End of Life

National Research Programme NRP 67

Implementation Plan

FNSNF
Fonds national suisse
Schweizerischer Nationalfonds
Fondo nazionale svizzero
Swiss National Science Foundation

Swiss National Science Foundation
Wildhainweg 3
P.O. Box 8232
CH–3001 Berne

Telephone +41 (0)31 308 22 22
Facsimile +41 (0)31 305 29 70

E-Mail nfp67@snf.ch

www.nfp67.ch
www.snsf.ch

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Content

What are National Research Programmes (NRP)?

The research carried out by National Research Programmes consists of targeted research that contributes to the solution of contemporary problems of national importance. Under the provisions of Article 6, paragraph 2, of the Federal Act on Research and Innovation of 7 October 1983 (as of 1 January 2011) the Federal Council selects the topics and foci to be researched in NRPs and mandates full responsibility for implementing the programmes to the Swiss National Science Foundation (SNSF, Division IV).

Article 4 of the Federal Ordinance on the Federal Act on Research and Innovation of 10 June 1985 (as of 1 January 2011) describes the purposes and contents of NRPs as follows:

> *"[1] National Research Programmes are a means to direct and support coordinated research projects that have a common goal. Where needed, National Research Programmes should strengthen scientific research capacities.*
>
> *[2] Topics of research are generally appropriate for National Research Programmes if:*
> *a. scientific research on the problem is of national importance;*
> *b. Swiss research can make a significant contribution to the resolution of the problem;*
> *c. solutions require research contributions from multiple disciplines;*
> *d. the research goals cannot be met exclusively through basic research, through research within a specific section of the administration, or through industrial applications research;*
> *e. research on the problem can be expected to produce research results that have practical applications within a five-year time period.*
>
> *[3] The following criteria should be taken into consideration in setting forth the topics of National Research Programmes:*
> *a. the programmes can provide the scientific basis for decision-making by government and the administration;*
> *b. the programmes can be conducted with international collaboration and are also of great interest to Switzerland."*

1. Summary

The purpose of NRP 67 "End of life" is to gain knowledge useful to guiding decisions and practices during the last stage of life and make this knowledge available to decision-makers in the health care system, as well as to politicians and professionals involved in the care of persons at the end of life. "Persons at the end of life" refers to persons—whether newborn infants, children, young people, middle-aged, elderly or very elderly people—who in all likelihood will live no more than a few months.

Perceptions and frameworks regarding the end of life are currently in a state of flux. New institutions, such as palliative care services or suicide assistance organisations, dedicate themselves to the needs of persons reaching the end of life. Demographic changes and new forms of family life challenge traditional models for support and provision of care to persons at the end of life. Living wills, the practice of suicide assistance, diverse expectations towards medical care, and high health care costs, have become the subject of heated public debate. Most people in Switzerland currently die in old age. Medical decisions influence the dying process in many cases. The focus of these decisions is to ensure a "good dying", and no (longer) to fight impending death. The discourse on "good" and "bad" dying has become increasingly pluralistic and intense in recent years.

New research is needed to understand these developments better. This is the rationale for NRP 67, which includes four main research areas:

- *Dying processes and provision of care:* The focus here is on the current state of care for persons at the end of life in Switzerland, on dying processes, and on attendant practices with a special focus on palliative care.
- *Decisions, motives and attitudes:* This area centres on decisions made during the dying process, and on the motives, convictions and attitudes underlying them.
- *Regulations and proposals for action:* The focus here is on normative rules such as legal regulation or ethics guidelines, as well as questions regarding distributive justice.
- *Cultural concepts and social ideals:* Death and dying have attracted a great deal of public interest in recent years. This research area includes questions regarding how death and dying are given meaning, cultural representations of death and dying, and relevant social normalisation processes.

The Federal Council commissioned the Swiss National Science Foundation on 24.2.2010 to carry out NRP 67 "End of life". This research programme is endowed with a budget of CHF 15 million. The Research Council of the SNSF has entrusted a steering committee with strategic leadership of the

NRP. The implementation plan was approved by the Head of the Federal Department of Home Affairs on 27.1.2011. The call for proposals for the NRP will be launched on 16.02.2011. An information event will be held for interested researchers on 23.3.2011.

