



Centrum voor  
Ethiek en  
Gezondheid

## Work programme 2021 - 2023

The Centre for Ethics and Health identifies and provides information about new and current ethical issues in healthcare and biomedical research that are relevant to government policy. Every two years, the Centre for Ethics and Health draws up a work programme containing the topics that the centre will focus on for the next two years. Following consultation with the members of the Council for Public Health and Society, the Presidium of the Health Council and the CEG Committee, this work programme was drawn up by the executive board and adopted in the CEG Presidium.

## CEG functions

The CEG primarily has a signalling function: identifying new ethical issues and developments as early as possible that raise ethical questions. In the context of its signalling function, the CEG publishes (digital) products such as reports, blogs, essays and overviews of arguments. These products provide an initial analysis of relevant aspects, arguments and problems.

The CEG issues two types of reports: agenda-setting reports and in-depth reports. Agenda-setting reports are brief, thought-provoking and innovative descriptions of current themes. In-depth reports are broader in scope and more detailed than the agenda-setting reports.

The CEG also has a knowledge and referral function and a networking function. The CEG will primarily perform these functions in relation to its signalling role, including to promote and support the impact of the published reports and other products, and to gather ideas for new current signalling topics. As part of its knowledge function, the CEG also maintains a website: [www.ceg.nl](http://www.ceg.nl). Stakeholders, interested parties and media can obtain information about the CEG's activities via this website and (social) media channels.

## Work programme for 2021-2023

In the period from 2021 to 2023, five products will be prepared and published for the purposes of signalling. The agreements about the working method, the duration of the reporting process and the type of final products will be decided in the CEG Presidium. This will be done based on an initial memorandum (action plan). Up-to-date information about the content and timeline for the CEG products can be found on the CEG website.

The following topics are included in the CEG work programme for 2021-2023:

### 1. Medical crowdfunding

Crowdfunding is used to raise money for a specific cause. Medical crowdfunding mobilises a large number of people to fund a specific medical cause with the help of (social) media, such as a contribution to hospital bills and medication expenses or a special treatment abroad. The basic principle is that many small contributors can reach the fundraising goal together. There are special crowdfunding platforms where the cause is advertised, and channels like Facebook, Twitter and Instagram are used to spread the word to as many people as possible. The number of medical crowdfunding campaigns launched by people in the Netherlands has increased sixfold since 2017 and grown faster than in other European countries.<sup>1</sup> In this agenda-setting report, the CEG will analyse the ethical aspects of medical crowdfunding. The aim of this report is to clarify the ethical questions surrounding medical crowdfunding for policymakers, care providers and potential users of crowdfunding in order to provide guidelines for a morally responsible policy and ethical framework for medical crowdfunding in the Netherlands.

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<sup>1</sup> Van Gestel M. (2019) 'Medische crowdfunden in opkomst – Medici waarschuwen voor 'schaduwzijde'. Volkskrant, 7 June 2019.

## 2. COVID-related evaluation from a medical-ethical perspective

In December 2020, the CEG published a bundle of essays on COVID-19. This essay bundle, titled 'Ethics in times of COVID-19', contains ethical reflections on the coronavirus pandemic. The thirteen essays in the bundle were written by guest authors. The essays present a variety of ethical and legal reflections on value-related issues that arose during the first 'coronavirus wave' in the Netherlands, and the reactions that followed. What value-related considerations did care providers, administrators and patients make? Each essay includes a description of an ethical issue in relation to the COVID-19 crisis and its effects and health care. The essays are available to read here (Dutch only): <https://www.ceg.nl/ethiek-in-tijden-van-corona>. In a future product to be developed, the CEG will aim to stimulate ethical reflection on the lessons that can be learned from the pandemic and possible next steps towards potential solutions. This product will be a follow-up to the essay bundle and the CEG report 'Justifiable selection in case of a pandemic' (2012).

## 3. Restorative justice

If something goes wrong in the healthcare process, it could damage the trust that patients and their loved ones have in healthcare. It is important to adequately address and learn from such incidents, also to help prevent similar situations in the future. The question, however, is whether various bodies are currently performing their role in a way that optimally contributes to this. In a survey by NIVEL (Netherlands Institute for Research of Health Services Research, 71% of those reprimanded indicated that the disciplinary case had only had a negative impact on their professional practice. Among those who received a warning, this figure was 41%. Consequences included avoiding high-risk patients and viewing every patient as a potential new complainant. This in-depth report will examine ethical obstacles in the current system and explore whether restorative justice could be useful as a starting point. The concept of restorative justice<sup>2</sup> takes repairing the harm from the event as a starting point. This process explicitly involves the patient and his or her loved ones, as well as the relevant care providers. The topic builds on the CEG's report 'Safe care, good care?' (2019).

## 4. Fertility issues in transgender healthcare

In the Netherlands, approximately 0.6% of men and 0.2% of women do not identify with their sex and would like to make changes to their body. Three clinical centres focus on transgender healthcare: Amsterdam UMC, UMC Groningen and the LUMC. The treatments undergone by transgender people can lead to diminished quality of reproductive cells (such as puberty blockers (~age 12) and cross-sex hormones (~age 16)) and infertility (in the event of surgery). Many transgender people would like to have children or may decide they want children at some point during their lifetime. This means that in the diagnostic phase and prior to starting treatment, consideration can and should be given to a possible (future) desire to have children and the possibility of freezing egg or sperm cells, ovarian tissue or testicular tissue (fertility preservation). Doing so ensures that the individual could still have their own biological child. There are various options for transgender people to have their own biological children. However, many of the available fertility treatments for transgender people are in the experimental phase and are (medically) burdensome. The short- and long-term consequences for the parent(s) and (future) child are also unknown, and the topic has raised discussions about the concept of parenthood. The advancing scientific possibilities therefore raise both ethical and legal questions. Although the number of people facing this issue is relatively small, these are fundamental questions that are urgent for the target group. In this brief agenda-setting report, the CEG will therefore describe the

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<sup>2</sup> Sidney W.A. Dekker, Hugh Breakey, (2016) 'Just culture:' improving safety by achieving substantive, procedural and restorative justice. *Safety Science* (85): 187-193.

ethical and legal questions raised by (new) fertility treatments for transgender people, and the implications these have for current policy.

#### **5. Free space**

Space has been left in the work programme to respond to current events (as was done in 2020 with the essay bundle 'Ethics in times of COVID'). The free space will allow us to quickly report on new bio-technological developments and/or current developments in the field of health and healthcare. The aim is to publish one report within this free space.

#### **Knowledge, referral and networking function**

Since its ten-year anniversary in 2013, the CEG has organised an annual lecture every November in which a renowned expert discusses an ethical theme or issue within healthcare. This lecture is named after Els Borst-Eilers (1932 – 2014). She served as Minister of Health, Welfare and Sport from 1994 to 2002 and was one of the founders of the CEG. During her career, Els Borst-Eilers devoted a great deal of attention to various ethical themes such as euthanasia, the donor registration system and scientific research with embryos, reproductive cells and foetal tissue.

The Els Borst Lecture will be also be held in 2021 and 2022. The topic and/or speakers will be chosen based on current events, recently published reports and forthcoming reports. For each CEG product, a communication and publication plan will be drawn up by the CEG's communication officer.