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Committee on Social Affairs, Health and Sustainable Development

Minutes

of the Hearing on "Manufacturing a new human species?" held in Strasbourg on 30 September 2015

Opening of the meeting

The Chairperson opened the hearing on "Manufacturing a new human species?", and welcomed the five experts:

- **Mr Jean-Yves Le Déaut,** General Rapporteur on science and technology assessment of the Parliamentary Assembly of the Council of Europe (PACE);

- **Mr Robin Lovell-Badge,** Group Leader at the Francis Crick Institute (formerly MRC National Institute for Medical Research), United Kingdom;

- **Mr George M. Church,** Professor of Genetics at Harvard Medical School and Director of personalgenomes.org, USA *(by video link)*;

- **Mr Luigi Naldini,** Director of Division of Regenerative Medicine, Stem Cells and Gene Therapy, San Raffaele Scientific Institute, Italy;

- **Mr Mark Bale,** Chairperson of the Council of Europe Committee on Bioethics (DH-BIO).

The Chairperson drew participants' attention to the background note in the files, providing information on the experts, as well as to the new hearing format which had also been used for the recent Committee hearing on "human rights and ethical issues related to surrogacy", involving in this case a moderation of the hearing by a journalist, **Mr Durand de Bousingen**, who would put specific introductory questions to the experts. They would have five minutes each to reply. This would be then followed by the exchange of views between all Committee members and the experts.

The Chairperson explained the reasons of organising this hearing; firstly as an opportunity to discuss possible ethical implications and concerns, secondly, the possible benefits and risks of this new technology, and thirdly, the role of parliamentarians in dealing with this new issue. He encouraged all members to actively participate in the hearing. He introduced **Ms De Sutter** acting as moderator, as the journalist had been delayed.

Ms De Sutter briefly explained the implications of gene-editing, taking into consideration the Convention on Biomedicine of the Council of Europe (Oviedo Convention). She presented the state of the art of research into human genetic engineering, and reminded the audience that the scientific community had called for a moratorium on the use of the technology to modify the human germline.

* Draft minutes approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 23 November 2015 in Paris.

Question to Mr Church: Could you please tell us about the possible implications of new gene-editing technologies, which have led to a call for a moratorium on germline genome modification in human beings?

Mr Church outlined the new gene-editing technologies. He felt that a broad discussion involving many stake-holders was quite valuable. He mentioned that two thousand gene therapies were currently in clinical trials and that current policies prohibited all new medical procedures until they had been proven to be safe and effective relative. He illustrated why germline modification might offer solutions where other medical practices fell short. *[For the full statement of Mr Church, see Appendix I.]*

Question to Mr Robin Lovell-Badge: What do you think are the potential benefits and risks of new gene-editing technologies, including in the field of embryo research?

Mr Robin Lovell-Badge explained that early human embryo research was a very important step, because it helped to understand the activity of specific human genes, compared with previous research on mice. He explained that understanding the development of human embryos in early stages could be very advantageous and lead to a better understanding of the interaction with the placenta, the implantation mechanism, stem cells evolution, the developing of cells on gonads, the genes' function to become germline cells, such as sperm and eggs etc. Also, he pointed out that it would be useful to develop a more efficient and accurate method, to be able to make changes to the genome in order to correct gene defects, and to improve the knowledge of how to treat infectious diseases, Alzheimer, etc. He referred to the two main risks of this new technology, mutations and "off target" events, but he explained that these side effects needed to be evaluated in further research, and seemed to be more frequent in somatic cells. He did not agree with the title of the hearing because even if manufacturing a new human species were possible, there would be a moral obligation of the scientific community to prevent suffering from disease. He suggested to title the hearing "How to use gene technology to solve problems". *[For the full statement of Mr Robin Lovell-Badge, see the audio recording of the hearing*].

Question to Mr Naldini: What are the alternatives to germline modification in human beings for curing genetic diseases?

Mr Naldini explained the goal of gene therapy to change the pathologic function of certain somatic cells from the medical perspective. Concerning the new technology available to edit gene information, he explained that it was still very challenging to use it on embryos and that it was easier to control side effects when using the technology on somatic cells. *[For the full statement of Mr Naldini, see the audio recording of the hearing].*

Question to Mr Mark Bale: Could you please give us an overview of the principles contained in the Convention on Human Rights and Biomedicine in relation to interventions on the human genome?

Mr Mark Bale briefly introduced the convention, in particular Article 13 on the modification of the human genome, according to which changes to the human genome were only permitted for diagnosis and treatment purposes, when the intention was not the modification of the genome of the descendants. He highlighted that this article did not prohibit current research.

He commented that some national delegations to the Council of Europe Steering Committee on Bio-ethics (DH-Bio) had raised safety concerns related to this new technology, as well as ethical questions. Fundamental questions related to biology and medicine were meant to be publicly debated, as explained in Article 28 of the Oviedo Convention. In accordance with the Convention's Article 32 related to monitoring scientific development, a survey to obtain data of the state of legislation in member states was currently on-going. *[For the full statement of Mr Bale, see the audio recording of the hearing].*

Question to Mr Le Déaut: What in your opinion should politicians and the Council of Europe do in relation to these new developments on gene-editing technologies?

