

Research in Palliative Care

Final report on the SAMS funding programme 2014–2018



 **SAMWASSM**

Schweizerische Akademie der Medizinischen Wissenschaften
Académie Suisse des Sciences Médicales
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Swiss Academy of Medical Sciences





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Editorial

As a hospital physician, I was disappointed when – many years ago – the palliative medicine subspecialty was introduced. As a result of increasing specialisation, our work had already become less holistic; with the advent of palliative care, even greater weight was attached to curative efforts, as responsibility for care was assigned to the relevant specialists.

Today, when I reflect on what has been achieved by the SAMS «Research in Palliative Care» funding programme, I see things differently and I'm convinced that this is precisely what was needed – researchers dedicating themselves to a neglected field, forming networks and improving practice through joint research activities.

For the SAMS, another reason why this programme has been so successful is the fact that palliative care research has always met those criteria which are now widely required or, one could even say, hyped. I'm thinking in particular of patient experience: patients and their needs have consistently been at the centre of palliative care and the associated research. The second hot topic is implementation science: palliative care research is invariably applied research, with a prime concern being that patients should benefit directly from the results.

But whatever may currently be in vogue, there are long-term trends to be con-

sidered. The ageing society is one such challenge that we need to address. Those projects dealing with the provision of palliative care at home point the way ahead: while 80 per cent of respondents would prefer to die at home, 80 per cent of all deaths currently occur in hospitals or homes. Here, new approaches are urgently needed.

The question remains whether five calls for proposals over a five-year period could be enough to ensure that research in this field, of the current quality, is permanently established in Switzerland. It will be difficult to obtain similar levels of funding from other institutions. However, thanks to the SAMS programme, the chances of success have been improved – with existing publications and joint submissions from the networks now established.

To ensure that it can continue to respond in a timely manner to deficits identified in academic medicine, the SAMS, with its limited resources, must always limit the duration of its funding programmes. Even though it sometimes does so with a heavy heart.

Daniel Scheidegger
Vice President, Swiss Academy
of Medical Sciences (SAMS)

A misty landscape with a rocky shoreline, a calm body of water, and a distant industrial structure. The foreground is dominated by large, grey, moss-covered rocks and patches of dry, yellowish-brown grass. The water is still and reflects the overcast sky. In the distance, a tall, thin industrial chimney or tower is visible through the haze.

Projects overview

Brief descriptions of selected projects pp. 6 – 11
List of all projects supported pp. 12 – 15

Developing a national database

Sophie Pautex, HUG / Steffen Eychmüller, Inselspital

Research topic

Who has access to palliative care in Switzerland, and what are the trajectories of patients admitted to palliative care units? Such data has not previously been available but is of great importance, according to the research team led by Sophie Pautex (Geneva University Hospital) and Steffen Eychmüller (Inselspital Bern). Basic data is needed in order to identify further gaps in research and improve the palliative care system in Switzerland. For this purpose, questionnaires were sent to six palliative care units across Switzerland. Information was collected concerning patients' condition on admission, the care received, the support offered, the decision-making process and the length of stay.

Results

379 responses were evaluated: according to this study, the average patient admitted to a palliative care unit is 73 years old, female, Protestant and has cancer. As the study demonstrated, it is more difficult for non-cancer patients to access palliative care services.

As expected, the study paints a heterogeneous picture of specialist palliative care in Switzerland. Within institutions, the trajectories of patients at the end of life vary widely. Who is admitted to a palliative care unit, and when, depends – the team concludes – on historical, regional

and personal factors. The researchers also aimed to show that it would be possible to establish a national palliative care database. The project is to be pursued with the goal of developing such a tool, involving all specialist palliative care institutions in Switzerland.