2. Introduction to the topic

Perceptions and frameworks regarding the end of life are currently in a state of flux. New institutions are emerging, such as palliative care institutions or suicide assistance organisations. Advance directives, the possibility of designating a patient-appointed proxy for the event of loss of decision-making capacity, suicide assistance, diverse expectations towards medical care, and high health care costs in the final months of life, have become the subject of heated public debate.

Medical progress and increasing affluence have led to higher life expectancy, with the result that most people in Switzerland die in old age. More than 50% of all deaths involve decisions that influence the dying process. In most cases, these are decisions to change the goals of care towards pain and symptom relief. The focus of these decisions is to ensure a "good dying", and no (longer) to fight impending death.

Medical care expenditure generally increases substantially in the final months of a person's life. In the last year of life, health care costs are on average ten times higher than at earlier stages of life.

Alongside economic analyses of the distribution of these costs, the NRP will focus on determining the appropriateness—or, in contrast, the futility—of end-of-life treatments and on their prioritisation and rationing. For example, new legal regulations are being demanded for suicide assistance and decisions to withdraw or withhold life-sustaining treatment. The forthcoming "adult protection law" will introduce new legal provisions, with living wills and the possibility of patient-appointed proxies for medical decisions.

Demographic shifts and changing family structures are putting traditional care models at the end of life into question. Access to specialised care at the end of life, for example admission to a hospice or in a palliative care ward, is unequally available depending on illness, dying process, level of education and information, age, sex, migration background and social status of the patient, and according to regional variations in care availability. This raises questions of distributive justice.

Suicide assistance has become the subject of public debate in recent years, with specific controversies surrounding assistance for the mentally ill, people with physical disabilities or polymorbid elderly persons. The increase in so-called suicide tourism in Switzerland points to the fact that practices and decisions at the end of life are judged and regulated differently in different central European countries. A social "normalisation" of suicide is currently apparent. Indicators for this trend are, on the one hand, a questioning of the state's role in the protection of life and the traditional role of doctors, part of which is criticised as paternalistic, and, on the other hand, the growing interest in suicide prevention. The suicide rate in Switzerland relatively high compared with other countries. It reaches its peak in old age here and elsewhere.

Furthermore, the discourse on "good" and "bad" dying has become more intensified and pluralistic in recent years. Varying—and at times contradictory—interpretations, semantics and narrations of death coexist, while traditional religious interpretations of suffering, dying and the protection of life are being eroded. Instead, the notion of selfdetermined dying is gaining in importance. This notion, however, reaches its limits for many dying persons, for example severely disabled newborns, extremely premature babies, or persons with dementia.

These developments in the area of death and dying, which also underlie the "National Palliative Care Strategy 2010–2012" and numerous international research projects, change the way in which affected individuals and their families experience the final stage of life. They also pose new challenges for medical teams and raise new questions for political decision-makers.

New research is needed to understand these changes and their effects better. Ideally, different disciplines should study the theme of the "end of life", taking into account different perspectives (patients, families, health care providers etc.) and cultures (French- and German-speaking parts of Switzerland, regions of mainly catholic or mainly protestant influence etc.). Basic empirical knowledge of dying processes, dying conditions and death-related decisions made at the end of life is still lacking. In particular, little is known about motives, convictions and attitudes on which such decisions are based.

A survey conducted under the "National Palliative Care Strategy 2010–2012" has revealed large research gaps in relation to palliative care in Switzerland, for instance in the area of provision of care, the study of decision-making processes, and quality assurance. Decisions on how to proceed have currently been almost completely lacking, for example regarding the practice of implicit medical rationing for very old people at the end of life, as have fundamental discussions on the institutionalisation, economisation, and legal frameworks of dying. The same is true of societal interpretations and widespread ideals, such as the notion of self-determined dying.

3. Objectives of NRP 67 “End of life”

The purpose of NRP 67 “End of life” is to gain knowledge useful to guiding decisions and practices at the end of life and to make this knowledge available to decision-makers in the health care system, as well as to politicians and professionals involved in the care of persons at the end of life. This knowledge is specifically intended to:

_ enhance the assessment of medical care received by individuals at the end of life and, in particular, to identify gaps or problems in the provision of care;

_ provide those affected and the health care professionals with a better basis for appropriate decisions and processes;

_ identify prerequisites for a just and dignified provision of care at the end of life, establish legal regulations as required, and reflect on the ethical implications;

_ facilitate the understanding of social developments and the prediction of future developments;

_ strengthen scientific competencies in the area of end of life and palliative care research.

