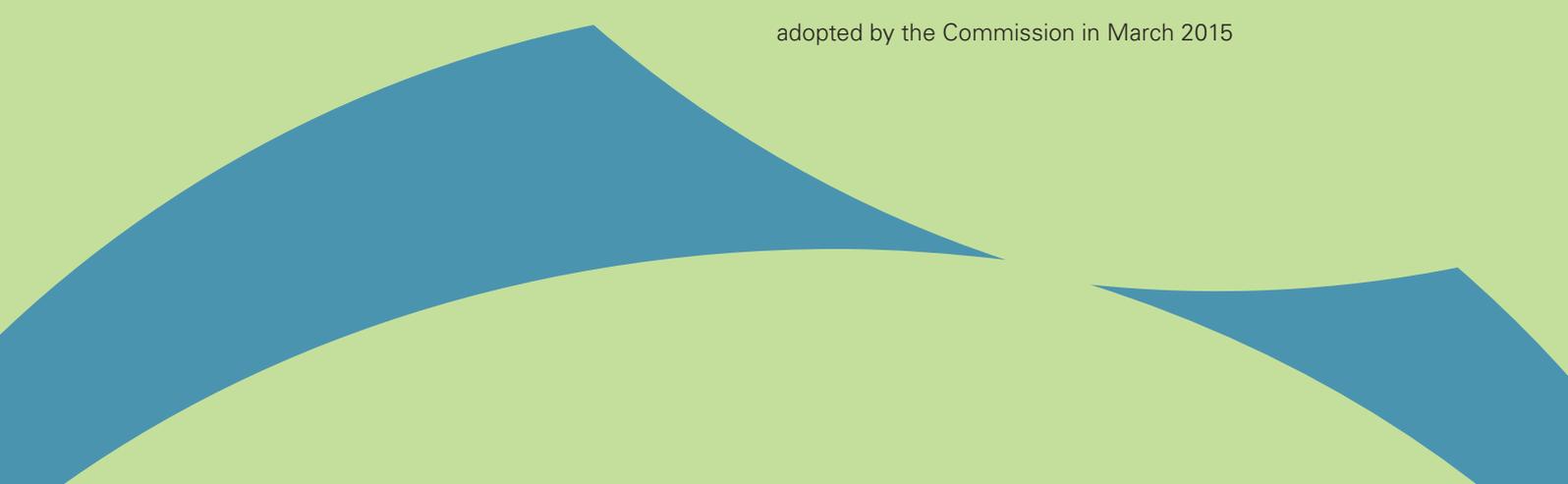


# Report on the Activities 2014

**for the attention of the Federal Council,  
Parliament and the general public**

adopted by the Commission in March 2015



# Contents

## Report on the Activities 2014 of the NEK

for the attention of the Federal Council,  
Parliament and the general public



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# Foreword

In March of the year under review, the **Commission was newly constituted**. The appointment of new members was required as more than half of the Commission's existing members had reached the end of their tenure. At a retreat held in Bern, the Commission reflected on its legal mandate and sought to elaborate a shared understanding of its role and responsibilities. The following topics were placed on the Commission's agenda, with working groups being established in each case: Culture of death and dying, Personalised medicine and Reproductive medicine.

In June, the Commission published an Opinion on **medical confidentiality in prisons**. In the light of tragic recent events, a number of French-speaking cantons were considering the possibility of imposing on health professionals an obligation to disclose information relating to the danger posed by detainees. The Commission recognizes the legitimacy and importance of authorities' efforts to ensure the protection of all members of society and of their rights to life, health and safety. However, it takes the view that it is not ethically acceptable to impose on medical staff an obligation to disclose information: such an obligation violates the fundamental rights of detainees and is detrimental to the interests of the public in the rehabilitation of offenders and public safety. It increases the risk that detainees will return to society without having received appropriate medical treatment. Finally, it has not been demonstrated that – compared with the existing system based on *optional* disclosure – an *obligation* to disclose information actually facilitates assessment of the danger posed.

