



Stakeholders Acting  
Together  
On the ethical  
impact assessment  
of Research and  
Innovation

## Policy developments in the ethics of research and innovation

### SATORI Newsletter Issue 4

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Compiled by Trilateral Research Ltd. on behalf of the SATORI consortium

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## Europe

### **Update: Close of the SATORI CWA consultation & final workshop**

The public consultation on the SATORI CEN Workshop Agreement (CWA) on ethics assessment for research and innovation has now closed. The draft documents were presented to a wide audience for comments. The SATORI mutual learning workshops also yielded additional discussion and comments on the CWA. All the comments received will be discussed and approved in the final plenary CWA meeting in Ljubljana, Slovenia on 1 February 2017.

### **Public stakeholder consultation: interim evaluation of Horizon 2020**

The results of this consultation will feed into the report on the interim evaluation of Horizon 2020, and aim to help the EC improve the implementation of Horizon 2020 and set the scene for the future discussions on the next EU research and innovation funding post-2020. Contribute via the link below.

Source:

[http://ec.europa.eu/research/consultations/interim\\_h2020\\_2016/consultation\\_en.htm](http://ec.europa.eu/research/consultations/interim_h2020_2016/consultation_en.htm)

### **Joint meeting of research integrity organisations to exchange results on academic ethics and integrity**

During its Joint Meeting in Bratislava (Slovakia) and Vienna (Austria) on 20 and 21 October 2016, the Slovak Research and Development Agency and the Austrian Agency for Research Integrity, welcomed ENRIO (the European Network of Research Integrity Offices), ENERI (the European Network of Ethics and Research Integrity), and ENOHE (the European Network of Ombudsmen in Higher Education).

Source: <http://www.enohe.net/news-updates/>

### **ALLEA Working Group Science & Ethics Meeting: revision of the ALLEA Code of Conduct**

In its final meeting of 2016 at the Royal Netherlands Academy of Arts and Sciences on 15 December 2016, the [ALLEA Permanent Working Group on Science & Ethics](#) (PWGSE) will finalise the revision of the ALLEA Code of Conduct and discuss the outlook for the coming year.

Source: <http://www.allea.org/events/allea-working-group-meeting-3/>

### **Questions raised about the influence and impact of EU research projects and CSR**

An article on [opendemocracy.net](http://opendemocracy.net) by David Sogge (an independent researcher and writer based in Amsterdam, affiliated with the Transnational Institute) analyses the effect of the IMPACT project (Impact Measurement and Performance Analysis of corporate social responsibility) suggesting that "Serious research efforts like that of the IMPACT Project may expose CSR's essential vacuity, but because their findings are ignored it marches forward unperturbed".

Source: <https://www.opendemocracy.net/transformation/david-sogge/corporate-wax-nose>

### **Deadline, for Member States to bring into force provisions to comply with Directive on disclosure of non-financial and diversity information, passes**

6 December 2016 was the deadline for Member States to bring into force the laws, regulations and administrative provisions necessary to comply with Directive 2014/95/EU of the European Parliament and of the Council of 22 October 2014 amending Directive 2013/34/EU as regards disclosure of non-financial and diversity information by certain large undertakings and groups. The Directive aims to improve undertakings' disclosure of social and environmental information.

Source: <http://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32014L0095>

### **EDPS: ethical approach to fundamental rights**

Giovanni Buttarelli, European Data Protection Supervisor (EDPS), blogs about innovation, ethical assessment and encouraging long term ethical analysis and prospective thinking towards technological innovation.

Source:

[https://secure.edps.europa.eu/EDPSWEB/edps/site/mySite/An\\_ethical\\_approach\\_to\\_fundamental\\_rights](https://secure.edps.europa.eu/EDPSWEB/edps/site/mySite/An_ethical_approach_to_fundamental_rights)

## **Austria**

### **Meeting of German-speaking national ethics committees on gene editing in Vienna**

Representative experts from ethics committees from Austria, Switzerland, and Germany met on 16 and 17 November 2016 in Vienna to discuss gene editing technologies and their implications. The Bioethics Commission of Austria will continue this international, up-to-date discussion and consider the corresponding legal situation in Austria, such as the Genetic Engineering Act, for example.

Source: <https://www.bundeskanzleramt.at/-/bioethik-kommission-diskutiert-zu-gen-chirurgie>

## **Denmark**

### **Debate: should private research be exempt from scrutiny by the Danish Committees for Scientific Dishonesty?**

Charlotte Rønhof (Confederation of Danish Industry) questions whether the Danish government proposal that only publicly financed research should be assessed by the Danish Committees for Scientific Dishonesty and makes the case that there should be no distinction between public and private research. Will policy makers pay heed?