A national palliative care database: a tool to better define the needs of palliative care patients in Switzerland

Prof. Sophie Pautex, Service de médecine palliative, Hôpitaux Universitaires de Genève. Co-author: Prof. Steffen Eychmüller, Universitäres Zentrum für Palliativmedizin, Inselspital Bern

01.01.2015 – 31.03.2016
CHF 97,600

Dying at life's beginning

Claudia Meier Magistretti, HSLU / Valerie Fleming, LJMU

Research topic

Each year, around 600 babies die in Switzerland in the period between the 22nd week of pregnancy and the first week after birth. These perinatal deaths are not widely discussed. For the parents concerned, however, this is an extremely painful experience which has a significant impact and may, at worst, lead to post-traumatic stress disorder, depression and other problems. As no studies concerning the needs of parents in this situation were available in Switzerland, the topic was addressed by a research team led by Claudia Meier Magistretti (Lucerne University of Applied Sciences) and Valerie Fleming (Liverpool John Moores University). The aim was to find out, via 20 narrative interviews, how affected mothers assessed the care provided from diagnosis to postnatal bereavement: what was important? What was helpful? What was missing?

Results

The interview results were validated and evaluated by specialists from the fields of medicine, psychology and theology, health insurers, self-help groups and counselling services. On this basis, a best-practice model was developed – a kind of checklist defining best professional practice for the various processes involved. The final report of the study notes, for example, how important it is that persons close to

the couple are present when the diagnosis is communicated, and that a physician is assigned to provide continuous information and support to the mother. After the birth, many parents also need support in building a relationship with their deceased child. It was also shown that the postnatal care provided by the midwife is of great importance, as she provides not only medical, but also practical and psychological support for the mother.

According to the researchers and the health insurers' expert report, all the measures included in the best-practice model are possible within the existing health system and basic care.

Where new life meets death: a research-based best practice model for palliative and bereavement care

Prof. Claudia Meier Magistretti, Institut für Sozialpädagogik und Bildung, Hochschule Luzern. Co-author: Prof. Valerie Fleming, Nursing and Allied Health, Liverpool John Moores University

01.03.2017 – 31.08.2019
CHF 159,000

Heart surgery and/or palliative care?

Tanja Krones, USZ

Research topic

In elderly patients, symptomatic aortic stenosis is associated with significantly increased mortality. A research team led by Tanja Krones (University of Zurich) is conducting interviews to investigate these patients' wishes with regard to care planning and future health crises. Do patients wish to undergo open heart surgery or a less invasive cardiac procedure? At what point do they wish to focus on a palliative care plan? What measures should be taken particularly in the event of complications during or after surgery?

Results

An aid to decision-making is to be developed, based on an analysis of interviews with patients, experts and relatives, as well as a systematic literature review. This instrument should make it easier for the patient, relatives and the interprofessional treatment team to find an individual path between the medical options available and the expected benefits and complications. Also to be developed is a continuing education tool to promote shared decision-making with elderly patients with symptomatic aortic stenosis. As these patients are generally managed by various physicians, this programme will address a variety of professionals – cardiologists, heart surgeons, geriatricians, palliative care specialists and GPs.

Shared Decision-Making and Advance Care Planning for elderly patients with symptomatic aortic stenosis

Prof. Tanja Krones, Klinische Ethik, Universitätsspital Zürich/Institut für Biomedizinische Ethik und Medizingeschichte, Universität Zürich

01.01.2019 – 31.12.2021

CHF 150,000

Refusal of food and fluids

André Fringer, ZHAW

Research topic and results

The first national survey on Voluntary Stopping of Eating and Drinking (VSED) was conducted as part of an empirical study by a research group led by André Fringer (ZHAW School of Health Professions). It found that most of the individuals concerned were around 80 years old and had cancer or other life-threatening conditions, with a life expectancy of less than a year. The reasons for their decision to stop eating and drinking included fatigue, fear of becoming dependent and losing their autonomy, and the lack of any hope of improvement. In most cases, death occurred after about 13 days.

