making and by describing the conditions and challenges of palliative support at the end of life.

## **Original title**

Decision-making practice at the end of life.  
The case of general practice

Duration: 28 months

Funding: CHF 173.550

Project number: 6740\_139270

## **Project leaders**

- Prof. Brigitte Liebig, Institute for Research and Development of Collaborative Processes, School of Applied Psychology, University of Applied Sciences and Arts North-western Switzerland (FHNW)
- Prof. Peter Voll, University of Applied Sciences and Arts Western Switzerland (HES-SO), Valais
- Antonella Carassa, Institute of Psychology and Sociology Faculty of Communication Sciences, University of Lugano
- Dr Heike Gudat Keller, Hospiz im Park, clinic for palliative medicine, care and assistance
- Dr Klaus Bally, Institute for family medicine, University of Basel

## **Co-operating institutions**

- Institutes for family medicine in Switzerland

## **Contact**

Prof. Brigitte Liebig  
Hochschule für Angewandte Psychologie FHNW  
Institut für Kooperationsforschung  
und -entwicklung  
Riggensbachstrasse 16  
4600 Olten  
Phone: +41 62 286 03 21  
E-mail: brigitte.liebig@fhnw.ch

# Understanding the wish to die in elderly nursing home residents

Little is known about the wish to die in elderly persons, and there are no studies available on the wish to die in residents of nursing homes. A better understanding of the wish to die in nursing home residents could help to improve the care of these vulnerable persons.

## Background

The wish to die has many facets: it can be a wish that death comes naturally, but it can also be an explicit wish for assisted suicide or active euthanasia. In palliative care, the wish to die has been studied in people with end-stage cancer. But up to now little is known about the wish to die in elderly persons living in nursing homes, even though these elderly persons are often in poor health and do not infrequently express a wish to die.

## Aim

This study looks at 380 elderly residents of nursing homes in three different regions of Switzerland (in the cantons of Vaud, Ticino and St. Gallen). All new residents at the participating institutions will be asked to take part to the study. Consenting participants will be assessed with regard to their death wish, their spiritual distress and their psychological state. Qualitative interviews will be conducted with some of the participants. Frequency, strength and cause of the wish to die will be determined. The study will focus particularly on elucidating the links between spiritual distress, depression and the wish to die.

## Significance

The results of this study will help medical staff and health professionals in nursing homes to better understand why some elderly people wish to die. In addition, the study – taking great care to safeguard the personal integrity and dignity of the individual – will make possible the development of concrete measures for care of persons whose wish to die is the expression of a distress.

## Original title

Understanding the wish to die in elderly nursing home residents: a mixed method approach

Duration: 36 months

Funding: CHF 457.539

Project number: 139362

## Project leaders

- Dr Stéfanie Monod, Service of Geriatric Medicine & Geriatric Rehabilitation, University Hospital of Lausanne (CHUV)
- Prof. Christophe Bula, Service of Geriatric Medicine & Geriatric Rehabilitation, CHUV
- Prof. Armin von Gunten, University Psychiatric Service for advanced age, CHUV
- Dr Claudia Mazzocato, Palliative Care Service, CHUV
- Dr Brenda Spencer, Institute of Social and Preventive Medicine, CHUV
- Dr Thomas Münzer, Geriatric Clinic, Competence Center for Health and Age, St. Gallen
- Dr Pierluigi Quadri, Regional Hospital of Lugano and Mendrisio, Lugano