4. Main areas of research

The focus of NFP67 includes four main research areas: “Dying processes and provision of care”, “Decisions, motives and attitudes”, “Regulations and proposals for action” and “Cultural concepts and social ideals”. These four sub-topics, or modules, enable the NRP to study the end of life from different scientific perspectives. The specific questions outlined under the following modules serve as examples and are meant to stimulate the development of innovative research projects.

4.1 Dying processes and provision of care

The first area of research focuses on the current situation for provision of care for individuals at the end of life in Switzerland. New knowledge in this area provides a basis for further research questions. CHF 4.5 million are budgeted for research projects that address this topic.

Dying processes and institutional contexts

The causes of death in Switzerland are largely known. However, there is scant knowledge of the corresponding dying processes and various situations as regards the provision of care, e.g. for different terminal illnesses such as severe disability in newborn or premature babies, tumours, cardiovascular diseases, different forms of dementia, or irreversible vegetative states. Furthermore, little research has been done on the links between elderly suicides, suicide assistance, and the availability of care. Possible research questions in this context are: Is it possible to describe typical dying processes? Are there differences between dying processes in hospitals and dying processes in nursing homes or at home? Why do so few people die at home? What happens with patients who die while waiting in vain for an organ transplant? The contents of death certificates might be of particular interest here. In addition: What actions are taken by professional and semiprofessional actors involved in dying processes, including nurses, doctors, priests, therapists, assistants, palliative care providers? What are their demands, difficulties and experiences? In view of demographic developments and changes to family structures, it is important to learn more about the roles and tasks of family members, taking into account gender aspects, in particular. Also of interest is the study of mourning processes in connection with different situations of care and dying processes. Finally, an ethnographic study of daily life in a palliative care ward or a hospice and the examination of thanatological practices that virtually “construct” the dying process in such contexts would be very revealing.

Palliative care

We currently do not know to what extent persons at the end of life have access to palliative care including support from doctors, nurses, social workers, psychologists and chaplains. Gaps in access to palliative care obviously exist both in the provision of basic primary medical care and nursing care, and with regard to specialised palliative care teams. It has not yet been established to what extent such services are available at home, in retirement and nursing homes, institutions for the disabled, or in hospitals. Furthermore, little is known about the symptoms and needs of patients at these locations. Research questions in this context are for instance: How can the need for palliative care on the part of persons at the end of life be realistically assessed and predicted? How common are palliative care wards, palliative counselling services, mobile palliative care structures and similar institutions? Are the primary care providers appropriately trained in basic palliative care? A comparative study of dying processes with and without basic palliative care could tell us more about the latter’s relevance. What is to be said with regard to the controllability of the dying situation; is the wish to control the situation and processes at all realistic? It is known that chronic pain and sleeping disorders can cause people to become depressed and suicidal: How is this influenced by the quality of palliative care? To compare dying processes with and without specialised palliative care, knowledge about quality indicators for different dying processes would be useful, as would medical studies comparing different interventions. The study of relevant aspects of social inequalities is of particular interest: Do social differences have an impact on access to the above-mentioned institutions? What role do social class, gender or an immigrant background play? Can differences be identified in the provision of pain relief to people at the end of life in Switzerland? Light must also be shed on initial and continuous training for doctors and health care providers on pain management and control of symptoms.

Costs of medical care at the end of life

It is a known fact that the costs of medical care during the final months of life are very high on average. What is not known is how these costs are shaped by gender, age, health, dying process, region, institution, etc. Nor do we know how high nursing or palliative care costs are, as compared with the cost of other medical treatments at the end of life. The concentration of costs at the end of life initially backs up the compression thesis[1], while in contrast the increase in chronic diseases, multi-morbid situations and persons who depend on care supports the medicalisation thesis[2]. Does the empirical evidence gained in Switzerland confirm either of these hypotheses? Medical care costs for persons at the end of life appear to fall as people's age of death increases. Can research confirm, for example, the assumption that accessing health care becomes increasingly difficult the older people get, and thus that the controversial practice of age-based rationing is already established?

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[1] This thesis is based on the assumption that people are living longer disease- and disability-free lives. They will therefore require treatment at a later stage in their lives (on average) and depend on assistance and care for a shorter period.

[2] The assumption that health care costs will rise due to the higher life expectancy and demographic aging.