The online survey on experiences with VSED was completed by 1681 family physicians and heads of outpatient or long-term care facilities. This was the first time that data on the course and management of VSED had been collected in Switzerland. While VSED may be a marginal phenomenon in everyday practice – accounting for only 1.7% of deaths in Swiss long-term care facilities – it can pose major challenges and ethical dilemmas for the professionals involved. This may be the case, for example, if health professionals cannot accept the patient's wishes. In addition, the management of VSED can be time-consuming for staff, requiring frequent discussions with the person concerned and with relatives.

Based on the results of the study and existing scientific knowledge on VSED, the researchers conclude that this subject needs to be professionally addressed, e.g. through training measures – not least because VSED (sometimes known as fasting to death) is increasingly becoming a topic of social debate.

Voluntary Stopping of Eating and Drinking (VSED) in Switzerland

Prof. André Fringer, Institut für Pflege, Zürcher Hochschule für Angewandte Wissenschaften ZHAW Winterthur.
Co-author: Dr Daniel Büche, Palliativmedizin, Universitätsspital St.Gallen

01.11.2015 – 30.04.2018
CHF 128,300

Palliative care at home for patients with ALS

Tenzin Wangmo, UniBAS

Research topic and results

Amyotrophic lateral sclerosis (ALS) is a degenerative disease of the central nervous system, for which there is no cure. Progressive damage to the motor neurons leads to muscle wastage. In most cases, life expectancy for patients diagnosed with ALS is two to three years. Care – including end-of-life care – is often provided at home by one or more relatives. This task often involves significant sacrifices, as patients with ALS rapidly become dependent on care.

A research group led by Tenzin Wangmo (Basel University) aimed to explore the needs of family caregivers and find out how they can best be supported during this emotionally and physically challenging period. An analysis of 48 relevant scientific articles indicated that this question had not previously been addressed in German-speaking Switzerland.

Interviewees were recruited via the association ALS Schweiz, the Muscle Centre St Gallen and the REHAB Basel. The questions concern the experiences of family caregivers – what types of support were not available, and what types of assistance (organisational and personal) would have helped them to cope with the caregiving burden.

Palliative Care at home: A multi-perspective study on the complex needs of ALS family caregivers

PD Dr Tenzin Wangmo, Institut für Bio- und Medizinethik, Universität Basel.
Co-authors: Prof. Tanja Krones, Klinische Ethik, Universitätsspital Zürich/Institut für Biomedizinische Ethik und Medizingeschichte, Universität Zürich

Prof. Bernice Elger, Institut für Bio- und Medizinethik, Universität Basel

01.05.2018 – 31.10.2020
CHF 100,000

Expressing gratitude at the end of life

Mathieu Bernard, CHUV

Research topic

Researchers led by Mathieu Bernard (Lausanne University) are exploring the idea that the expression of gratitude by a patient to a caregiver at the end of life can have positive effects on the quality of their relationship. It is known from previous studies that psychological factors can have a significant impact on quality of life for both patients and their relatives. But how can patients be supported in expressing their gratitude to caregivers?

Results

In this study, a two-step gratitude-based intervention is being carried out in 30 patient-caregiver dyads. The first step is the writing of a «gratitude letter», in which the patient expresses his or her feelings of gratitude to the relative and vice versa. The second step is a «gratitude visit», where the writer personally reads out or hands over the letter. Because such visits may be highly emotional, the researchers emphasise that the way in which the letter is handed over must be flexibly managed. The effects of the intervention on patients and their caregivers are subsequently to be investigated via questionnaires and detailed interviews with 20 dyads. The content of the letters – made available by the study participants – will also be studied.

The interim results indicate positive effects on the burden for caregivers, and

especially on depressive states. In the post-intervention interviews, participants report, in particular, the intensity of their feelings and the importance of leaving a written trace. Another advantage of the gratitude-based intervention, according to the project leader, is that it involves little effort and does not require substantial staff training.