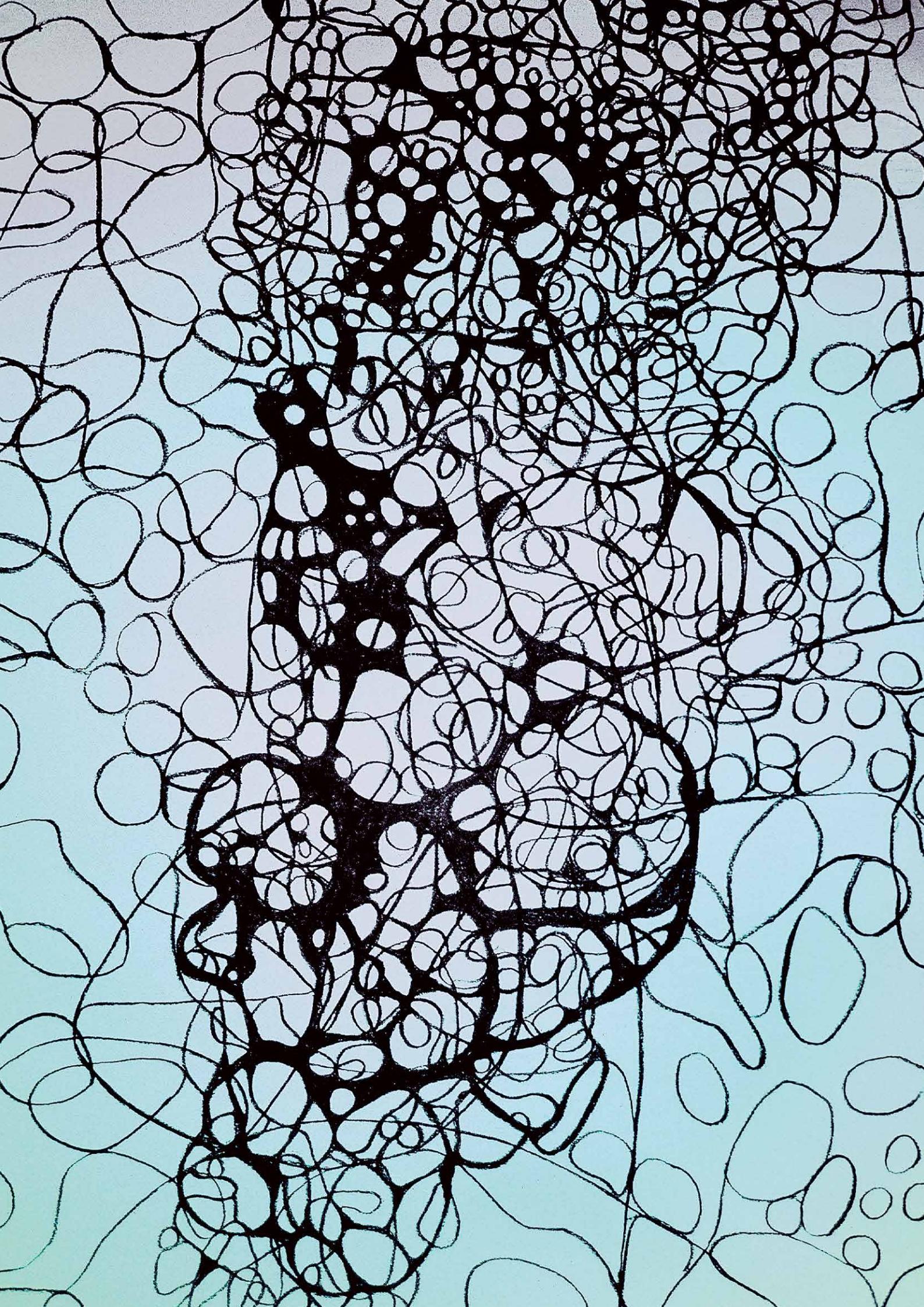
## Co-operating institutions

- University Hospital of Lausanne, CHUV
- Geriatric clinic, St. Gallen
- Regional Hospital of Lugano and Mendrisio

## Contact

Dr Stéfanie Monod  
Service de gériatrie et réadaptation gériatrique  
du CHUV  
Chemin de Sylvana 10  
1066 Epalinges  
Phone: +41 21 314 77 86  
E-mail: stefanie.monod-zorzi@chuv.ch





## Regulations and action proposals

**Legal regulations and social norms also affect the end of life.**  
The research projects in this module investigate whether (planned or current) laws, regulations, and guidelines meet practical needs in hospitals, long-term care facilities, and at home. They explore social norms, such as autonomy and the related decision-making capacity of the dying.

# Self-determination at the end of life

Medical decisions at the end of life are closely connected with the dogma of patient self-determination.

This dogma will be critically examined from a legal standpoint, with the research being guided by the concrete needs of dying patients and the experiences of medical health care personnel.

## Background

The importance of self-determination in connection with medical treatment has increased over the last decades. The patient's living will, for example, allows persons to make their own end-of-life decisions even when they are no longer competent and able to give informed consent. This study starts out from the assumption that the legal basis does not in all aspects do justice to medical practice and the reality of dying patients and that it therefore should be re-examined. This should not be confined to looking at how the problem of self-determination has been handled up to now. Instead, the task is to work out solutions for the legal basis of end-of-life medical decisions that are in accord with the medical and psychological realities. Based on that, the project will make specific proposals for regulations by the lawmakers and draft guidelines for medical health care personnel with no legal training.