4.2 Decisions, motives and attitudes

The second area of research primarily centres on decisions made in the context of the dying process, and on the motives, convictions, and attitudes underlying them.

The research projects focusing on this topic should aim to improve our understanding and assessment of existing practices and decisions and to help us influence them more appropriately. CHF 3.5 million are budgeted for research projects that address this topic.

Medical and related decisions

Difficult medical decisions to be studied include decisions to withdraw or withhold treatment, i.e. not to attempt resuscitation, to discontinue dialysis, to introduce pain and symptom management, to implement total parenteral nutrition and artificial ventilation, to take intensive medical measures or apply palliative and terminal sedation. Knowledge also needs to be gained on socially controversial decisions such as suicide assistance, termination of life, killing on request, or mercy killing. The questions surrounding the relevance, assessment and impact of the concept of brain death and the attendant decision-making practice at the end of life offers further topics for investigation. Of interest here is how decisions are reached, what the procedures are, who is involved and to what extent the concept of patient autonomy plays a role. An emphasis will be put on studying the roles of family members, health care providers and doctors in decisions at the end of life. Possible research questions in this context are: How is information management handled in the care teams? To what extent are decisions planned and prepared in a way that will allow them to be considered "timely" when taking stock? Are structures in place to support this? Our knowledge of the frequency and content of living wills is also quite limited. Thus, we are interested in learning who completes such wills, what templates are preferred and—most of all—what wishes and requests are expressed in them. Another question is how living wills influence actual decision-making. The relationship between patients and their families and the medical team is another point of interest, as is the extent to which the wishes and expectations of patients differ depending on their state of health.

Attitudes and motives

The outlined (medical) decisions are underpinned by attitudes and motives, which also require exploration. To what extent do convictions about the "sanctity of life" and the emphasis given to quality-of-life criteria play a role? The influence of religious and other beliefs and the relevance of professional experience for decisions at the end of life, as well as differences between different institutions, professions and medical areas of specialisation, are to be investigated. Finally, it is important to examine the doctor-patient or provider-patient relationship in real life, its changes, and how it influences the dying process. Does the "shared decision-making model" play a role in today's clinical practice? Of particular interest is the question of how trust between dying people and caregivers and the asymmetrical distribution of information between them influence decisions. Last but not least, the different attitudes, motives, expectations and concepts of the human being held by patients, their families and their friends are to be studied.

Allocation decisions

Another question surrounds the management of scant resources and hence the allocation decisions taken at the bedside (micro-level), in institutions (meso-level) and in health care policy (macro-level), as well as the interdependencies between these levels. The following research questions present themselves in this context: According to what notions and attitudes do the treatment team regulate access to medical resources at the bedside? What impact on medical decisions do ex ante and ex post uncertainties with regard to the dying process have at the end of life? Such questions occur in more accentuated form in oncology and intensive medicine as well as in connection with day-to-day decision-making in geriatric wards or nursing homes. How, for instance, does one manage risk? What role does the "rule of rescue" (measures to save a patient whose life is acutely threatened are always prioritised) play in daily clinical work? Topics to be studied at the meso-level include personnel policy decisions, the wording of treatment guidelines and their impact on access to treatment at the end of life. Decisions taken at the macro-level, e.g. on expanding the health care infrastructure, also have an influence on survival and costs. However, this influence remains largely unexplored today. Finally, ways must be found to lighten the financial burdens borne by caregiving family members and relatives.

Suicide assistance

Suicide assistance is a special feature of Switzerland and it is observed with great attention throughout the world. In Switzerland, doctors often collaborate with organisations offering suicide assistance. However, little is known about the decision-making, reasons, attitudes and motives of those who request suicide assistance or about the role played by doctors and those providing suicide assistance. Possible research questions in this context are: How many people request suicide assistance, and for what reasons? What roles do doctors assume in the current practice (in Switzerland as opposed to in Oregon or the Benelux countries)? To what extent are suicide helpers from the relevant organisations involved in decision-making? What is the impact of media coverage and advertisements placed by the organisations offering suicide assistance? In view of the domestic and international significance of suicide assistance, a logical step would be to establish the principles of permanent monitoring. Changes could thus be registered immediately and responded to appropriately. Another important question is how to deal with suicide assistance that is not carried out under a doctor's responsibility or with a prescription drug. Moreover, it is important to study organised suicide assistance as a phenomenon in its own right.

