

Minutes of the European Group on Ethics in Science and New Technologies

Brussels, 7-8 November 2018

1. **Welcome and approval of the meeting's agenda and of the previous meeting's minutes:** approved
2. **Nature of the meeting:** non-public
3. **List of points discussed:**

DAY 1 – 7 November 2018

Update from the Secretariat

- Jim Dratwa provided an update with regard to the three streams of work of the EGE (Artificial Intelligence, Future of Work, Gene Editing) and on the policy context.

Update from the Members

- Christiane Woopen attended the 2018 International Conference of Data Protection and Privacy Commissioners, intervening in the Creative Café session alongside Jeroen van den Hoven; also the conference “Flourishing in a data-enabled society” held by ALLEA and the Royal Society.
- Anne Cambon-Thomsen informed that she is a member of the jury of the Canadian initiative ‘Across the Oceans’ which will provide research funding as of early next year.
- Emmanuel Agius informed that he will present the Future of Work Opinion at the European Social Week in February 2019 in Milan. He already presented the EGE work at a COMECE conference in October.
- Barbara Prainsack informed the group on discussions around the political meaning of the High-level group on AI going on in the UK.
- Anne Cambon-Thomsen provided an update on the ongoing revision of the bioethics law in France. It was already delivered to États Généraux, and currently a Parliamentary committee is interviewing experts, including Anne Cambon-Thomsen. It is to be voted in Parliament early next year.
- Nils-Eric Sahlin informed that he is involved in three topics of SAPEA work: making sense of science; micro-plastics; future of ageing. He stressed once again the importance of scientists working together with ethicists.

Opinion on the Future of work

- Minor, editorial aspects of the Opinion were discussed (in recognition that most members had already electronically provided their approval of the latest version of the draft Opinion).
- This editing discussion included:
 - Agreement that a footnote explaining the use of the term ‘work-life balance’ shall be inserted and the term only to be used where it is not possible to paraphrase it (e.g. balance between paid work and private life).

- In the recommendations, it was agreed that selection by algorithm should remain as a separate point in the recommendations.
- In the recommendations, it was decided to replace the term ‘digital identity’ by ‘meaningful control of data’.
- In the recommendations, it was agreed to make the ‘personal activity accounts’ as an example rather than a sole solution.
- Following this discussion, the text of the Opinion was agreed and adopted.
- It was highlighted that Jeroen van den Hoven will prepare a summary of the main novelties of the Opinion (300-500 words) to be included at the start of the text.
- The members briefly discussed the delivery and the dissemination of the Opinion. Jim Dratwa explained that a news alert would be released to coincide with the official handover and publication of the Opinion and a dissemination email sent to Commission services, policymakers and relevant stakeholders. The members were encouraged to disseminate the Opinion widely upon its publication.
- Additional suggested recipients for the Opinion were put forward, including those preparing the new research framework programme, Member States’ ministries responsible for research policies etc.

Opinion on Gene editing

- The Chair opened discussion on the topic of the new Opinion on Gene Editing, suggesting to draw good practices and lessons learned from the experience of the previous Opinion.
- The Group discussed the scope of the upcoming Opinion, with reference to the formal request letter from Commissioner Moedas. There was a general consensus that the Group would tackle both human, as well as non-human (including non-human primates), somatic and germline editing, as well as normative regulation.
- The members reported on their various experiences and expertise on the topic of gene editing, and made reference to previous useful literature in the domain.
- It was agreed that the Opinion should not be technology-driven and a preference to frame it around concepts or ethical principles emerged.
- The challenges of making a detailed technological review, against the background of rapidly advancing techniques, was highlighted, as were the risks of speculating in too great a detail on the direction of future technological developments.
- It was stressed that issues enhancement should be addressed in the Opinion (e.g. the division between enhancement and therapy). The border between humans and animals should be explored.
- Gene drives and environmental consequences is another important aspect to address in the Opinion.
- Risk assessment, liability and accountability aspects are essential too. These could be discussed in the context of existing legislature.
- History of regulatory approaches in this area should be born in mind, in particular the use of the distinction between genes that could have occurred naturally and those that could not, and its role in legislation. Relevance of the July 2017 ruling of the Court of Justice of the EU on the scope of the GMO Directive was highlighted. Attention was drawn to the Statement by the Group of Chief Scientific Advisors on Gene Editing and the Implications for the GMO Directive (and its explicit reference to the forthcoming EGE Opinion).
- Reference was made to the work of the Nuffield Council in this area, namely, its ethical review (2016); and report on human reproductive uses (July, 2018). The

Nuffield's ethical analysis took a three-pronged approach, examining implications regarding individuals who are edited; the impact on society; and the impact on the notion of a human being (including human dignity).