## Aim

This study works with recognised methods in the field of law; to compare different draft legislation, findings and experience of other legal systems will be utilised. For a better assessment of what practical needs the regulation must cover, the project will study empirically what problems confront medical personnel in clinics and care facilities for the seriously ill.

## Significance

The results of this study will be important for lawmakers, the authorities and the courts, since decisions on the end of life are being made increasingly at the legal level and through legal means. But also the medical profession and further health care personnel need clear regulations. They all need to know whether a decision is not only appropriate from a social or medical perspective but also has a sound legal basis.

### Original title

Self-determination at the end of life in the Swiss legal framework: a critical analysis of the legal duty of having to decide for oneself

Duration: 36 months

Funding: CHF 328.528

Project number: 6740\_139261

### Project leader

- Prof. Regina E. Aebi-Müller, University of Lucerne

### Contact

Prof. Regina E. Aebi-Müller  
Universität Luzern  
Frohburgstrasse 3  
6002 Luzern  
Phone: +41 41 228 77 35  
E-mail: regina.aebi@unilu.ch

# Assessing decision-making incapacity at the end of life

Whether or not a person is competent to make decisions at the end of life is of great importance; for instance, decision-making incapacity can be the prerequisite for the patient's living will taking effect. This study examines conditions and possibilities of the medical assessment of decision-making capacity.

## Background

The last phase of a person's life is often accompanied by a state of decision-making incapacity (mental incapacity and decision-making inability). But precisely at the end of life, there are often complex decision-making situations that require mental capacity and decision-making ability. This means that physicians have to assess whether a patient is competent. If physicians determine that a patient is not (or no longer) competent to make a health care decision, this has consequences for the further way of proceeding. It may trigger the use of the patient's living will, or a person with a medical power of attorney for the patient will be consulted.

## Aim

In a first phase of this study, the literature on the topic will be reviewed and existing assessment instruments analysed. In a second phase, 300 physicians will be surveyed to investigate empirically what the current assessment practice in Switzerland is. The third phase consists of integration and ethical discussion of the results and proposals for the drafting of guidelines. This phase will be monitored by a multidisciplinary, international panel of experts. In addition, the researchers also plan to develop a training module for physicians.

## Significance

This study will make an important contribution towards the establishment of national standards for the assessment of decision-making capacity. These are important in view of the increasing acceptance of patient self-determination. The results can be helpful for the development of future guidelines, for example by the Swiss Academy of Medical Sciences.

### Original title

Decision-making incapacity at the end of life and its assessment in Switzerland

Duration: 36 months

Funding: CHF 338.332

Project number: 139294

### Project leaders

- Prof. Nikola Biller-Andorno, Institute of Biomedical Ethics, University of Zurich
- Dr Manuel Trachsel, Institute of Biomedical Ethics, University of Zurich

### Contact

Prof. Nikola Biller-Andorno  
Universität Zürich  
Institut für Biomedizinische Ethik  
Pestalozzistrasse 24  
8032 Zürich  
Phone: +41 44 634 40 81  
E-mail: biller-andorno@ethik.uzh.ch

# Legal regulations at the end of life: where is government intervention needed?

For people at the end of life, it is often difficult to decide on their own how much medical care they should be given. To what extent should medical decisions fall to third parties (family members, physicians, hospices, nursing home directors, health insurance companies)? How much government control is needed?

## Background

Persons who – together with dying persons or in their place – must make decisions on life-sustaining treatments or measures hastening death carry a great deal of responsibility. At present, the law does not lessen their burden of responsibility, as there are no clear decision criteria. At the same time, the persons involved in the decision-making process at the end of life are influenced by various factors (for example, cost incentives). This situation can result in decisions and actions that are not always for the good of the dying person.

## Aim

To ensure that decisions at the end of life are in the interest of the persons concerned, appropriate legal regulations are indispensable. The establishment of the living will and the prevailing criminal law provisions do not suffice. For instance, the issue arises as to whether regulations are needed to guarantee the independence and the personal and specialist qualifications of personnel providing assistance to die. In addition, there is the question as to whether the law should more precisely define what resources and infrastructures for life support measures must be made available. And, not least, it should be discussed whether and how decisions at the end of life and their implementation should be monitored.

