



## Swiss Summer Academy in Palliative Care Research

The research network “palliative care research switzerland” (pcrs) is organizing a Summer Academy for post-/doctoral researchers and academics involved in research projects. The Summer Academy intends to strengthen participants’ skills in end-of-life and palliative care research in Switzerland.

**Date:** 26<sup>th</sup> to 28<sup>th</sup> of August 2020

**Place:** Murten (Switzerland), Münchenwiler Castle



Bern University  
of Applied Sciences



SWISS NATIONAL SCIENCE FOUNDATION



End of Life  
National Research Programme NRP 67



# Swiss Summer Academy in Palliative Care Research

The research network “palliative care research switzerland” (pcrs) is organizing a Summer Academy for post-/doctoral researchers and academics involved in research projects. The Summer Academy is intended to strengthen participants’ skills in end-of-life and palliative care research in Switzerland.

The Summer Academy will promote knowledge exchange and collaboration between disciplines, provide education and training, and serve as a platform for networking and development of new projects in end-of-life and palliative care research.

## General information about the Summer Academy

- Date: 26<sup>th</sup> to 28<sup>th</sup> of August 2020
- Place: Murten (Switzerland), Münchenwiler Castle
- Language: English
- Costs: CHF 500.–
- Deadline for project submissions: 1<sup>st</sup> of February 2020
- Contact person: Claudia Michel, [claudia.michel@bfh.ch](mailto:claudia.michel@bfh.ch)

## Target Audience

The Summer Academy’s target audience comprises doctoral candidates / early postdoctoral candidates and other researchers who wish to deepen their skills in end-of-life and palliative care research. For each topic, there will be an input by experts, followed by a case study session to discuss ongoing research projects. Therefore, researchers are invited to submit descriptions of their projects (see details below). Note: Submitting a research project is not a requirement for participating in the Summer Academy.

The interdisciplinary Committees of the research network “palliative care research switzerland” will review the submitted project descriptions. Candidates will be informed regarding their submission in April 2020.

For further details and inquiries, please contact Claudia Michel: [claudia.michel@bfh.ch](mailto:claudia.michel@bfh.ch)

For general information, consult our website: [www.palliative-care-forschung.ch/](http://www.palliative-care-forschung.ch/)

## Expert Insights and Case Study Sessions

Senior-level international and national researchers from a broad spectrum of disciplines have been invited to serve as experts at the Summer Academy. They will provide insights into their own research and offer advice regarding participants’ projects during case study sessions.

Contributions are structured according to the following topics:

### 1. Access to Palliative Care for Vulnerable Groups

Philip Larkin, Chair of Palliative Care Nursing, Palliative and Supportive Care Service, Lausanne University Hospital and University of Lausanne

In recent years, the belief that palliative care is a human right has been proposed. Linked to this is a fundamental shift and broadening in the application of palliative care to a wider cohort of people living with chronic life-limiting illness. However, despite the positive developments evident in both literature and clinical practice, there remains clear evidence of a lack of equity and access for some groups who may be considered vulnerable based on misplaced assumptions and understanding of their palliative care needs.

Using a framework of social justice as a lens to understand inequity, this presentation will argue that human rights are not enough to understand the reality of vulnerability in society and how it can be addressed in the context of palliative and end-of-life care. Using specific examples from clinical practice, the challenge and opportunities to enhance better access to palliative care will be addressed and its outcome in terms of “real-world” service delivery.

### 2. Self-determination in End of Life Care

Ralf Jox and Eve Rubli Truchard, Chair of Geriatric Palliative Care, Palliative and Supportive Care Service and Service of Geriatric Medicine and Geriatric Rehabilitation, Lausanne University Hospital and University of Lausanne

Since its beginning in the 1960s, modern palliative care has been characterized by a particular focus on respecting the autonomy and self-determination of every patient, but also of the family members. More than ever, our current Western societies are individualistic and cherish the value of self-determination, including



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Switzerland. At the end of life, however, we do not only want to be self-determined, but we also tend to depend heavily on others and sometimes we want to delegate decisions to others. Moreover, self-determination at the end of life is limited by impaired decision-making capacity, conflicting values such as the protection of life, as well as organizational and financial restraints. Concrete questions and controversies arise around the following topics (not exclusive): respecting patient autonomy in daily care and nursing practices, patient autonomy and surrogate decision making, advance care planning, wishes to hasten death and assisted dying, tension between the autonomy of the patient and that of the family or the professionals.

### 3. Trust at the End of Life

Reiner Anselm, Chair of Systematic Theology and Ethics, Faculty of Protestant Theology, Ludwig-Maximilians-Universität München

Patient autonomy has long been regarded as the gold standard of medical ethics. It is the patient's free, informed will that legitimizes any medical intervention. The background to this concept is the idea of the free, self-determined citizen. Disease is accordingly understood as an interruption of this self-determination, which is to be restored with the help of medicine. The formula "voluntas aegroti suprema lex est" follows this principle. At the end of life, however, this concept often seems to reach its limits; complex disease processes make decision making difficult, self-determination in cases of severe physical dependence is not easy to determine. In this situation, it seems more appropriate not to understand the doctors as assistants of one's own self-determination, but to entrust them with decisions on what might be the best way for me as a person. In addition, dying can be understood as a gradual separation of body and mind. Dying people increasingly leave the care for the body to others, especially doctors. It is up to them to take care of the body and thus enable the patients to die in a way that corresponds to their personal ideas. At the same time, however, it is clear that the principle of trust can only supplement, not replace, autonomy. Trust must be based on respect for the patient's will and values.