Impact of a gratitude-based intervention on patients and caregivers in a palliative care context: a pilot study

PD Dr Mathieu Bernard, Service de soins palliatifs et de support, CHUV/Université de Lausanne. Co-authors: Prof. Gian Domenico Borasio, Dr Betty Althaus and Emanuelle Poncin, MA, Service de soins palliatifs et de support, CHUV/Université de Lausanne

01.04.2018 – 30.09.2020
CHF 120,000



List of all projects supported

Impact of a gratitude-based intervention on patients and caregivers in a palliative care context: a pilot study

PD Dr Mathieu Bernard*, Service de soins palliatifs et de support, CHUV, Lausanne

CHF 120,000

Monitoring of Patients Needs, Professional Triggers and delivered Basic Palliative Care Interventions in Routine inpatient, ambulatory and home Care of Advanced Incurable Cancer Patients: MENTOR-Cancer, a phase I/II complex intervention study

Dr David Blum, Onkologische Palliativmedizin, KSSG, St.Gallen

CHF 80,000

* Due to layout constraints, only the main grantee is named.

French validation of the Integrated Palliative care Outcome Scale (IPOS)

Prof. Gian Domenico Borasio, Service de soins palliatifs et de support, CHUV, Lausanne

CHF 114,350

Validation d'un outil d'identification des patients nécessitant des soins palliatifs généraux ou spécialisés

Prof. Gian Domenico Borasio, Service de soins palliatifs et de support, CHUV, Lausanne

CHF 169,500

Palliative sedation in Switzerland – medical routine or specialized care?

Prof. Georg Bosshard, Klinik für Geriatrie, USZ, Zürich

CHF 106,261

**Projet «Serious game» SG-EoL_R1 -
Un outil pédagogique pour une meilleure
détection et des soins palliatifs
de qualité au plan psycho-spirituel**

Prof. Pierre-Alain Charmillot, HE-Arc
Santé, Delémont

CHF 58,775

**Variation of palliative care in cancer
patients in Switzerland**

Prof. Kerri Clough-Gorr, Institute of
Social and Preventive Medicine,
UniBE, Bern

CHF 131,000

**How do people at the end of life
achieve and maintain existential
wellbeing?**

Dr Philippe D'Andrès Carruzzo,
CHUV/Palliative Care Program
McGill University, CA

Fellowship: CHF 44,330

**INDEX - Intranasal Dexmedetomidine
for procedural pain management in
elderly adults in palliative care**

Dr Nathalie Dieudonné-Rahm, Service
de médecine palliative, HUG, Genève

CHF 25,000

**Efficacy of a Modular Intervention
to promote Dignity and Mental Well-
Being by a Palliative Consultation-
Liaison Service in Swiss Acute
Hospital Care: A Pilot Randomized
Controlled Trial**

Dr Sandra Eckstein, Palliative Care,
USB, Basel

Part 1: CHF 50,000

Part 2: CHF 117,985

**Respect for patient self-determination
as quality indicator in palliative care:
current state, problems and solutions
in acute care hospitals**

Prof. Bernice Elger, Institute for
Biomedical Ethics, UniBAS, Basel

CHF 236,491

**Voluntary Stopping of Eating and
Drinking (VSED) in Switzerland**

Prof. André Fringer, Institut für Pflege,
FHSg, St.Gallen/ZHAW, Winterthur

CHF 128,300

**Activity of Daily Living Support in
End of Life care: Impact of the edu-
cation-based intervention program
«AdKinPal» for palliative care nurses**

Prof. André Fringer, Institut für Pflege,
FHSg, St.Gallen/ZHAW, Winterthur

CHF 127,378

**Development of an educational
program for relatives of patients with
refractory cachexia: An explorative
sequential mixed methods study with
a focus on alleviation of challenges
concerning nutrition, weight and
quality of life**