## Significance

From a legal perspective, the study will show how human rights to life and integrity, self-determination and dignity can be realised in an area where autonomous decision-making is often no longer possible and the persons concerned need special protection. The goal is to develop, for the benefit of policy and society, a practicable regulatory model for assisted dying in medical and social institutions. With this, the study will contribute towards protection of seriously ill and elderly persons and, in the interest of the actors involved, establish legal certainty.

## Original title

Regulating end-of-life decisions in clinics, nursing homes and hospices: Human rights standards and administrative law instruments

Duration: 36 months

Funding: CHF 327.397

Project number: 139262

## Project leaders

- Prof. Bernhard Rütsche, Faculty of Law, University of Lucerne
- Prof. Regina Kiener, Faculty of Law, University of Zurich

## Contact

Prof. Bernhard Rütsche  
Universität Luzern  
Professor für Öffentliches Recht und  
Rechtsphilosophie  
Rechtswissenschaftliche Fakultät  
Frohburgstrasse 3  
6002 Luzern  
Phone: +41 41 229 53 69  
E-mail: bernhard.ruetsche@unilu.ch

# **Self-determined death? Assisted suicide and autonomy**

**In the debate on assisted suicide, a person's right to determine how and when he or she dies is widely recognised. However, there is a dispute concerning the conditions under which a person's decision to end his or her life with another person's assistance can be considered autonomous.**

## **Background**

Throughout the intensive debate on more restrictive regulation of assisted suicide in Switzerland, the right to autonomy was considered highly important by all sides. However, it became clear that there is a great lack of clarity and disagreement regarding the conditions that a person must fulfil for the decision for assisted suicide to be viewed as autonomous. For example, both advocates and opponents of more restrictive regulation gave autonomy as the reason for their positions.

## **Aim**

This study will clarify what conditions proposed in the debate can sensibly be brought in relation to autonomy and how these conditions can be specified. When examining the philosophical, legal, psycho-logical and public debates, the research team will test two working hypotheses: (1) An exacting definition of autonomy that would justify restrictions on assisted suicide cannot be defended in a liberal context, and (2) Some of the proposed conditions can be traced back to other values that differ from autonomy, such as welfare, protection of life or human dignity. For this reason, they should not be considered in the determination of the conditions for autonomy.

## **Significance**

Clarification of the conditions for autonomy is not only indispensable for academic debates but also for policy and public discussion on the regulation of assisted suicide. By determining a definition of autonomy, the study opens up an important perspective on the current debate: if restrictions cannot be justified based on autonomy (for example, for healthy persons with a death wish), what importance should be placed on the principle of respect for autonomy? On the issue of regulation of assisted suicide, should values other than autonomy, such as welfare, protection of life or human dignity, be taken into stronger consideration?