As regards future activities, the Commission has decided, under the heading of **Culture of death and dying**, to explore the various possibilities and difficulties associated with the notion of a good death or dying in dignity. This requires engagement with the various parties concerned – with those who are dying and their relatives, with carers, physicians and nursing staff and also hospital authorities, as well as the health insurers' perspective. Not least, there

is a need to consider not only medical, but also emotional, social and cultural aspects. While public debate tends to focus on assisted suicide, the "culture of death and dying" involves a broader approach: the dying hope for the alleviation of pain, as well as personal support and comfort, and if this is provided the desire for suicide may be renounced in many cases. As the dying look back – albeit selectively – over their lives, they will see that the key to learning how to die is learning how to live.

In the area of **Personalised medicine**, the Commission is focusing on **biobanks**. A large number and wide variety of public and private biobanks currently exist in Switzerland and worldwide. In this context, diverse and competing interests are at stake – patients' rights to privacy and data protection, the interests of research and research locations, commercial interests of companies in the biotech and pharma sector and, lastly, the general public interest in medical advances. The challenge from an ethical perspective is to strike the best possible balance between these individual and wider interests, and to create a favourable framework for their promotion. Here, it should be borne in mind that biobanks require public confidence, and that this is decisively strengthened by a transparent public debate.

In the area of **Reproductive medicine**, the Commission responded to a query from the Federal Commission on Basic Health Care Services and Fundamental Principles (ELGK) concerning reimbursement by health insurers of the costs of non-invasive prenatal tests (NIPT). The essential question to be addressed was whether the financing of such tests under social insurance would contribute to a change in attitudes towards people with disabilities, and whether the restriction of coverage to pregnant women at increased risk was acceptable or violated the principle of equal access enshrined in the Health Insurance Act (KVG).

Bern, March 2015  
Otfried Höffe, Chair

# 1. Legal foundations and mandate

The Swiss National Advisory Commission on Biomedical Ethics is an extra-parliamentary body, which was established by the Federal Council on 3 July 2001.

In carrying out its tasks, and especially in formulating its opinions, the Commission is obliged to remain independent of political, industrial and scientific interests.

The legal basis for the Commission is provided by:

- ✓ Article 28 of the Reproductive Medicine Act of 18 December 1998 (see below) and
- ✓ the Ordinance on the National Advisory Commission on Biomedical Ethics of 4 December 2000 (SR 810.113).
- ✓ In addition, the Commission's deliberations are governed by the NEK-CNE Rules of Procedure of 29 October 2009.

The Commission's mandate is to conduct a careful and comprehensive assessment of ethical issues arising in the areas of medicine and healthcare, focusing in particular on new scientific knowledge and technological developments. It thus contributes to a process of opinion-forming, at all levels of society, which is evidence-based and guided by arguments.

The emphasis is placed on the preparation of opinions and recommendations, and on communication with the public. The NEK-CNE does not, however, review individual research projects; this remains the responsibility of Switzerland's cantonal ethics committees.

## Federal Act on Medically Assisted Reproduction

(Reproductive Medicine Act, RMA)  
of 18 December 1998 (status as of 1 January 2013)

### Chapter 3: National Ethics Commission Art. 28

1. The Federal Council shall establish a national ethics commission.
2. The commission shall monitor developments in assisted reproductive techniques and gene technology in the area of human medicine and comment from an ethical perspective, in an advisory capacity, on associated social, scientific and legal issues.
3. In particular, the commission shall have the following tasks:
  - a. to draw up additional guidelines relating to this Act;
  - b. to identify gaps in the legislation;
  - c. to advise the Federal Assembly, the Federal Council and the cantons on request;
  - d. to inform the public about important findings and to promote debate on ethical matters within society.
4. The Federal Council shall determine the other tasks to be carried out by the commission in the area of human medicine. It shall enact implementing provisions.

# 2. Opinions

## 2.1 Overview of Opinions prepared by the Commission in the period under review

In 2014, the Commission addressed the following topics:

### Opinions

#### Opinion no. 23/2014

On the obligation to disclose information covered by medical confidentiality in prisons (published online on 6 June 2014)

#### Opinions prepared as part of Federal Council consultation procedures

NEK-CNE response to the first internal consultation on the complete revision of the Federal Act on Human Genetic Testing (HGTA, SR 810.12), 27 October 2014.

