

**Joint statement following the meeting between the EGE and Smer in Stockholm on
24 May 2023**

The European Group on Ethics in Science and New Technologies (EGE) and the Swedish National Council on Medical Ethics (Smer) met today, 24 May 2023, to discuss ethical issues related to disruptive and rapid digital developments, with a focus on ethical implications with particular regard to democracy, human rights and the future of health and healthcare.

The EGE Opinion on “Democracy in the digital age” has been the starting point of the discussions. The Opinion stems from the request of the President of the European Commission, in the context of the revision of the European Democracy Action Plan and of the development of the Defence of Democracy package. Overall, it analyses the challenges of the digital age and identifies measures to safeguard and promote democracy.

The EGE Opinion focuses on the role of online platforms, politics, media, civil society organisations, universities and other actors in opinion-shaping. Looking to the future, it also explores the role that digital technologies might play in developing wider and more inclusive civic spaces and enhancing public participation. It is informed by a ‘thick’ (moral) understanding of democracy that defines democracy as the people’s rule underpinned by fundamental rights and societal values such as solidarity, equality and freedom. Protecting democracies, understood in such a comprehensive way, requires strengthening the rule of the people in a way that is broader and deeper than merely safeguarding free elections.

The issues addressed in the EGE Opinion are also highly relevant for the future of health, healthcare and research. Smer has previously worked on issues related to digitalisation and artificial intelligence in health care and research. It has, for example, presented publications on self-monitoring and wearables, artificial intelligence, health data and the use of robotics in health care. Issues related to digitalisation and democracy, and the values embedded therein, have also been emphasised in the Council’s work during the pandemic.

The pandemic has highlighted issues concerning democratic decision making, human rights and global justice, trust in science and information, and ultimately the ability of societies to cope with catastrophic

events. Different digital tools (such as health apps and health surveillance) have been adopted at an increasingly rapid pace. Digital platforms have emerged as important infrastructures related to democratic values in society, enabling people to connect across countries and worldwide. These platforms can be used as means to drive positive change on a global scale. However, the developments of recent years have demonstrated that digital platforms can both favourably and detrimentally affect democratic discourse. They have been used to spread harmful information and drive political polarisation. This has harmed public health, deepened divisions between groups in society, and damaged interpersonal trust. This is particularly problematic when society faces major and difficult threats such as war, the climate crisis, and health crises like pandemics.

Protecting democracy is an ongoing effort. Today, the norms and principles providing the foundations for human rights, democracy and the rule of law – on which the EU was built – are being called into question. Developments such as the rise of populist and nationalist movements, the growth of anti-democratic sentiments, geopolitical threats from authoritarian rulers, and growing social and economic inequalities put a strain on democracy and its values. At the same time, digital capabilities continue to evolve, the most recent example of which was the launch of ChatGPT-3 and -4, the advanced language processing tools based on AI technologies, with unknown capacities.

The future impact of AI technologies is unpredictable and can pose profound risks to society and humanity. Regulation that safeguards and strengthens human rights and democratic values is therefore fundamentally important. In healthcare, it is of key importance that alternative access to services is available to people who prefer not to use digital tools. Similarly, ‘consenting’ to sharing data must not become a precondition for obtaining access to essential services such as healthcare. In its Opinion, the EGE highlights that the provision of public goods that satisfy basic needs, such as healthcare – which it describes as a precondition for a thriving democracy – should be insulated from market rationales and dynamics. Healthcare should remain available and accessible to all people independent of their ability to pay. People in need of healthcare need to be treated as patients, not consumers. In the digital era, we must ensure that people’s basic needs do not need to be met on market terms.

In conclusion, the EGE and Smer jointly emphasise the following:

We highlight that – especially in times of rapid technological change – ethics councils and committees remain of crucial importance for societies. One of their key roles is to provide ethical analysis, especially in the context of governance and policy-making, in relation to the development of our societies in general and the technological advances in society, medicine and healthcare, notably.

We recognise that the pandemic, climate change, wars and natural disasters have challenged society and broadened the range of what we consider (bio)ethical questions. We call for efforts from all parts of society to stand up for human rights and democratic values to confront the challenges we are facing today.

We also recognise the potential impacts of AI technologies and digital platforms on society. *We strongly urge* governments, authorities and other stakeholders to safeguard individual privacy and autonomy, and enhance the value that digital technology use creates for people and societies, rather than merely for companies. In this context, we welcome the ongoing efforts of governments and other stakeholders in the EU to introduce ethical considerations into the core of any future discussion and development of governance of AI and digitalisation – in health care and society as a whole.

We call for an increased effort towards the creation of inclusive digital public spaces that support respectful exchange and dialogue, as well as for stronger legal measures against the spread of mis- and disinformation.

We strongly emphasise the importance of maintaining cooperation between ethics councils in different countries and on the European and global level. The European Group on Ethics in Science and New Technologies and the Swedish National Council on Medical Ethics are committed to such collaboration in the future.