Prof. André Fringer, Institut für Pflege,
FHSg, St.Gallen/ZHAW, Winterthur

CHF 70,000

**Palliative care members' attitudes
towards assisted suicide: a mixed
methods study**

Dr Claudia Gamondi, Clinica di Cure
Palliative e di Supporto, EOC, Bellinzona

Fellowship: CHF 40,000

Project: CHF 83,500

A Mixed Methods Study on Perinatal Palliative Care Services in Switzerland

Dr Manya J. Hendriks, Klinik für Neonatologie, USZ, Zürich

CHF 171,759

A nurse-led patient-centred intervention to increase advance directives for outpatients in early stage palliative care: a randomized controlled trial with an embedded explanatory qualitative study

Prof. Katia Iglesias, Haute Ecole de Santé HES-SO, Fribourg

CHF 200,000

Alzheimer's Disease-specific Intervention of Advance care planning (ADIA)

Prof. Ralf Jox, Chaire de soins palliatifs gériatriques/Institut des humanités en médecine, CHUV/UniL, Lausanne

CHF 173,200

Does the «Dementia-pall-intervention against symptom burden» (POS-DemA) improve dementia care in Swiss nursing homes?

Prof. Andrea Koppitz, Departement Gesundheit, ZHAW, Winterthur/Hochschule für Gesundheit HES-SO, Fribourg

Fellowship: CHF 20,000

Project: CHF 120,000

Pain Intervention for people with Dementia in nursing homes (PID)

Prof. Andrea Koppitz, Departement Gesundheit, ZHAW, Winterthur/Hochschule für Gesundheit HES-SO, Fribourg

CHF 114,775

Shared Decision-Making and Advance Care Planning for elderly patients with symptomatic aortic stenosis

Prof. Tanja Krones, Klinische Ethik, USZ/Institut für Biomedizinische Ethik und Medizingeschichte, UZH, Zürich

CHF 150,000

Interventions to Improve Palliative Care in Advanced Dementia

Dr Andrea Loizeau, UZH/Marcus Institute for Aging Research, Harvard University, US

Fellowship: CHF 47,836

Facts boxes for burdensome medical interventions in dementia palliative care (DemFACTS)

Prof. Mike Martin, Psychologisches Institut, UZH, Zürich

CHF 222,648

Where new life meets death: a research based best practice model for palliative and bereavement care

Prof. Claudia Meier Magistretti, Institut für Sozialpädagogik und Bildung, HSLU, Luzern

CHF 159,000

A national palliative care database: a tool to better define the needs of palliative care patients in Switzerland

Prof. Sophie Pautex, Service de médecine palliative, HUG, Genève

CHF 97,600

Comparing the effectiveness of palliative care for elderly people in long term care facilities in Europe and Switzerland

Prof. Sophie Pautex, Service de médecine palliative, HUG, Genève

Part 1: CHF 170,500

Part 2: CHF 64,700

Compétence/sensibilité transculturelle dans la communication clinique en soins palliatifs spécialisés

Prof. Pascal Singy, Service de Psychiatrie de Liaison, CHUV, Lausanne

CHF 88,171

Patient-needs-based multi-professional delivery of Palliative Interventions by oncologists and oncology nurses: a randomized Phase II trial

Prof. Florian Strasser, Onkologie und Palliativmedizin, KSSG, St.Gallen

CHF 80,000

Mobile health technologies for palliative care patients at the interface of in-patient to out-patient care: A feasibility study to predict deterioration of patients' health status and aiming to prevent unplanned hospital re-admissions

Dr Gudrun Theile, Prof. Matthias Guckenberger, Kompetenzzentrum Palliative Care, USZ, Zürich

CHF 132,863

Palliative Care for Patients with Severe Persistent Mental Illness

PD Dr Manuel Trachsel, Institut für Biomedizinische Ethik und Medizingeschichte, UZH, Zürich

CHF 217,836

Palliative care at home: A multi-perspective study on the complex needs of ALS family caregivers

PD Dr Tenzin Wangmo, Institut für Bio- und Medizinethik, UniBAS, Basel

CHF 100,000

Gesundheit und Entscheidungen am Lebensende von Menschen mit Behinderung – eine Längsschnittstudie