4.3 Regulations and proposals for action

The third area of research, for which CHF 2.5 million are budgeted, regards normative rules, e.g. in public law, constitutional law, cantonal health laws, social insurance laws, criminal and civil law, as well as court decisions, for instance on the practice of suicide assistance. Also relevant are the rules of conduct of the medical profession and the so-called "soft law", such as the ethical guidelines of the Swiss Academy of Medical Sciences (SAMS), ethical guidelines of the Swiss Nurses Association (SNA) or the recommendations of the Swiss Society of Neonatology on the "Care of infants born at the limit of viability". The ethical guidelines of individual hospitals or nursing homes with regard to suicide assistance and the recommendations of clinical ethics commissions or individual ethics support services are also of normative relevance.

Statutory regulations

The primary aim is to take up discussion on an appropriate regulation of suicide assistance under criminal law (Article 115 Criminal Code) and on the equally controversial killing on request (Article 114 Criminal Code). In particular, the different proposals with regard to a new legal regulation of suicide assistance are to be examined. Examples of research questions in this context are: How is the practice of indirect euthanasia to be judged, and how should it be legally evaluated? Do the frequent decisions to discontinue or forego treatment as well as terminal sedation require special legal regulation? What form might such regulations take? What is the relationship between the legal issues involved? How do the new provisions on living wills and on representation for medical decisions under the new "Adult protection law" impact on clinical decisions? This will provide a basis for the appraisal of Swiss provisions and for comparisons with the legal framework established in, e.g., Germany and Austria.

Professional ethical and related guidelines

Suicide assistance is regulated in the professional rules of conduct of the FMH, which make reference to the SAMS guidelines for the treatment and care of patients at the end of life. The question here is to what extent such regulations are satisfactory, or whether a formal legal regulation would be more appropriate or even necessary. Similar questions can be raised with regard to the SAMS guidelines for living wills, "do not attempt resuscitation" decisions, as well as for palliative care and difficult decisions in intensive medicine for adults as well as newborns. What role do these ethical guidelines play in doctors' or nurses' everyday work? Are they known and accepted, or do they perhaps need to be revised? Another question surrounds the relationship between the ethical guidelines and provisions of the Criminal Code on the treatment and care of patients at the end of life. Is there a risk that judges might leave SAMS and professional guidelines aside in conflict situations? How are doctors, health care providers and family members involved in legal decision-making?

Questions regarding just distribution

The practice of prioritising or "posteriorising" medical measures and the criteria for rationing or restricting care at the end of life are to be investigated from a legal, ethical and health-costs-related perspective. Normative debates have more particularly surrounded allocation criteria and their application at the macro-, meso- and micro-levels. The often limited effect of costly new medication requires that we ask whether, and to what extent, economic analyses of the cost-effectiveness of treatments should be allowed to play a role in decision-making at the end of life. Furthermore, we need to clarify which palliative care measures should be covered by health insurance and where the line is to be drawn, for instance with regard to the financing of spiritual, social and psychological care at the end of life.

Normative rules in a cultural context

It is obvious that culturally determined habits and social norms strongly influence how decision-making situations are viewed. Practices such as the termination of artificial respiration, total parenteral nutrition for patients in vegetative states, and treatment for newborns with severe disabilities, are viewed differently across Europe. There is also a lack of consensus with regard to suicide assistance or euthanasia by doctors, which is legal in the Benelux countries (see chapter 4.2). A cultural anthropological question merits consideration here: to what extent can normative rules be traced back to cultural interpretations (see chapter 4.4). In addition, we may ask the legal and ethical question as to how the dynamic of normative rules is influenced by modern mobility and the migration of doctors and caregivers, on the one hand, and of patients at the end of life, on the other. A central question closely linked to cultural perceptions is that of futility, or pointlessness, of medical measures at the end of life. It would be interesting, if scientifically grounded assessment benchmarks could be developed to assess futility or—more positively—the usefulness of treatments at the end of life.

4.4 Cultural concepts and social ideals

Death and dying have been publicly debated over the past twenty years or more. This contradicts the long-held view that these topics are suppressed by society and laden with taboos. Indeed, we might go as far as to say that death and dying have been "discovered". In the programme's fourth area of research, for which CHF 2.5 million are budgeted, researchers will look at how death and dying become the subject of discourse and social norms, or respectively, of institutionalisation. The elements described below are closely intertwined.