### **Original title**

Assisted suicide and autonomy

Duration: 36 months

Funding: CHF 225.074

Project number: 6740\_139272

### **Project leader**

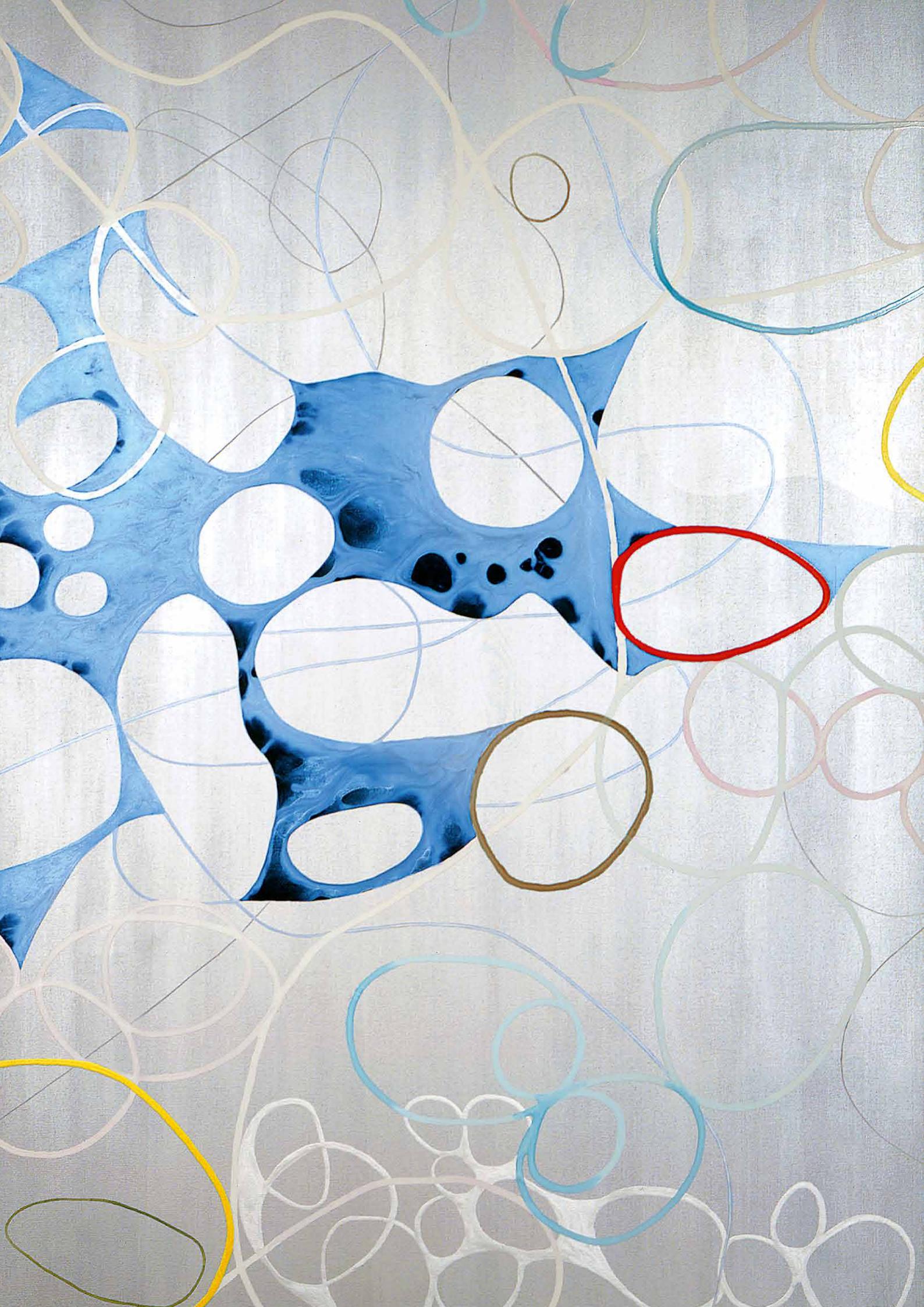
- Prof. Peter Schaber, Ethics Research Institute, University of Zurich

### **Co-operating institutions**

- University research focussing on ethics, University of Zurich
- Institute for biomedical ethics, University of Zurich
- Centre of competence medicine – ethics – law Helvetiae, University of Zurich
- Law Institute of the University of Lucerne

### **Contact**

Prof. Peter Schaber  
Arbeits- und Forschungsstelle für Ethik  
der Universität Zürich  
Zollikerstrasse 117  
8008 Zürich  
Phone: +41 44 634 85 26  
E-mail: schaber@philos.uzh.ch



## Cultural concepts and social ideals

**Questions of meaning and moral values also play a role at the end of life. The research projects in this module examine how factors such as spirituality, religious belief, current life situation, and cultural backgrounds contribute to shaping dying processes and decisions at the end of life.**

# Facing the loss of a parent – how is institutional support interiorised?

**When a parent dies, children are dependent on support from outside the family. Based on bibliographical narratives of persons who lost a parent when they were adolescents, this study examines how they experienced the integration of institutional help in their lives.**

## Background

The context of this project is interdisciplinary efforts to improve institutionalised support for dying processes in palliative care-oriented facilities such as hospices or hospitals. The focus of the study is not on the dying but on family members of the dying. The experience of losing a closest relative puts adolescents into a crisis situation – and one in which they often utilise support services. The question is: what effect do the support services subsequently have in the course of the adolescents' lives? This question has been neglected in the research so far.

## Aim

This study aims to fill a research gap. Twenty open-ended interviews will be conducted with persons who lost a parent to illness when they were adolescents. The recorded narratives will be analysed using a detailed linguistic analysis.

## Significance

In coming years, the problems connected with support for family members of the dying will have increased urgency in palliative care-oriented institutions and in social policy. This study will produce the needed basic knowledge. The findings will be used in practice as decision-making bases for institutions. For adequate support of adolescents, it is important to understand what biographical significance this support can have. The expected results should inform the designing of the support programmes.

## Original title

The habitual foundations of adolescents facing the loss of a parent – how is institutional support interiorised?