Prof. Monika Theresa Wicki, Departement Weiterbildung und Forschung, HfH, Zürich

CHF 99,000

Specialised Paediatric Palliative CaRe: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings (SPhAERA)

Dr Karin Zimmermann, Pädiatrische Palliative Care, Universitäts-Kinderspital, Zürich

Part 1: CHF 50,000

Part 2: CHF 200,000

Context

In Switzerland today, around 90% of deaths occur, not suddenly, but after a period of illness and nursing care. For most people, therefore, the end of life is a process – of varying duration. Even so, until ten years ago, palliative care services in Switzerland remained very limited, compared to what was available in other countries. For this reason, the federal and cantonal authorities decided that palliative care should be promoted as part of the National Health Strategy platform.

The term palliative care is used internationally to refer to measures designed to alleviate the suffering of patients who are terminally ill, and to ensure that they have the best possible quality of life at the end of life. This is a topic with which the SAMS has been concerned for some time. In 2014, with support from the Stanley Thomas Johnson and Gottfried and Julia Bangarter-Rhyner foundations (see Box), it launched the funding programme «Research in Palliative Care 2014–2018».

The programme covered a wide variety of areas relevant to palliative care: treatment of physical symptoms, psychosocial and spiritual care, support on ethical issues, and questions relating to infrastructure and care planning. Oncology was deliberately excluded since funding for research in this field is already available from other sources.

What is the SAMS?

The Swiss Academy of Medical Sciences (SAMS) was founded in 1943 as a research funding institution. It promotes high-quality research, supports early-career scientists and strengthens research fields which, though important, are not yet well established in Switzerland. In addition, it serves as a think tank, supporting positive developments in medicine and healthcare. Among its core activities is the publication of medical-ethical guidelines for practitioners. www.sams.ch

Who served on the evaluation committee?

A broad-based, interdisciplinary expert committee was appointed to evaluate the proposals submitted. The committee was chaired by the SAMS Vice President responsible for research at the time.

Professor Peter Meier-Abt, Bern (SAMS, Chair, until Dec. 2016)

Professor Martin Schwab, Bern (SAMS, Chair, from Jan. 2017)

PD Dr Klaus Bally, Basel

PD Dr Eva Bergsträsser, Zürich

Professor Gian Domenico Borasio, Lausanne

Professor Manuela Eicher, Lausanne

Professor André Fringer, Winterthur

Professor emeritus Urs Martin Lütolf, Zürich

Professor Isabelle Noth, Bern

Professor Sophie Pautex, Genève

Professor Kai M. Rösler, Basel

Dr Michael Röthlisberger, Bern (SAMW, ex officio, until Aug. 2016)

Dr Myriam Tapernoux, Bern (SAMW, ex officio, from Nov. 2016)

What foundations were involved?

The Stanley Thomas Johnson Foundation supports projects in the fields of culture, education, humanitarian aid and medical research. It aims to improve people's quality of life and promote mutual cultural understanding. The foundation, based in Bern, owes its existence to the widow of the British industrialist Thomas Stanley Johnson. www.johnsonstiftung.ch

The Gottfried and Julia Bangerter-Rhyner Foundation exclusively supports medical research and social projects. The foundation's assets derive from the entrepreneurial activities of the prominent Bernese industrialist Gottfried Bangerter, who also played an active role in political life. www.bangerter-stiftung.ch







Q&A

Why was this funding programme important?

Compared to other countries with a similar age structure and rising life expectancy, Switzerland was lagging behind in palliative care research. For this reason, the National Palliative Care Strategy (2010–2015) explicitly called for a research offensive. Research remains important both for the quality of services provided and for a shift in perspective in therapeutic medicine.

What can be said about the diversity and quality of the proposals?

138 proposals were submitted, and 34 projects were supported. The quality of the proposals increased from call to call. Diversity was apparent not only in the topics and in the professions of the lead applicants (physicians, nursing and social scientists) but also in the originating institutions (universities, universities of applied sciences, university and cantonal hospitals).

