

Debate about ethical issues in new developments must go on

The 21st edition of the NEC Forum took place in The Hague, on 10 and 11 May. The NEC Forum is a European platform consisting of representatives of 28 National Ethics Councils (NEC) in the European Union. As the Dutch currently hold the EU presidency, this year's event was staged by The Netherlands Centre for Ethics and Health (CEG). Invited guests from the Netherlands and elsewhere found inspiration in a varied programme on topical issues in ethics and health and intensive discussions on health policies, as well as exchange of ideas and best practices.

In a video message displayed on the opening day, Minister Edith Schippers welcomed those present to the event. This was followed by a talk from Pim van Gool, Chairman of the Health Council of the Netherlands, who is also one of the two chairs of the CEG. Isodoros Karatzas, head of the Division of Ethics and Research Integrity, welcomed the participants on behalf of the EU Commission. Professor Maartje Schermer, vice chair of the CEG committee and conference chair for this event, guided the transition to the conference programme. First of all, she introduced Professor Dick Willems, chairman of the CEG committee, who then took charge of the morning programme.

Ethics of e-Health

The first two speakers, Roser Beneito and Eugenio Mantovani, drew their audience's attention to privacy issues in relation to e-Health. Dr Beneito pointed out that the increasing use of all sorts of apps has implications for the sharing of personalised data, for anonymity, and for privacy in a context where people are increasingly sharing data. An ethical framework designed to regulate this issue is still in its infancy. Mr Mantovani discussed the protection of personal privacy, based on the right to protection of personal data.

The next pair of speakers, Kjell Asplund and Ignaas Devisch (who actually wears an i-watch), focused on the medicalisation of young people. According to professor Asplund 'self-tracking' has the potential to help promote people's health, but it can also become an obsession and degenerate into a form of 'narcissism'. An increasing focus on the overquantified self can lead to neurotic behaviour. Professor Devisch pointed out that, while e-Health can support individual autonomy, it can also become an imperative and lead to 'oughtonomy'.



Dementia

After lunch, dementia was on the agenda. Professor Pim van Gool chaired this afternoon session. Professor Jonathan Montgomery spoke about an ethical framework (based on the 2009 Nuffield Report) that could assist with decisions about dementia and with its diagnosis (or early diagnosis). In her presentation, Dorothea Touwen focused on the needs of elderly people, and the impact of these needs on care. She illustrated this with the case of Mr Fischer, a dementia patient. Throughout his life, Mr Fischer had been a principled vegetarian. Now, in a nursing home, he was experiencing a desire to eat meat and had even begun filching meatballs from the plates of those sitting beside him. How should the patient's children proceed in such a situation? Should they adhere to their father's previous wishes or should they comply with his current desires?



Jan Molenaar and Cees Hertogh not only covered the scientific perspective, they also spoke as hands-on experts on caring for a spouse or parent who is suffering from dementia. Professor Emeritus Molenaar addressed this issue from the situation of care at home. He advocated greater investment in care, including the use of professionals to support informal caregivers. He also gave his views on the current state of medical science, and concluded by saying: "Let us make it [medicine] an art and science again". Professor Hertogh examined the situation from the nursing perspective. Although our system of nursing homes is one of the best in the world, it does have a rather negative image. After a period of experimentation with various types of housing, Professor Hertogh urged the

authorities to reconsider the option of nursing home care for dementia sufferers who require palliative care (or geriatric palliative care). These presentations, revealed, and rather strikingly so, people's fear of loneliness.



The future: new technologies and values

On the second day, at the CEG's invitation, a group of secondary school pupils from Leiden joined the conference goers. They were attending the conference as part of their schoolclasses in philosophy. Maartje Schermer introduced session chair Inez de Beaufort who, together with Minister Els Borst, was a founding member of the CEG.

Annelien Bredenoord introduced the ethical debate entitled "the ethics of germline editing: a very short history". Subject to certain conditions, genetic testing, selection and screening have been ethically and legally permissible since the 1970's. Recently, two new technological developments have sparked an international debate. One was Mitochondrial Replacement Therapy (MRT) and the other was CRISPR/Cas9, a technique that makes modification of the germline much easier and quicker. John Harris argued in his lecture in favour of these scientific developments, and provoked reflection on the often furious arguments aimed at stopping these developments.



After the break, there was a musical interlude by guitarist Hafez Ismaili M'hamdi. Hafez is also a talented young scientific researcher in medical ethics. His music provided a transition to the section in which three talented young researchers were invited to give a brief presentation, and to make the connection to the European debate on values.

Saskia Nagel kicked off with a presentation about technological (and neuro-technological) self-shaping and imperatives of self-determination, based on the values of autonomy. Loredana Persampieri spoke on the theme of 'reproductive tourism and surrogacy', and the medical and legal risks associated with this development. Eline Bunnik got the audience thinking about the issue of expanding the options for using experimental drugs, if standard treatment options are no longer sufficient. The three presentations were followed by a lively debate.



Professor Pauline Meurs, chair of the Council for Health and Society, and one of the chairs of the CEG closed the meeting of the European National Ethics Councils by once again emphasising the importance of this conference. It is vital for the debate on ethical issues to continue, taking in consideration that the focus should not involve being for or against a particular development. Explaining values and arguing about this help to make the debate more transparent, and will help to make a balanced decision on a position, as "Prudence is a core European value in bioethics".