Mr Le Déaut recalled that research was linked with development, but asked the audience who was going to set the limits? Who was going to decide which genes were going to be changed with this new technology? He addressed the problem of how national parliaments could draft laws on evolving science. He emphasised the necessary balance with human rights, fundamental freedoms, data protection, etc. He indicated the difficulty in drafting legislation, mainly because the issue was very technological and a moving target, but he highlighted the Oviedo convention as a framework to be developed. He pointed out that Bio-ethics Committees and other bodies had to keep up with progression in research, even when it was difficult for different cultures to agree on international conventions concerning difficult issues like surrogacy, artificial procreation, etc. *[For the full statement of Mr Le Déaut, see the audio recording of the hearing].*

Mr Durand de Bousingen asked about safety concerns regarding the new gene-editing technologies and what would happen if problems occurred for individuals or their descendants?

Mr Naldini explained that researchers were currently only modifying cells, trying to change “off target” consequences (unwanted mutations) only in vitro.

Mr Lovell-Badge said that it was far too early to apply the new techniques to clinical research. His opinion was that it was necessary to look at safety concerns in every specific application.

Mr Church pointed out that “off target” side effects happened also in somatic therapy, and that in embryos the risks were smaller because the number of cells being manipulated was much smaller. In his opinion, the point was not to get to zero risk, but with lowering current risks.

Mr Geraint Davis said that the main change the new technique implied was from natural to artificial selection. He asked what would happen if changes went wrong in different generations and whether it might be possible to re-edit genes and go back again. He showed concern about the possibility of creating a "superior" human species. He pointed out the big differences in technology expertise between different countries and continents.

Mr Lovell-Badge answered that theoretically it might be possible to go back on editing genes. He made it clear that making changes on genes needed a strong and good regulation to prevent errors. Finally, he indicated that this technology might turn out to be very helpful for social justice and for people living in developing countries, fighting diseases like malaria or Ebola.

Mr Church indicated that the cost of these new technologies was very high and could be thought of as unfair to developing countries.

Mr Bale gave the example of emerging technologies and devices already on the market. He remarked on the necessity of facing social justice regarding this issue.

Mr Durand de Bousingen asked about possible measures and developments to be taken by the Council of Europe in relation with genetic engineering technology?

Mr Le Déaut answered that it was necessary to inform people, to educate the general public, but also members of the parliament. He indicated the utility of Technology Assessment Offices to help in this task. He highlighted that the European Parliament, the Council of Europe Parliamentary Assembly and national parliaments had an important role to play in setting up legislation and regulations on new technology. He gave the example of France, where there was a parliamentary evaluation body, to keep abreast of new developments. He recalled the case of pre-implantation diagnosis in France many years ago, which had had many critics at the time, but had been well recognised later.

Mr Mahoux also gave the example of Belgium ten years ago, when he had participated in establishing two new laws, one on pre-implantation diagnosis and the other on experimentation on embryos, with a satisfactory result in his point of view. He showed concern about the eugenic potential of the new technologies, and asked for the necessary guarantees and protections to be put in place to avoid this. He called for transparency in research and taking into consideration the human rights perspective.

Lord Prescott expressed the view that technology was moving faster than politicians, human rights and human kind. He pointed out the risk of few stakeholders participating and deciding, probably the ones with better understanding and mainly in favour of the new technologies, instead of a democratic majority. He pointed out that it may be not necessary for all people to understand, but politicians had to make adjustments.

Mr Durand de Bousingen asked how to provide for a legal framework worldwide, to prevent bad practices in certain countries.

Mr Bale pointed out key issues related to the way the Oviedo Convention worked and could possibly be reviewed or re-interpreted.

Mr Geraint Davies, expressed concern about the research going only where the money was, like for instance alcohol resistance or problems of balding patients in developed countries. He asked where the money for research was currently going – it didn’t seem to be going to developing countries.

Mr Kiral pointed out the lack of information about this technology and the differences in research capacities in different countries. There were many stereotypes. Proper analysis and data, better international

communication, and the taking into consideration of the religious influence in some countries were needed. International organisations were well placed to cope with the issues raised by the new technologies, which could, if used well, possibly cure currently incurable diseases.

Mr Rudelli, the Holy See's representative, asked where the limit of this technology was, even abstracting from religion and taking into consideration only human beings and their basic human rights, ethical limits, etc.

Mr Lovell-Badge said that any law or regulation should be proportional to the risks posed.

Mr Naldini explained that it was too early to undertake embryo research for the purpose of reproduction, but that gene-editing technology might make it possible to eliminate nefarious mutations. He looked for consensus in the scientific community on where to draw the line.

The moderator asked for brief conclusions from all the experts.