Duration: 28 months

Funding: CHF 102.429

Project number: 6740\_139300

## Project leaders

- Prof. Benno Schimmelmann, University Hospital for Psychiatry, Bern
- Dr Caroline Grosser, Nursing and Social Education Research Unit, University of Bern Psychiatric Services (UPD)
- Dr Christoph Abderhalden, Nursing and Social Education Research Unit, University of Bern Psychiatric Services (UPD) (deceased in March 2013)

## Contact

Dr Caroline Grosser  
Universitäre Psychiatrische Dienste Bern  
Abteilung Forschung/Entwicklung Pflege und Pädagogik  
Bolligenstrasse 111  
3000 Bern 60  
Phone: +41 31 930 97 18  
E-mail: caroline.grosser-ummel@gef.be.ch

# Meaning in life, spirituality and personal values at the end of life

Not finding meaning in life is one of the most important reasons for people wanting to end their lives. But what does meaning in life mean for persons at the end of life? This question will be examined in the three largest language regions of Switzerland using a new interview method.

## Background

The number of assisted suicides in Switzerland is increasing steadily. Recent studies have shown clearly that people's wish to shorten their lives is not so much due to pain or other health complaints. Instead, psychological reasons are decisive, including mainly the loss of meaning and purpose in life. What makes this complex, however, is that each person sees meaning in life in a different way.

## Aim

This study aims to identify the areas that are decisive for finding meaning in life for persons at the end of life (persons with a life expectancy of fewer than six months) in Switzerland. Based on previous research findings, particular attention will be paid to personal values and spirituality. Finally, the study will investigate the way in which these factors affect persons' wish to end their lives. To achieve these aims, a new interview method will be used that allows the participating patients to themselves define the factors that give meaning to life in their situations. In addition, the interview will capture information on their spirituality, personal values and the wish to choose the timing of their death.

## Significance

The results will describe the areas that can provide meaning in life for persons in the last phase of their lives. They will also show the effect of meaning in life, spirituality and personal values on persons' wish to shorten their lives at the end of life. The results can aid the organisation of better care for patients with serious illness. Following a pilot phase, it is planned to use the results as a basis for developing new, meaning-centred supportive intervention for persons in the last phase of their lives.

### Original title

Meaning in life, personal values, spirituality and wishes for hastened death at the end of life

Duration: 24 months

Funding: CHF 162.939

Project number: 139313

### Project leaders

- Prof. Gian Domenico Borasio, Chair in Palliative Medicine, University of Lausanne
- Dr Mathieu Bernard, Chair in Palliative Medicine, University of Lausanne
- Dr Claudia Gamondi, Oncology Institute of Southern Switzerland (IOSI), Hopital San Giovanni of Bellinzona
- Dr Florian Strasser, Cantonal Hospital of St.Gallen

### Cooperation partner

- Dr Martin Fegg, University Ludwig Maximilians of Munich, Germany

### Contact

Prof. Gian Domenico Borasio  
Université de Lausanne  
Centre Hospitalier Universitaire Vaudois  
Av. Pierre Decker 5  
1011 Lausanne  
Phone: +41 21 314 02 88  
E-mail: borasio@chuv.ch

# Imagination and communication of trust at the end of life

**At the end of life, patients often experience uncontrollable events and processes. These often include symbolic imagery as a form of experience. When all action has reached its limits, imaginative ranges of understanding and behaviour open up that are important for trust at the end of life. This project aims to elaborate orientation knowledge and provide help to interpretation for spiritual and pastoral care of the dying.**

## Background

In pastoral and spiritual care it is often difficult to understand the highly symbolic things that dying persons say and to respond appropriately. Persons near death often describe unusual, imaginative experiences or use symbolic language to express themselves. This is both a challenge and an opportunity for end-of-life care. The relation between trust and symbolic communication in such situations has not been studied very much. This project seeks to close this gap.

## Aim

The study aims to understand how trust influences behaviour and perception in dying processes. For this reason, the study will investigate different ways in which persons express near-death imaginative experience. This includes, in particular, dreams of dying, deathbed visions and near-death experiences. We will examine the extent to which imaginative experience and symbolic communication near death aid self-interpretation and the processing of the experienced loss of control. Methodologically, the study is based on narratives of experiences, such as dreams and visions, as experienced by persons near death.

## Significance

The project will lead to a deeper understanding of trust-based coping strategies near death and the symbolic language of the death experience. In this way, we will gain orientation knowledge and provide help to interpretation for spiritual and pastoral care of the dying. The study wants to make a contribution towards better spiritual and pastoral care in Switzerland. In this study we will be looking closely at and interpreting phenomena that clearly play an important role for the dying but that have received little attention in research. This has been the case even though these phenomena clearly have an important function at the end of life when it comes to processing momentous experiences, such as loss of control or fear of death.