- Reference was made to the Nuffield's working party on gene editing in livestock and the House of Lords Select Committee report on genetic editing in mosquitoes.
- Consideration of the European dimension of this topic (and by extension the EGE's added value on this issue): e.g. European values, European regulatory framework.
- A preliminary discussion on various ways of structuring the Opinion took place:
- Various starting points were proposed, including the EGE Statement on Gene editing of 2016, or specific legal provisions (namely, Article 13 of the Oviedo Convention).
- As a possible approach, it was suggested to begin by identifying areas of consensus and of disagreement on the subject (among the group, stakeholders as well in the wider society.) Also, the problematic nature of categories, concepts and divisions applied to this area.
- An examination of how ethical principles are framed and applied differently in different sectors (human, animal, plant, agriculture, industry etc) was proposed as an alternative structure. Where are the differences, and what are the implications for policies? Recommendations could be structured according to fields of application.
- The Group then briefly discussed the areas where external insight would be most useful and potential external experts to invite to hearings and the roundtable. The need to hold exchanges with relevant Commission services was also highlighted.
- A short discussion on language aspects followed, including the etymology of terms such as 'gene editing' and 'genetic engineering'.

Structural exchange of views with Michel Servoz, Special Adviser to President Juncker for Robotics, Artificial Intelligence and the Future of Labour.

- Barbara Prainsack presented the EGE's Opinion on the Future of Work, highlighting the defining features of the Group's approach and key findings.
- Michel Servoz then sketched out the broad lines of his work developing a paper on the Future of Work and the impact of digitalisation.
- He commended the work of the EGE and the depth of its analysis on the topic. He highlighted several key issues, including the importance of good governance of AI technologies; the role of skills; and social protection systems that are 'fit for purpose'.
- The discussion that followed touched on topics such as the role of corporate responsibility in developing employee skills; EU labour law and the place of trade unions; and broader societal trends such as populism.

DAY 2 – 8 November 2018

- Christiane Woopen reported on the presentation of the Opinion that she delivered the previous evening in the Permanent Representation of Germany. Jim Dratwa thanked and encouraged every EGE member in terms of presenting the EGE work, particularly the latest Statement and upcoming Opinion.
- Louiza Kalokairinou, member of the SAM Unit, briefly introduced herself and explained that she would provide support on gene editing.

Opinion on Gene editing (continued)

- Carlos Casabona presented a potential outline of the Opinion, which formed a basis for continuing discussions on the structure.

- An exchange took place on the main challenges/conflicts within the topic area, including the interpretation of Article 13 of the Oviedo Convention, the new regulation of clinical trials, risk assessments, and the impact of demarcation and categorisation in the field.
- The role of stakeholders was highlighted, particularly in the context of a chain of responsibility.
- Reference was made to the ethical concerns generated by the increasing accessibility of gene editing technology, as well as the blurred line between basic research and clinical research.
- Further exploration of an ethics pillar-based framework was made, including discussion on the various aspects of individual ethical principles (e.g. freedom, in terms of agency, determinism, reproductive freedom, etc.)
- It was agreed that the Opinion should also examine core concepts/notions e.g., ‘editing’, ‘gene/genome’, ‘naturalness’.
- The Group discussed the importance of public participation in debates on this topic. The question of how the EGE may engage the public in the development of its Opinion was explored. Suggestions included a possible video competition aimed at schools around Europe.
- It was suggested that the Group might engage with representatives or judges of the Court of Justice of the European Union regarding the Court ruling on the GMO Directive.

AOB

- A brief discussion on the importance of constructive collaboration with the AI High Level Expert Group took place, culminating in the request to the Secretariat to organise a meeting between the two Chairs.
- The Group agreed that the ethics and governance of AI constitutes an ongoing activity of the EGE and a priority.
- The next steps regarding the organisation of expert hearings for upcoming plenary meetings were discussed.

4. Conclusions/recommendations/opinions

- The Opinion “Future of Work, Future of Society” was adopted unanimously.
- It was decided to organise the Round Table on Gene Editing in May/June 2019.

5. Next steps

- Secretariat to finalise the editing of the Opinion, taking into account revisions submitted and agreed during the meeting and by email the preceding days.
- Laura Palazzani to send to the Group the Opinion produced by the Italian Council on Bioethics.
- Secretariat to re-send the instructions to create an EU login.
- Secretariat to explore the feasibility of organising a video competition for schools.
- Jonathan Montgomery to send the Nuffield Council paper on naturalness to the Group.
- Secretariat to try to organise a meeting between the Chair of the AI High Level Expert Group and the Chair of the EGE.

- Louiza Kalokairinou to prepare a short overview on the main developments in the field of gene editing.

6. Next meeting

16-17 January 2019, Brussels

7. List of participants

Day 1: Emmanuel Agius, Eugenijus Gefenas, Julian Kinderlerer, Andreas Kurtz, Jonathan Montgomery, Herman Nys, Laura Palazzani, Barbara Prainsack, Carlos Maria Romeo Casabona, Nils-Eric Sahlin, Anne Cambon-Thomsen, Christiane Woopen (Chair), Jim Dratwa, Aylin Avcioglu, Maija Locane, Joanna Parkin

Day 2: Emmanuel Agius, Eugenijus Gefenas, Julian Kinderlerer, Andreas Kurtz, Laura Palazzani, Barbara Prainsack, Carlos Maria Romeo Casabona, Anne Cambon-Thomsen, Christiane Woopen (Chair), Jim Dratwa, Aylin Avcioglu, Maija Locane, Joanna Parkin, Louiza Kalokairinou