The endowment of meaning

In a society with no shared notion of "meaningfulness", the individual is left to face death alone. The decline of religion has left a relative vacuum, and the churches have largely lost their function of bestowing meaning. In view of the aforementioned removal of taboos, we must seek to identify the interpretations that are taking or have taken the place of traditional religious semantics, for instance when the meaning of suffering and death are invoked. To what extent has the notion of "death as transition" been replaced by that of "death as the end", or not? This is linked to the rediscovery and reintegration of the spiritual dimension in modern medicine, which plays an important role in the selfdefinition of palliative care.

Cultural concepts

In the past few decades, we have seen the rise of different cultural concepts pertaining to "good" and "bad" dying. In some cases, a new "ars moriendi" has been called for. What cultural representations and collective interpretations have shaped these concepts? The ideal of a "natural death" is of interest here: often it is thought to constitute the opposite of an inhumane death amidst modern medical methods and equipment. The ideal of "self-determined dying" is currently also of great importance. This raises questions regarding how the notion of self-determined dying is linked to social individualisation processes, and how changing views towards elderly suicides ("normalisation" of elderly suicide) are linked with the idea of self-determined dying.

Social norms

Cultural concepts give rise to social norms which find their way into the self-help literature and are spread by the media. Such norms can therefore directly influence palliative practices. An institutionalisation of dying is emerging. In this context, it should be asked to what extent there is a social expectation that dying should be accompanied by personal growth and/or that those who die should go through certain phases. The norms being disseminated in the context of palliative care are of particular interest here: What normative representations do they in turn derive from? What is "good" dying? And what representations, identities, and politics of the body are created in the vicinity of palliative care institutions, which are influenced by new norms on how to die? Good dying usually means conscious dying. This leads to the question: what are the norms that influence dying processes that are not consciously lived through?

5. Research strategy guidelines

All research projects must deal with the situation of people at the end of life in Switzerland and hold out the prospect of a scientific contribution to the goals of the NRP "End of life". Moreover, projects should follow the research strategy guidelines set out in the following:

Multidisciplinarity/Interdisciplinarity

If possible, research projects should integrate approaches of different disciplines, i.e. they should work along multidisciplinary lines. As far as this is feasible, they should be organised in interdisciplinary terms and allow for working methods from different disciplines.

Cooperation and processing of available data across different projects

Collaboration with other projects within and outside NRP 67 as well as international cooperations are encouraged. In each case, it must be established whether relevant data or results from other projects is already available regarding either decisions and practices at the end of life or research on palliative care. For example, the "National Palliative Care Strategy 2010–2012", or international studies such as Euronic, Ethicus, Eureld, Prisma, Euro Impact, or Opcare 9, should be considered. Another option might be to cooperate with the Federal Statistical Office (FSO) or the Swiss Health Observatory (Obsan).

Perspectives across different areas of research

Projects that cover and combine aspects from more than one of the programme's research areas (see chapter 4) are welcome. Individual projects that deal with topics from different areas of research are encouraged to address complementary research questions cooperatively.

Comparative research design

Systematic comparative research designs, for example to explore regional differences in access to medical care at the end of life, different dying processes subject to specific interventions, or decision-making practices as compared to other countries, would be of particular interest. Switzerland offers good conditions for researching different cultural practices and ideas concerning the end of life.

Diachronic perspective and longitudinal studies

Thanks to a scheduled running time of up to five years, NRP 67 is conducive to diachronic research and longitudinal studies. These may concern, for instance, interventional studies or studies on developments in the area of suicide assistance and other controversial decisions at the end of life. For instance, it would be desirable to repeat the Eureld study in order to compare developments in Switzerland with those in other countries. Longitudinal studies would also be an option for studying access to palliative care or changing notions of "good" dying.

Promotion of junior researchers and setting of research structures

NRP 67 aims to strengthen scientific competencies by supporting junior academics and scientists. Projects that emphasise this aspect by, e.g., enabling dissertation projects or strengthening basic research structures and platforms, are encouraged.

6. Practical uses and addressees

The practical uses of NRP 67 "End of life" are as follows: Provision of a knowledge base to assist the authorities, politicians, professionals, private persons and public institutions in pending decisions and developments with regard to the end of life. Furthermore, the knowledge gathered in NRP 67 should serve to make the public debate on the end of life more evidence-based. Another aim is to have a lasting positive effect on end of life and palliative care research in Switzerland.