## Original title

Hermeneutik des Vertrauens am Lebensende –  
Imaginatives Erleben und symbolische Kommunikation in Todesnähe

Duration: 36 months

Funding: CHF 216.307

Project number: 145093

## Project leaders

- Prof. Pierre Bühler, director, Institute for Hermeneutics and Philosophy of Religion, University of Zurich
- Prof. em. Brigitte Boothe, Clinical Psychology, Psychotherapy and Psychoanalysis, University of Zurich
- Prof. Ingolf U. Dälfert, Chair for Systematic Theology, Symbolism and Philosophy of Religion, Institute for Hermeneutics and Philosophy of Religion, University of Zurich
- Dr Andreas Hunziker, managing director and senior researcher and teaching associate, Institute for Hermeneutics and Philosophy of Religion, University of Zurich
- Prof. Ralph Kunz, Chair for Practical Theology, University of Zurich
- PD Dr Simon Peng-Keller, Institute for Hermeneutics and Philosophy of Religion, University of Zurich

## Contact

PD Dr Simon Peng-Keller  
Institut für Hermeneutik und  
Religionsphilosophie  
Kirchgasse 9  
8001 Zürich  
Phone: +41 44 634 54 00  
E-mail: simon.peng-keller@theol.uzh.ch

# End-of-life in prison: legal context, institutions and actors

Nursing homes are increasingly becoming dying institutions for very elderly persons in need of care. This study examines how the diversity of modern societies – that is, the increasing variety of ways of life – is affecting how the end of life is handled in nursing homes.

## Background

When nursing home residents are no longer completely able to express their wishes and needs for a “good dying”, the nursing staff in particular takes on a supporting role. For the nursing homes, there is also in today’s society a necessity to deal with the marked diversity of residents and personnel, especially those with an immigration background.

## Aim

This study aims to throw light on the social actions and the cultural interpretations of “good dying” in nursing homes. It will focus on how nursing homes handle social diversity, especially in the immigration context. Here the study will examine how communitisation and individuality take shape. The method will be an open ethnographic research strategy. The study will be conducted in three types of nursing home units that exhibit different forms of communitisation. The assumption is that the different forms of communitisation will produce different handling of the end of life.

## Significance

The study will gain a better understanding of how social diversity structures the end of life in nursing homes, and how the persons involved interact. This understanding will contribute towards deriving in the present a set of elements of professional competency and the corresponding bases for a good end of life.

## Original title

End-of-life in prison: legal context, institutions and actors

Duration: 36 months

Funding: CHF 302.099

Project number: 139296

## Project leaders

- Dr Ueli Hostettler, Domain of Sociology, Social Policy and Social Work, University of Fribourg
- Dr Marina Richter, Domain of Sociology, Social Policy and Social Work, University of Fribourg
- Prof. Nicolas Queloz, Faculty of Law, University of Fribourg

## Co-operating institutions

- Detention centre Lenzburg
- Detention centre Pöschwies

## Contact

Dr Ueli Hostettler  
Université de Fribourg  
Domaine Sociologie, politiques sociales  
et travail social  
Rte des Bonnesfontaines 11  
1700 Fribourg  
Phone: +41 26 300 78 10  
E-mail: ueli.hostettler@unifr.ch

# Alternative religiosity and its consequences at the end of life

Life and death are a central topic for religions and religiosity. This study examines the conceptions, distribution and consequences of alternative religious ideas and practices with regard to dealing with dying in Switzerland.

## Background

In Switzerland, with the far-reaching changes in the religious landscape, the importance of alternative religious concepts and practices is increasing steadily. This study examines these alternative concepts with regard to shaping and handling the end of life. Characteristic of alternative religiosity is often the reference to the individual, world affirmation, scepticism towards the concept of a personal God and religious institutions, and reference to spirituality rather than religion.

## Aim

Focusing on three case studies, the study will examine alternative religious/spiritual ideas regarding their significance for the actions of institutions, affected persons and nursing staff. The focus will be on the phase of life when physicians, nursing staff and patient believe that the patient will soon die. Experiences, needs and problems in dealing with the end of life will be investigated using interview and the conceptions which frame these practices will be examined through an analysis of foundational texts. The study thus aims to cast light on not only needs but also implementation problems on the background theories.