## 2.1 Summaries of NEK-CNE Opinions

### Opinion no. 23/2014

#### On the obligation to disclose information covered by medical confidentiality in prisons

The Commission unanimously recommends that the current system – based on optional disclosure – should be maintained. An obligation to disclose information does not facilitate assessment of the danger posed and thus does not represent a means of improving public safety. On the contrary, such an obligation may well adversely affect public safety since, having served their sentence, detainees will return to society without having received appropriate medical treatment, particularly as regards their mental health. In addition, the obligation to disclose information would tend to discourage physicians from exercising their profession in prisons. It would also violate detainees' right to privacy and run counter to internationally recognized ethical principles. The Commission's position is based on various arguments which militate against obligatory disclosure: under the current system, health professionals can already be released from the duty of medical confidentiality in certain circumstances; the proposed changes confuse or mix care and expert medical assessment; and confidentiality is indispensable if a therapeutic relationship is to be established. Trust is central to an effective physician-patient relationship, and obligatory disclosure violates the principles of non-discrimination and equivalence, since the health services provided for detainees must be similar to those available to the community. Obligatory disclosure thus contravenes health professionals' ethical principles and code of conduct.



All NEK-CNE publications (Opinions and consultation responses) are available for download at: [www.nek-cne.ch](http://www.nek-cne.ch)

# 3. Communication with the public

In the period under review, the following public events were held by the Commission:

As mentioned in last year's report, a media conference was held on 13 February 2014 to present the Opinion on medically assisted reproduction (no. 22/2013).

As is customary, to accompany its annual **two-day meeting** – held in Appenzell (Canton Appenzell Innerrhoden) on 23/24 October 2014 – the NEK-CNE organised an evening event for the public, including a panel discussion, on the subject of **Culture of death and dying**. This event, held in Appenzell's town hall, attracted considerable public attention; the interest displayed by the audience was overwhelming. The topic was deliberately chosen by the Commission as a counterpoint to the debate on assisted suicide: calls for physician-facilitated suicide often spring from fear of the end-of-life period, and of dependence or helplessness. At the same time, "technical" questions associated with assisted suicide – what is permissible/prohibited? – may obscure a more fundamental human question: How can mortality, leave-taking and death be integrated into life, without this leading to negativity or depression? An introduction to this topic was provided by the Commission's Chair, Professor Otfried Höffe. Taking into account the expe-

riences of Dr Karen Nestor (palliative care specialist at St Gallen Cantonal Hospital), Franziska Waber (head of nursing and care at the Evangelisches Pflegeheim Bruggen) and Stephan Guggenbühl (former Appenzell Cantonal Priest), the following questions were then discussed: What is our experience of the care provided for the dying? How has it changed in recent years? What difficulties arise – for the dying and for their relatives? The panel discussion was moderated by Commission member Professor Brigitte Tag. The event was extensively reported, with half a dozen articles appearing in the local press.

In addition, the Commission and its Chair and members were also present in the media in various contexts throughout 2014. Particular mention should be made of contributions and interviews on the topics of the culture of death and dying, assisted suicide, intersexuality, reproductive medicine and cost-effectiveness in healthcare.

In 2014, the Commission launched a **new website**, with its own domain name. While the structure of the site is unchanged and it continues to comply with the Federal Administration's corporate design, it is no longer part of the Federal Office of Public Health website, but has its own address: [www.nek-cne.ch](http://www.nek-cne.ch).

# 4. National and international cooperation

At the national level, the Commission agreed to hold a **new series of public symposiums from 2015** to approx. 2018 – in cooperation with the Central Ethics Committee (CEC) of the Swiss Academy of Medical Sciences (SAMS) – on the subject of **Autonomy in medicine**. On 8 May 2014, a joint meeting of the Commission and the CEC was held in Bern to prepare the new series of events. Papers on Autonomy: a multifaceted concept were given by Bernard Baertschi, *Maître d'Enseignement et de Recherche* at the Institute for Ethics, History and the Humanities, Geneva University, and Professor Claudia Wiesemann, Head of the Department of Medical Ethics and History of Medicine, Göttingen University.