Mr Le Déaut expressed the need for ethical thinking, but also the issue of responsibility to allow research. He was in favour of a balance between the two. He concluded that there was work ahead both for scientists and politicians.

Mr Bale called for proportional regulation to be put into place.

Mr Church talked about the need for the correct balance between safety and efficiency.

Mr Lovell-Badge said that the public should be worried only in countries without regulation. He said that public discussion might be helpful for transparency.

The moderator summarised that knowledge, information and prediction were the three words to be analysed in this context.

For more information on the hearing, please see the links below:

- Complete record of the hearing:
    - Original: http://clients.dbee.com/coe/webcast/index.php?id=20150930-2&lang=lang
    - EN http://clients.dbee.com/coe/webcast/index.php?id=20150930-2&lang=en
    - FR http://clients.dbee.com/coe/webcast/index.php?id=20150930-2&lang=fr
- Interviews related to the hearing:
    - https://youtu.be/_BV2i0IFhzw

APPENDIX I

Mr George Church's full statement

Could you please tell us about the possible implications of new gene-editing technologies, which have led to a call for a moratorium on germline genome modification in human beings?

Thank you for the opportunity to address this important question. The short answer is that the new gene-editing technologies based on CRISPR are much more specific, efficient, less expensive and more widely adopted than any previous method to alter human genes. Because these features put both somatic and germ line modification within easy grasp, some feel that the situation merits a moratorium on germ line genome modification. Others feel that adequate safeguards are already in place. Most of us feel that broad discussion involving many stake-holders, including patients, is quite valuable.

To put the issue into context, let me mention that two thousand gene therapies are currently in clinical trials regulated by the EMA and US and Chinese FDAs. At least one of these has been approved -- the European therapy called Glybera. Sometimes these gene therapies are described as "gene-editing" and sometimes this term is reserved for the more precise technologies of CRISPR and Zinc finger nucleases (the latter in clinical trials for curing HIV). Thus far, gene therapy experiments have been restricted to adults and children, except for mitochondrial gene therapies which are permitted in embryos in the UK. Importantly, current policies prohibit all new medical procedures until they are proven safe and effective relative to current practice through pre-clinical trials in animals and human cells. Gene editing is not exceptional in this regard.

It might be useful to bring up three situations that illustrate why germ line modification might offer solutions where other medical practices fall short:

The first would involve cases where, for a particular disease, both parents have only disease-causing DNA variants and, thus, in the absence of intervention, their children will too. This can occur in the one fifth of marriages worldwide which are consanguineous. This situation cannot be addressed by embryo selection and would, in some cases, be impractical to address by post-natal gene therapy. In these cases, treating sperm such that they no longer carry the disease variant could be the best option.

The second situation would concern the cases in which adult gene therapy would carry the risk of "off target" effects that could cause, for example, cancer. Here, risk goes up directly with the number of cells treated. Thus, treatment of one sperm cell could be a billion times less risky than the treatment of a billion somatic cells after birth.

The third situation would be cases where embryo selection via prenatal genetic diagnosis is not medically acceptable to mothers with harmful reactions to hormones used in this procedure or unacceptable to other parents who, for religious or other reasons are not willing to risk the non-implanted embryos -- but are willing to alter sperm cells.

The Convention on Human Rights and Biomedicine says "seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants." It may be helpful to put the effects of CRISPR into this context. For example, parents today frequently expose their germ line to highly mutagenic environmental sources, such as chemotherapeutic agents, X-ray/CT scans, ethanol, and high altitude. Should intentional exposure to random mutations be more acceptable than engineered changes shown to be safe and effective? Clearly impacting future generations makes germ line modification special, but future generations were not consented for such things as eliminating smallpox via vaccines or descendant-impacting decisions on wealth and environmental management.

Prices have been plummeting a million-fold for many genetic technologies. Somatic gene modifications could spread far more rapidly than germ line modifications, since only 1% of the population per year (that is births) are of the correct age for germ line impact, while somatic gene therapy is applicable at any age. Furthermore, germ line can take decades to have impact, while somatic therapies could have impact in weeks.

Committee on Social Affairs, Health and Sustainable Development
Commission des questions sociales, de la santé et du développement durable

Hearing on « Manufacturing a new human species? » / *L'audition sur le thème « La fabrication d'une nouvelle espèce humaine ? »*

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Strasbourg, 30 October 2015 / *Strasbourg*, *30 octobre 2015*

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Ms / *Mme* Ayşegül ELVERİŞ.....Co-Secretary to the Committee / *Co-secrétaire de la commission*
Mr / *M.* Raul MALLAINA GARCIA .....Co-Secretary to the Committee / *Co-secrétaire de la commission*
Ms / *Mme* Fatima NOUICER ..... Assistant / *Assistante*
Ms / *Mme* Sylvie ELTER..... Assistant / *Assistante*
Ms / *Mme* Alina BELIAEVA..... Assistant / *Assistante*