## Significance

The study will produce knowledge about the consequences that have to be expected in medicine's/nursing's dealing with the end of life owing to changes in the religious context. In addition, solution-oriented strategies will be drafted for dealing with problem areas in health practice influenced by alternative religiosity and in orthodox medicine.

## Original title

Spirituality and end of life. The consequences of alternative religiousness in palliative care

Duration: 36 months

Funding: CHF 302.792

Project number: 139280

## Project leaders

- Prof. Dorothea Lüddeckens, Institute of Religious Studies, University of Zurich
- Dr Rafael Walther, Institute of Religious Studies, University of Zurich
- Prof. Helmut Zander, Chair of History of Religions and for the Dialog of Religions, Faculty of Theology, University of Fribourg

## Contact

Prof. Dorothea Lüddeckens  
Universität Zürich  
Religionswissenschaftliches Seminar  
Kirchgasse 9  
8001 Zürich  
Phone: +41 44 634 47 19  
E-mail: dorothea.lueddeckens@uzh.ch

# End of life and diversity in nursing homes

People in prison are not free to choose how and where they die. This means that the issue of dying with dignity requires special attention in the prison setting. This study examines what it means to die in prison and what ethical, legal and security-related issues are important.

## Background

Under the law, persons in prison are supposed to have the same access to an equivalent range of services, including medical care, as the rest of the population. The majority of the issues and problems related to end-of-life in the general population are the same in the prison setting. But it must be considered that the conditions and processes connected with the end-of-life in prisons present a number of hurdles. These make meeting the demands of care and pain relief in the setting of incarceration and punishment more difficult. What is more, Swiss prisons house a steadily growing number of older persons. Also, the trend is for stricter and longer sentences, as can be seen in changes in prison sentence practice and in the new option of the lifelong detention. This increases the number of persons who will die in prison. Ongoing discussion about good dying and palliative care shows that precisely those persons who cannot choose how and where they die require special attention.

## Aim

Using ethnographic methods, case studies and legal analyses, this study examines end-of-life issues from the perspective of different actors and at different institutional levels in the Swiss penitentiary system. The aim is to analyse the legal and institutional bases and current practice in dealing with the end-of-life and dying in different prisons. Further, the research team will reconstruct specific cases from the perspective of the persons involved (inmates, family members, staff, other institutional actors) and document emerging institutional solutions and examples of good practice.

## Significance

This study takes up a new and growing social problem. It deals with institutional handling issues and good practice with regard to the end-of-life in the context of the Swiss penitentiary system and will thus serve the interests of both the practical and the research realm.

### Original title

'Doing death' and 'doing diversity' in nursing homes

Duration: 24 months

Funding: CHF 273 010

Project number: 139365

### Project leaders

- Prof. Heinzpeter Znoj, Institute of Social Anthropology, University of Bern
- Dr Corina Salis Gross, Institute of Social Anthropology, University of Bern

### Contact

Dr Corina Salis Gross  
Institut für Sozialanthropologie der  
Universität Bern  
Länggassstrasse 49a  
3000 Bern 9  
Phone: +41 31 631 36 33  
E-mail: corina.salisgross@anthro.unibe.ch

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The Swiss National Science Foundation (SNSF) is the most important Swiss institution for the promotion of scientific research. On behalf of the Swiss federation, the SNSF promotes scientific research in all disciplines, from philosophy, biology and medicine to nano-sciences. The key part of its activity entails scientific assessment of research projects. Annually, it provides 700 million Swiss francs of funding to support almost 3000 projects in which 8000 researchers are involved.

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Postfach 8232  
CH-3001 Bern

Tel.: +41 (0)31 308 22 22  
Fax: +41 (0)31 305 29 70  
E-mail: [nrp67@snf.ch](mailto:nrp67@snf.ch)

[www.snsf.ch](http://www.snsf.ch)  
[www.nrp67.ch](http://www.nrp67.ch)



### **The NRP 67 in brief**

NRP 67 is a research programme that will provide a basis for improving decision-making in end-of-life care in Switzerland. NRP 67 has a budget of CHF 15 million, and the programme duration is from 2012 to 2018. A total of 33 research projects have been approved for the programme.

### **The NRP 67 aims to:**

- produce a useful knowledge base for guiding practices and decision-making at the end-of-life
- deliver evidence to inform medical, nursing, social, and pastoral practice
- identify gaps and problematic situations in the provision of care