The Commission is also among the sponsors of the TA-SWISS study **Prenatal genetic diagnosis**, in which its representatives (Professor Frank Mathwig and Dr Elisabeth Ehrensperger) are actively involved as members of the Supervisory Group. Professor Brigitte Tag explained the Commission's position on the TA-SWISS study **Personalised Medicine** when it was presented in Bern in March 2014.

Professor Brigitte Tag represented the Commission at two **hearings** on preimplantation genetic diagnosis (PGD), held in Bern by the Green Liberal parliamentary group on 21 February and by the National Council Committee for Science, Education and Culture on 27 March; she also represented the Commission at a hearing on oocyte donation held by the Council of States Committee for Science, Education and Culture on 31 October.

In April, Commission member Professor Markus Zimmermann gave a paper on ethical positions concerning extremely premature infants at a conference held at Zurich University Hospital. This event was organised by the Centre for *Medicine – Ethics – Law Helvetiae* (MERH) in cooperation with the Neonatology Clinic. The Commission was represented by its General Secretary, Dr Elisabeth Ehrensperger.

In September, at a conference in Bern held by the *Swiss Protestant Women's Federation* ("Child – gift or strategy"), Commission member Professor Frank Mathwig gave a paper entitled "Tristram's world: On some consequences of the new reproductive technologies". The Commission was represented by its General Secretary.

In April, the Commission's scientific collaborator Dr Simone Romagnoli attended a lecture on *Euthanasia in Swiss law* by Bernardo Stadelmann, Vice Director of the Federal Office of Justice, which was held at Fribourg University as part of a series of lectures on contemporary philosophical challenges relating to human life. He also attended an interdisciplinary conference entitled *From the repaired human to the enhanced human: what kind of impacts on individual and society?* held in November at the EPFL SwissTech Convention Center.

The Commission has **regular exchanges** with the Federal Ethics Committee on Non-Human Biotechnology (ECNH), the Expert Commission for Human Genetic Testing (GUMEK), the Federal Commission for Drug Issues (EKDF) and TA-SWISS, in whose Steering Committee the Commission's General Secretary, Dr Elisabeth Ehrensperger, has the status of a guest without voting rights. In August, the General Secretary attended the annual meeting of the extra-parliamentary social policy commissions. Among the topics discussed were the parliamentary initiative «Rutz Gregor. Extra-parliamentary commissions. Activities of the decentralised Federal Administration» and the evaluation of the Swiss Centre of Expertise in Human Rights (SCHR), or the possible establishment of a permanent national human rights institution. At a series of *Orphan Diseases* workshops, organised by the Federal Office of Public Health, the General Secretary also monitored the development of measures to improve the care provided for patients with rare diseases.

## **Trinational meeting of German-speaking ethics commissions in Berlin**

At the second meeting of the ethics commissions of Germany, Austria and Switzerland (DACH), held in Berlin on 10 and 11 March, discussions focused on questions relating to the welfare of the child in a medical context, arguments for and against compulsory vaccination, and the opportunities and risks of personalised medicine in view of increased data collection and networking. Representing the Commission at this event was a delegation comprising the Chair, Professor Otfried Höffe; Professor Valérie Junod, Professor Katja Rost, Professor Brigitte Tag, Professor Markus Zimmermann and Maya Shaha, PhD; and the General Secretary, Dr Elisabeth Ehrensperger. Brigitte Tag reflected on the welfare of the child in Swiss law, Maya Shaha discussed Swiss vaccination practice from a

nursing perspective, and Valérie Junod explained the legal situation in Switzerland with regard to bio-banks. For 2015, the Commission has invited the German Ethics Council and the Austrian Bioethics Commission to Bern; the trinational meeting is to be held on 16 and 17 April 2015. The Commission's General Secretary will be responsible for preparing and organising this event.

### UNESCO

At the 21st Session of the *International Bioethics Committee* (IBC) and the Joint Session of the IBC and the *Intergovernmental Bioethics Committee* (IGBC), held in Paris from 8 to 12 September, the Commission was represented by Professor François-Xavier Putallaz, who is a member of the IBC. Five topics were discussed: (1) the principle of global benefit sharing, and in particular the question of how individuals can benefit from the findings of research in which they are involved; (2) updating the IBC's *reflection on the human genome and human rights*; (3) revision of the UNESCO Recommendation on the Status of Scientific Researchers; (4) addressing the ethical aspects of converging technologies (ongoing work of the Council of Europe's Committee on Bioethics); and (5) adoption of a Statement on the Ebola Virus Epidemic.

