

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

Brussels, 18 October 2019

1. Approval of the agenda and minutes

2. Nature of the meeting: non-public

3. List of points discussed:

- Updates from the Commission and EGE members
- Discussion on Gene Editing Opinion (and chapter on gene editing in animals and de-briefing of EGE Roundtable and IDBEST)

Updates from the Commission and EGE members

- An overview of the forthcoming changes to the political structure of the European Commission, including the delay and potential start dates of the new Commission.
- Reminder that an EGE meeting has been scheduled during the meeting of the NEC Forum in Zagreb on 14-15 May 2020.
- The secretariat to circulate new privacy consent forms obtaining member permissions to the publication of their photos and information on the EGE website.
- Update regarding the revision of the French bioethics law.

The meeting was chaired and moderated by Herman Nys, Vice-Chair of the EGE.

Discussion on Gene Editing Opinion

Exchanges centred primarily on the draft chapter on animals and on drawing the key messages from the roundtable and IDBEST.

➤ Chapter on gene editing in animals

The draft chapter on animals was presented section by section. Members welcomed the text and a discussion followed on potential refinements, re-structuring suggestions and areas to be developed.

General comments included:

- The importance of laying out the broader context for the chapter, including e.g. relations between humans and animals, instrumentalisation of animals, levels of interest at play, existing or longstanding ethical concerns, then funnelling down to what is specific about gene editing, what is distinctive and new about this technology?
- The need to develop and refine the five bullet points on ethical concerns, including determining which are general points to be addressed in the introduction and which should be developed and argued as key ethical concerns of the EGE.
- The need to restructure and refine the flow of the chapter (e.g. a coherent integration of the ethical concerns, including the sub-section of non-human primates).
- The need to develop the recommendations, including: a recommendation on ‘3Rs + R’ (Recourse to innovation, and the requirement for research teams to include a project team on alternatives to animal experimentation); a recommendation that responds to concerns about hypes, claims and over-promises by promoting more research into the efficacy of animal research (a more sophisticated analysis of impact of animal research projects).

Specific suggestions included:

- The crucial importance of ‘stepping back’ and drawing attention to a tendency to engineer animals to fit societal structures, environmental conditions and demands that humans have created: is this problematic, if so why? What ideal world would we want (e.g. reduction in the consumption of animal proteins)? Are there better alternative models?
- The suggestion to nuance the anthropocentric focus of the chapter (e.g. by discussing potential uses of gene editing techniques in veterinary medicine, animal welfare, biodiversity applications etc.), while taking into account that certain of these applications are developed in order to mitigate human-created situations for animals.
- The need to include a reference to the legal framework covering gene editing in farm animals (refer to exchanges during the Roundtable on the GMO Directive and issues around its application to farm animals).
- Include a reference to patenting (possibly in relation to humanisation, or xenotransplantation) with cross-reference to larger section/Annex on patenting elsewhere in the Opinion.
- Shorten the text on gene drives to a reference directing readers to the gene drives chapter.
- Include a short discussion on biodiversity (e.g. reference to potential increase of biodiversity through generation of new species, preservation of ecosystems and with potential reference to CITES and gene drives).

➤ De-briefing on the EGE Roundtable and the IDBEST

Members provided positive feedback on the EGE public roundtable on gene editing and International Dialogue on Bioethics and Ethics in Science and Technologies (IDBEST). Discussion followed on the key themes, messages and conclusions that emerged from the preceding two days of events.

The following themes were highlighted:

- Governance questions, including:
 - The relative value of various governance mechanisms and the requirements for them to be applied effectively or enforced (e.g. moratoria, WHO registry, global observatory). What lessons can we draw from the governance of other new and emerging technologies?
 - Dimensions of how to govern globally (e.g. tension between harmonising and diversity/subsidiarity no ‘one-size-fits-all’; tensions between ethics, hard law, soft law).
 - Consideration of the values, parameters embedded in the design of institutions and systems.
- On participatory processes: the call for a wide societal deliberation is a common refrain. The challenge now is to design and implement it. What institutional innovations are required here? Potential suggestions include using new technologies to reignite public debate, examples of the MIT 'deliberatorium', involve.org.uk, tools for education and schools.
- On meanings attached to the human genome: discussion on IDBEST exchanges on the non-inviolability of the germline, genome not to be construed as the grounding of human dignity.
- Therapy, enhancement and considerations of human diversity: desirability or otherwise of ‘removing disability’, positions of disability groups, examples of conditions such as deafness or Asperger’s can be re-framed as difference, an asset. Also, the reminder that the application of gene editing technologies in relation to reproduction through IVF can only eliminate a very small number of genetic diseases.
- Scrutinising use of language: including the distinction between gene editing and genome editing; or the rhetoric on the supposed “precision” of the technology across different domains of application. How much imprecision are we willing to accept? Agreement to use/develop the text provided by Barbara Prainsack in the introduction to the Opinion.

A brief discussion also took place on the structure of the opinion, the organisation and content of the cross-cutting chapter and the need to ensure that the ‘humans’, ‘animals’, ‘plants’, and ‘gene drives’ chapters can function as self-standing chapters for those readers who have more specific, targeted interests when reading the Opinion.

4. Conclusions/recommendations/opinions

- Call for volunteers to take work forward on the humans chapter, cross-cutting issues (in particular governance section) and introduction (paragraphs on scrutinising the use of language).

5. Next steps

- Member(s) are asked to come forward to volunteer to draft the following sections of the Opinion:
 - Revise and develop the ‘Humans’ chapter (refining and continuing the work of the secretariat in filling the new structure, drawing on the written comments of Siobhan O’Sullivan).
 - Develop paragraphs on governance (for eventual inclusion in the cross-cutting issues chapter).
 - Develop/fine-tune the text scrutinising language around gene editing (to be included in the introduction).
- Anne Cambon-Thomsen to re-work and develop the draft chapter on gene editing in animals and to send the new draft text to all (in particular to Jeroen van den Hoven, Julian Kinderlerer, Carlos Casabona) by 15 November.
- Jeroen van den Hoven, Julian Kinderlerer, Carlos Casabona to provide Anne Cambon-Thomsen with further feedback and inputs on that basis, by 25 November.
- Christiane Woopen to develop the overarching introduction to the Opinion.
- Julian Kinderlerer to revise the ‘Plants’ chapter based on feedback from the September plenary meeting.
- Barbara Prainsack to develop ‘Gene drives’ chapter based on the revised structure.

6. Next meeting

Plenary meeting on 5-6 December in Brussels.

7. List of participants

Emmanuel Agius, Anne Cambon-Thomsen, Carlos Casabona, Julian Kinderlerer, Andreas Kurtz, Herman Nys, Jeroen van den Hoven, Jim Dratwa, Louiza Kalokairinou, Maija Locane, Joanna Parkin.