The addressees of NRP 67 "End of life" therefore comprise:

- Researchers in Switzerland in the relevant disciplines;
- Leading research programmes and institutions abroad;
- Members of parliament concerned with this topic;
- Swiss political parties;
- Authorities at the Confederation, cantons and municipalities concerned with this topic;
- Health care institutions and their organisations (e.g. H+, Curaviva, Spitex-Schweiz, OdASanté);
- Institutions and organisations involved in care for the dying (e.g. churches, hospices, Voluntas);
- Affected professionals, or their associations and societies (e.g. SNA, Swiss Association for Nursing Science (ANS), SAMS, FMH);
- Patient support organisations that represent the interests of people at the end of life (e.g. Exit, Dignitas, Swiss Cancer League);
- Affected institutions of pre-, post-graduate, and continuing education;
- The media and interested sections of the public.

7. Schedule of the programme

Research conducted under NRP 67 "End of life" is limited to five years. In an initial phase, selected projects will be executed with a running time of no more than 36 months. The second phase will be used to study certain topics more closely and extensively. For this purpose, projects can be extended at the invitation of the Steering Committee under a concept similar to a Bonus of Excellence. Intervention studies may apply (giving reasons) for a running time of over 36 months.

In the event of any thematic gaps, the Steering Committee may decide ad hoc to launch a complementary second call for proposals both in the first and in the second phase.

8. Submission procedure and project selection

The Implementation Plan as well as forms, rules of procedure and instructions for the submission on the *mySNF* portal can be found on the following website: www.snf.ch.

A two-stage submission procedure has been set up: Interested researchers must submit a pre-proposal first. After assessment of the pre-proposal they may be invited to submit a full proposal.

Pre- and full proposals have to be submitted online on the *mySNF* portal. For the use of *mySNF,* prior user registration on the homepage of https://www.mysnf.ch is required. Previously opened user accounts are still valid and provide unlimited access to all the funding instruments of the SNSF. To submit proposals in time, a new user account has to be opened two weeks before the submission deadline at the latest. The submission of the documents by postal delivery is only accepted in exceptional cases after consultation with the programme coordinator.

The Steering Committee expects pre- and full proposals to be submitted in English, unless it can be shown that either German or French is intrinsically better suited to the research topic. For evaluation purposes, the pre- and the full proposal must be written in the same language. The running time of NRP 67 is 60 months. The duration of individual research projects is limited to a maximum of 36 months. Exceptions can be granted for intervention studies, if valid reasons are given. Decisions to either extend or not extend projects will be made when the programme is in progress, and not before.

Pre-proposals can be submitted together in one package for joint projects. It is important that these pre-proposals are on a par with independent, individual pre-proposals. They will be reviewed individually and must therefore each contain all relevant information.

Collaboration with research groups in other countries is encouraged, provided that the planned cooperation a) brings significant added value which could not be achieved without cross-border cooperation or b) substantially enriches Swiss research in respect to content or methodology. Decisions on possible (co-)financing of research projects abroad will be made on a case-by-case basis. In the framework of NRP 67, the Austrian Science Fund (FWF) agreed to participate in the "lead agency process". The German Research Foundation (DFG) has decided not to participate in NRP 67.

8.1 Pre-proposals

The deadline for submission is 20 May 2011. The pre-proposal should provide an outline of the planned research project as well as information on the following points:

Data to be entered directly in the *mySNF* portal:

_ Basic data and abstract,

_ National and international co-operation,Budget: estimate of financial support required for salaries and running costs.

Documents to be uploaded in PDF format:

_ Project description

- Research topic and objective of the project,
- State of research,
- Research plan: approaches and methods,
- Timeframe and milestones,
- Expected benefit and possible application of results,
- List of the five most important publications in the same field as the pre-proposal,
- List of the five most important publications of the applicants or the research team,.

The project description must be submitted using the template document provided on the *mySNF* portal and must not exceed six A4 pages (including cover page).

_ Short CVs of the applicants of a maximum of two A4 pages each. CVs that exceed this length will not be considered.

The Steering Committee evaluates the submitted pre-proposals and makes a final decision based on the review criteria outlined below. In making its decisions, it may refer to the opinions of experts from abroad. Authors not invited to submit a full proposal will be informed accordingly by means of a ruling.