### European Union

Professor Otfried Höffe represented the Commission at the sixth meeting of the European Commission's International Dialogue on Bioethics (IDB) and the subsequent Round Table, held in Brussels on 21 and 22 October. IDB meetings, organised by the European Group on *Ethics in Science and New Technologies* (EGE) and the *Bureau of European Policy Advisers* (BEPA), bring together national ethics councils from EU member states (represented in the NEC Forum) and representatives of leading non-European national ethics commissions. This was the third IDB meeting attended by Switzerland. The aim of the 2014 event was to address ethical questions relating to broad public participation in the generation of knowledge

and innovations, particularly in connection with the development of new health technologies. At the Round Table, a statement was prepared on the ethics of public participation and health, as a contribution to the European Commission's political strategies and guidelines in the areas of healthcare and new technologies.

Dr Paolo Merlani represented the Commission at the 20th **NEC Forum** and a meeting of the EGE, organized by the Italian National Bioethics Committee and held in Rome on 18 and 19 November. Six topics were addressed: (1) Biological and health data: ethical and legal issues; (2) Research culture and research integrity: ethical challenges; (3) Ethics and neurosciences; (4) Citizenship and science; (5) Ethics in education; and (6) Delivery of health care and robotics.

Professor François-Xavier Putallaz represented the Commission and Switzerland at the 10th **Global Summit of National Ethics / Bioethics Committees**, held in Mexico City from 22 to 24 June. Around fifty countries were represented at this event – not just European countries (e.g. France, Germany, Italy, the UK and Scandinavia), but also numerous African, Arab and Asian countries (e.g. Tunisia, Saudi Arabia and Japan), as well as the US and Israel. This was the first time Switzerland had participated in the event. At the plenary session, Professor Putallaz spoke on the topic of *"Independence of the NEK-CNE in a direct democracy"*. The next Global Summit will be held in Berlin in 2016.

Professor Brigitte Tag spoke on the subject of intersexuality at the 64th annual meeting of the *Society for the Study of Social Problems* (held in San Francisco in August), on preimplantation genetic diagnosis at the XIth Turkish-German Symposium on Medical Law (in Istanbul in October), and on the Swiss legal situation regarding assisted suicide at a legal policy symposium on this topic (in Triberg im Schwarzwald in December).

# 5. Working groups

In the period under review, NEK-CNE working groups met to discuss the following topics:

## 5.1. Medical confidentiality in prisons

The working group held two meetings. The Opinion was unanimously adopted and was published online on 6 June 2014.

## 5.2. Culture of death and dying

The working group met once in 2014 to develop a concept for an Opinion covering a broad range of issues. The goal is to prepare, on behalf of the Commission, an Opinion on the topic of “Culture of death and dying”, in which the emphasis is to be placed on questions of meaning and value (wishes, ideals, fears, values, approaches to the end of life), and on considerations concerning what constitutes a good or bad death, rather than on normative aspects and justifications for what is prohibited, required or permitted in the context of end-of-life decisions. This work will address not only the individual perspective of the dying, their relatives, friends and members of treatment teams, but also the social perspective and thus society’s conceptions and ideals.

## 5.3. Personalised medicine – Biobanks

The working group held one meeting in the period under review. Exchanges were mainly conducted through electronic channels. A draft for the structure of an Opinion was discussed at a plenary meeting of the Commission held on 11 September.

## 5.4. Reproductive medicine

The working group held three meetings in the year under review. It prepared a detailed response to an inquiry submitted by the FOPH Health and Accident Insurance Directorate – at the request of the Federal Commission on Basic Health Care Services and Fundamental Principles (ELGK) – concerning reimbursement of the costs of non-invasive prenatal tests (NIPT) under the basic health insurance scheme. This procedure had not been completed by the end of 2014. The Commission plans to publish an Opinion on this topic in 2015.