What additional activities did the funding programme involve?

A closing symposium was held in Bern in November 2019, providing insights into the projects supported. The large number of participants demonstrated how the funding programme had contributed to research community building.

What did the funding programme achieve?

In 2008, there were only 12 publications on palliative care in Switzerland. Today – partly thanks to the SAMS funding programme – between 70 and 80 articles are published per year in Switzerland. The funding programme helped, for example, to improve data availability and to build cross-institutional research networks. In many projects, it became clear that further investigation of the research topic would be important.



Where is there still a particular need for research?

There is still considerable scope for research in relation to sociological, psychological, theological, economic and philosophical aspects.

Why is the SAMS terminating the funding programme after only five annual calls for proposals?

The SAMS is active in various areas, and its resources as a funding institution are therefore limited. It sees itself as a think tank, identifying relevant developments in medicine and society at an early stage and providing initial funding. For this reason, the duration of its funding programmes always has to be limited.

How can palliative care research projects be funded in the future?

At present, there are no indications that palliative care projects will be specif-

ically funded in Switzerland, although a substantial need exists. However, the research capacity created and the networks established should mean that palliative care projects now have a better chance of securing competitive funding under standard schemes, such as SNSF project funding.

How can it be ensured that this topic remains on the research agenda in Switzerland?

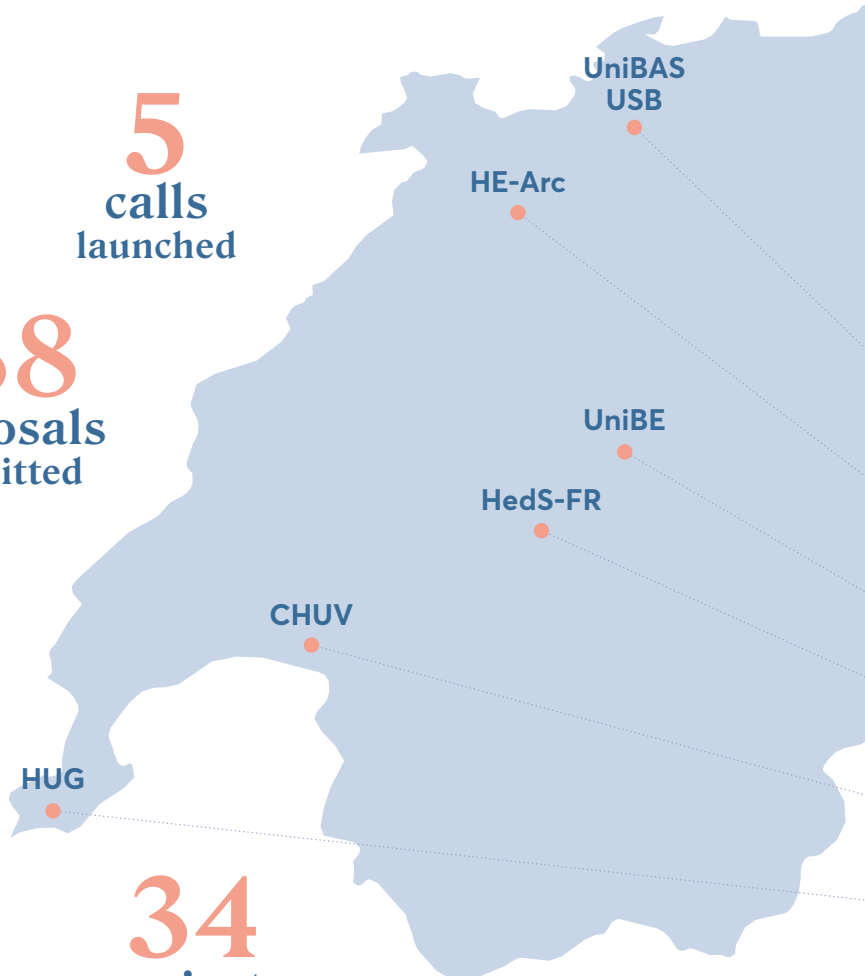
Palliative care needs to be better integrated at academic institutions so that it remains attractive for young researchers. In addition, experienced, interdisciplinary research teams would need to be established over the long term, so that Switzerland can also compete at the international level.