### 4. Health Promoting Palliative Care

Allan Kellehear, 50<sup>th</sup> Anniversary Professor (End-of-Life Care), Faculty of Health Studies, University of Bradford, England

Health Promoting Palliative care is a public health approach to the practice of palliative care. Where we usually think of public health in terms of the surveillance sciences – epidemiology, health services research, or public health ethics – health promoting palliative care emphasizes public health methods for change – community development, social ecology, public education, policy development, and health promotion. Furthermore, although many university departments emphasize actions-in-the-community, the health promoting palliative care approach also requires changes to the way we relate to each other as palliative care professionals. This workshop will outline and discuss these characteristics of health promoting palliative care describing both the key practice methods and their relationships with traditional population health research and individual clinical practice.

### Extra Workshop: Social Sciences in Palliative Care Research

This workshop will first introduce the political economy of social sciences research in palliative care. We will examine the major

fashions and biases in past and current social sciences work in "death & dying" and also subsequently in palliative care. Additionally, we will identify research areas that have been neglected and discuss why these areas may be important to what we currently know. We will then explore the historical reasons for this particular pattern of research, including the epistemological habits, institutional incentives, and methodological biases observed over the past 50 years. The challenges of creativity, originality, and contribution to change, which are so important to the social sciences research traditions, will be assessed employing the field of palliative care as a case study. The session will be concluded by reflecting on the future of social science in palliative care in the light of its research history.

Allan Kellehear, 50<sup>th</sup> Anniversary Professor (End-of-Life Care), Faculty of Health Studies, University of Bradford, England

### Submission of Project Descriptions

If you are interested in discussing your research project, please send us a description. Applications from both Swiss and international institutions are welcome to be submitted. Please send the following information as an MS Word document or a PDF file to Claudia Michel (claudia.michel@bfh.ch):

#### Assignment to session

To what session(s) of the Summer Academy does your research project belong?

1. Access to Palliative Care for Vulnerable Groups
2. Self-determination in End of Life Care
3. Trust at the End of Life
4. Health Promoting Palliative Care

#### Provide five keywords to describe your project.

#### What is your research project about?

Please provide information (2–5 pages) about your research project according to the following format: Title, abstract, purpose, methods, scope, results, and conclusions (if already available)

#### Reason(s) for your interest in the Summer Academy

For example, topics and questions you wish to receive insight into.

#### General information

Please provide: name, discipline, organization, address, city, phone number and e-mail address

Your information will be sent to the inter-/national experts to help them prepare for their sessions.

**The Submission Deadline is the 1<sup>st</sup> of February 2020.**

### Summer Academy registration

Those who wish to participate in the Summer Academy without submitting a project are kindly requested to send an e-mail to Claudia Michel (claudia.michel@bfh.ch). They will be informed as soon as registration opens for the Summer Academy.

## Organization

The research network „palliative care research switzerland“ (pcrs) is in charge of organizing the Summer Academy. An interdisciplinary steering committee leads the network, assisted by a broad membership committee. The coordinator is responsible for operational issues.

## Coordinator

**Dr. Claudia Michel**, Institut Alter, Berner Fachhochschule (BFH), Bern

## Steering Committee

- **Prof. Dr. Sophie Pautex**, Unité de gériatrie et de soins palliatifs communautaires, HUG, Genève
- **Prof. Dr. Steffen Eychmüller**, Palliativzentrum, Universitäts-spital Bern
- **Prof. Dr. Marc-Antoine Berthod**, Haute école de travail social et de la santé (EESP) Lausanne
- **Dr.ssa Claudia Gamondi**, Clinica di Cure Palliative e di Supporto, IOSI, Bellinzona
- **Dr. Corina Salis Gross**, Institut für Sozialanthropologie, Universität Bern, Schweizer Institut für Sucht- und Gesundheitsforschung, Universität Zürich

## Membership Committee

- **Prof. Dr. Regina Aebi-Müller**, Rechtswissenschaftliche Fakultät, Universität Luzern
- **Dr. Mathieu Bernard**, Service de soins palliatifs et de support, CHUV, Lausanne
- **Dr. Gora da Rocha**, Haute école de santé, HES-SO Genève
- **PD Dr. Monica Escher**, Equipe mobile douleur et soins palliatifs, HUG, Genève
- **Dr. Claudia Kohli Reichenbach**, Theol. Fakultät, Universität Bern
- **Prof. Dr. Andrea Koppitz**, Institut für Pflege, ZHAW, Zürich
- **Prof. Dr. Brigitte Liebig**, Hochschule für Angewandte Psychologie, FHNW, Privatdozentin Institut für Soziologie, Universität Basel
- **PD Dr. Claudia Mazzocato**, Service de soins palliatifs, CHUV, Lausanne
- **Prof. Dr. Eva Soom Ammann**, Departement Gesundheit, BFH Bern
- **Barbara Steffen-Bürgi**, Zentrum Schönberg, Bern
- **Dr. Monika T. Wicki**, Interkantonale Hochschule für Heilpädagogik (HfH), Zürich
- **Dr. Karin Zimmermann**, Kompetenzzentrum Pädiatrische Palliative Care, Universitäts-Kinderspital Zürich, Departement Public Health - Pflegewissenschaft, Universität Basel
- **Dr. Franziska Zúñiga**, Departement Public Health – Pflegewissenschaft, Universität Basel

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