8.2 Full proposals

In the second stage of the submission procedure the Steering Committee will invite the authors of the selected pre-proposals to submit detailed *full proposals* online via the *mySNF* portal in accordance with standard SNSF rules and guidelines. If the Steering Committee should identify a need for coordination between different projects, the applicants concerned will be informed accordingly when invited to submit their proposal and asked to cooperate if necessary.

Based on external national and international reviews as well as an internal evaluation, the Steering Committee will decide which research proposals are to be submitted to the National Research Council (Division IV; Presiding Board) for approval or rejection.

For approved projects, the request for release of funds must be submitted no later than four months after the date of the ruling

8.3 Selection criteria

Pre- and full proposals will be reviewed on the basis of the following criteria:

_ **Academic quality:** Theory, research questions, research design and methods must be presented comprehensibly. The projects must reflect the state of the art in the field in question and meet international academic standards.

_ **Academic originality:** The projects must contain an innovative component as compared to completed or running research projects in the same field.

_ **Academic track record:** Applicants who submit pre- or full proposals must have a proven track record in their field and meet the personal and formal requirements for submission (see Regulations of the Swiss National Science Foundation on Research Grants). The academic track record involves, in particular, successfully completed research activities and high-level national and international publications.

- **Compliance with the goals of the NRP 67:** Proposals should reflect the programme's scientific objectives as outlined in the implementation plan and comply with its overall framework.
- **Feasibility:** The proposed study must be shown to be feasible (e.g. in ethical terms or with regard to availability of and access to data, personnel recruitment and timely completion).
- **Multi- or interdisciplinarity:** Projects with research questions that can be addressed by different disciplines or that demand approaches that transcend the boundaries between disciplines are encouraged. Applicants must show how they intend to secure interdisciplinary cooperation.
- **Application and implementation:** The potential for practical application and implementation of results is a key element of National Research Programmes. Projects of high practical relevance are therefore given priority.
- **Personnel and infrastructure:** Adequate personnel resources and an adequate infrastructure must be secured for the project.

Division IV of the Administrative Offices check whether the formal criteria are met, before forwarding the proposal for content review (cf. Funding Regulations of the SNSF). Pre- and full proposals that do not meet the formal criteria will not be processed further.

8.4 Schedule and budget

The following schedule has been set for NRP 67:

Call for pre-proposals	16 February 2011
Submission of pre-proposals	20 May 2011
Invitation to submit full proposals	End of August 2011
Submission of full proposals	1 December 2011
Final decision on full proposals	February 2012
Start of research	April 2012

NRP 67 will operate with a total funding of CHF 15 million. The provisional allocation of this funding to different types of activities is as follows:

Module 1	CHF 4.5 million
Module 2	CHF 3.5 million
Module 3	CHF 2.5 million
Module 4	CHF 2.5 million
Implementation and administration	CHF 2.0 million

8.5 Contact persons

For questions concerning the submission and evaluation procedure or NRP 67 in general, please contact the programme coordinator Stephanie Schönholzer at nfp67@snf.ch or 031 308 22 22.

Contact person in financial matters is the division IV head of finances Marcel Schneider, mschneider@snf.ch or 031 308 21 05.

9. Actors

Steering Committee

Markus Zimmermann-Acklin, Dr., Department of Moral Theology and Ethics, University of Freiburg, Switzerland (President)

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

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

Silvia Käppeli, PD Dr. Dr., Zentrum für Entwicklung und Forschung Pflege, University Hospital Zurich

Sophie Pautex, PD Dr., Equipe Mobile Antalgie et Soins Palliatifs, Département de réhabilitation et gériatrie, University Hospital of Geneva

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

Ursula Streckeisen, Prof. Dr., Pädagogische Hochschule Bern, and PD Dr., Institute of Sociology, University of Berne

Brigitte Tag, Prof. Dr. iur. utr., Chair of Criminal Law, Criminal Proceeding and Medical Law, University of Zurich

Delegate of the National Research Council

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

Programme Coordinator

Stephanie Schönholzer, Dr., Swiss National Science Foundation (SNSF), Berne

Head of Knowledge Transfer

Mathis Brauchbar, advocacy AG, Zürich

Representative of the Federal Administration

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

State Secretariat for Education and Research (SER), Berne

Claudine Dolt, Dr.