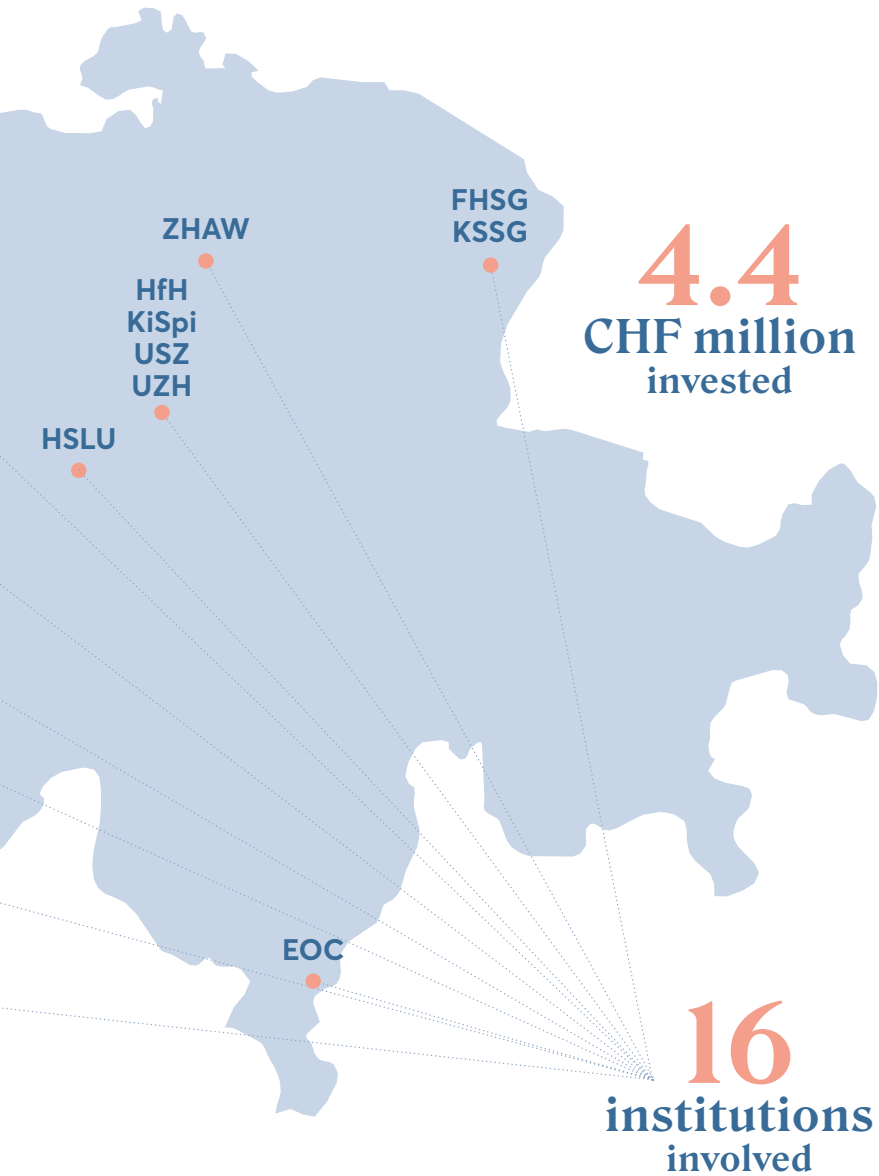
The programme in numbers

5
calls
launched

138
proposals
submitted

34
projects
supported







Swiss Academy of Medical Sciences

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sams.ch/en/palliative-care

Content

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