## 5.5. Cost / benefit evaluations

At the plenary meeting held on 26 June, the Chair of the working group, Maya Shaha, PhD, presented an overview of cost/benefit evaluations in healthcare. The document included a proposal that the topic should be approached from the perspective of the difficulties encountered by elderly people with multimorbidity, and be pursued under the heading of “Care for the elderly”. While the Commission acknowledged the relevance of this issue, it decided to defer work on the topic. The working group will continue to consider related issues and, should it see a need for action, it will notify the Commission.

# 6. Experts consulted

In the period under review, the following experts were consulted for the ongoing work of the Commission:

## On the topic of Medically assisted reproduction

At the meeting of the working group on non-invasive prenatal tests (NIPT) held on 15 October:

- ↳ Felix Gurtner (FOPH Health and Accident Insurance Directorate, Health Care Services Division, Medical Services Section),
- ↳ Michèle Siegenthaler (FOPH Health and Accident Insurance Directorate, Health Care Services Division, Medical Services Section).

## On the topic of Personalised medicine – Biobanks

At the plenary meeting held on 26 June:

- ↳ Karsten Borgwardt (Tübingen University)
- ↳ Christine Currat (Lausanne Institutional Biobank, CHUV)
- ↳ Peter Grolimund (Data and Health Association)
- ↳ Georges Imbert (Biobanking project leader, Novartis)
- ↳ Vincent Mooser (Lausanne Institutional Biobank, CHUV)
- ↳ Aurel Perren (President, Biobank-Suisse Foundation)
- ↳ Beat Rudin (Data Protection Officer, Canton Basel-Stadt)
- ↳ Effy Vayena (Scientific Coordinator, Institute of Biomedical Ethics, Zurich University)

# 7. Plenary meetings

In 2014, the Commission held six ordinary plenary meetings (on a total of seven meeting days).

With the exception of the two-day meeting, which was held at the Town Hall of Appenzell i.R., all the meetings took place in Bern.

# 8. Secretariat

The NEK-CNE Secretariat comprises two employees, representing a total of 1.4 full-time equivalents:

The General Secretary is Dr Elisabeth Ehrensperger (80 % position); Simone Romagnoli, PhD (60 % position) serves as a scientific collaborator.

# Members of the Commission

Chair **Otfried Höffe**, Prof. Dr. Dr. h.c. mult., Emeritus Professor of Philosophy and Director of the Research Centre for Political Philosophy, Eberhard Karls University Tübingen

**Annette Boehler**, Prof. Dr. med., Specialist in Pulmonology FMH and Internal Medicine FMH; Honorary Professor, Faculty of Medicine, Zurich University

**Kurt Ebnetter-Fässler**, Dr. med., Specialist in General Medicine FMH, Appenzell

**Samia Hurst**, Prof. Dr. med., Associate Professor of Bioethics, Geneva University Medical School

**Valérie Junod**, Prof. Dr. iur., Honorary Professor, Geneva University; Associate Professor, Lausanne University

**Bertrand Kiefer**, Dr. med., lic. theol., Editor-in-chief of *Revue médicale suisse*, Geneva

**Frank Mathwig**, Prof. Dr. theol., Honorary Professor of Ethics, Bern University; Theology and Ethics Officer, Federation of Swiss Protestant Churches (SEK)

**Paolo Merlani**, PD Dr. med., Head of Intensive Care Unit, Lugano Regional Hospital

**François-Xavier Putallaz**, Prof. Dr. phil., Honorary Professor of Philosophy, Faculty of Theology, Fribourg University

**Katja Rost**, Prof. Dr., Professor of Sociology and Adjunct Professor of Economics, Institute of Sociology, Zurich University

**Benno Röthlisberger**, Dr. med., Head of Medical Genetics Division, Aarau Cantonal Hospital

**Bernhard Rüttsche**, Prof. Dr. iur., Professor of Public Law and Philosophy of Law, Lucerne University

**Maya Shaha**, PD, PhD, RN, Senior Lecturer IUFERS University of Lausanne and Scientific collaborator University Hospital Berne

**Brigitte Tag**, Prof. Dr. iur. utr., Professor of Criminal Law, Criminal Proceedings and Medical Law, Zurich University

**Markus Zimmermann**, Prof. Dr. theol., Honorary Professor, Department of Moral Theology and Ethics, Fribourg University



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