Source: [http://www.altinget.dk/forskning/artikel/di-uhensigtsmaessig-at-skelne-mellem-offentlig-og-privat-forskning?ref=newsletter&refid=22414&SNSubscribed=true&utm\\_source=Nyhedsbrev&utm\\_medium=e-mail&utm\\_campaign=forskning](http://www.altinget.dk/forskning/artikel/di-uhensigtsmaessig-at-skelne-mellem-offentlig-og-privat-forskning?ref=newsletter&refid=22414&SNSubscribed=true&utm_source=Nyhedsbrev&utm_medium=e-mail&utm_campaign=forskning)

## France

### France publishes decree on research involving the human person

With this decree, a 2012 law dated 12 March 2002 comes into force. The main purpose of these new norms is to categorise research protocols on human beings based on the risks taken by the participants. The protection awarded to the participants by law is then proportional to the risks. The proposed legislation was revised to comply with [Regulation \(EU\) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on clinical trials on medicinal products for human use, and repealing Directive 2001/20/EC.](#)

Source (the new legislation, in French):

<https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000033394083&dateTexte=&categorieLien=id>

## Italy

### In Utero Germline Editing: call for professional societies to create clear guidelines and policies related to ethical concerns

News coverage from the European Society of Gene and Cell Therapy (ESGCT) 2016 Annual Congress, held in Italy, reports that scientists are worried that the “unethical uses of technology could lead to potential moratoriums on their research, which could prevent advances that could help treat diseases”. Untrustworthy science cannot perform its proper role in society.

Source: [http://www.medscape.com/viewarticle/871158#vp\\_2](http://www.medscape.com/viewarticle/871158#vp_2)

## Netherlands

### Interview with Dr. Gerrit Kimsma on a ‘good death’ and healthcare ethics

In an in-depth interview, Dr. Kimsma (Dutch physician and associate professor of medical ethics) has shared his views on euthanasia laws in the Netherlands. While largely favouring patients’ choice for a medical death of their choice if there are no options for cure or acceptable care, he expresses reservations about new regulations in the Netherlands that make it possible for people with ‘fulfilled lives’ to start the euthanasia process.

Source: <http://ottawacitizen.com/news/local-news/dutch-lessons-dr-gerrit-kimsma-on-a-good-death-in-the-netherlands>

## Slovenia

### Consultation on responsibility and hierarchy in science

The second public consultation of the Civil Society Monitor for Ethics in Science (organised by the Civil Society Monitor for Ethics in Science, Slovenian National Commission for UNESCO, and Scientific Research Centre of the

Slovenian Academy of Sciences and Arts) on 21 November 2016 discussed problems related to questions of responsibility and hierarchy in science.

Source: <http://www.zrc-sazu.si/sl/dogodki/odgovornost-in-hierarhija-v-znanosti>  
<https://www.facebook.com/events/1849578878609490/>

### **Ethics in Science: Public Consultation on the establishment of the Civil Society Monitor for Ethics in Science**

The Civil Society Monitor for Ethics in Science has been established as a result of the public consultation on ethics in science, and as a reaction to recent media exposures of scientific misconduct. The collateral damage of the latter is significant; it damages the reputation of the entire scientific community. Paradoxically, media exposures of scientific misconduct have proved to be one of the few mechanisms forcing the scientific community to seriously confront and resolve its problems. Co-organisers: Slovenian National Commission for UNESCO, Scientific Research Centre of the Slovenian Academy of Sciences and Arts, and Kvarkadabra - newspaper for interpreting science. Dates: 27 October 2016, Scientific Research Centre of the Slovenian Academy of Sciences and Arts

Sources: <http://www.zrc-sazu.si/sl/dogodki/vabilo-na-javni-posvet-civilnodruzbeni-monitor-etike-v-znanosti>

<https://www.facebook.com/events/975096532618056/>

Video recording of the meeting: <http://www.kvarkadabra.net/2016/11/posnetek-posveta-monitor-etike/>

## **Spain**

### **Spanish airlines refuse to transport lab animals**

In the last week of October 2016, reports show Spanish airlines Iberia and Air Europa refused to transport laboratory animals to and from the Canary Islands, the Spanish territory located off the coast of Morocco. The embargo affected around 30 research projects funded by national funding agencies, the Spanish Ministry of Economy and other European programs. The European Animal Research Association (EARA), together with the Spanish Society of Laboratory Animal Sciences (SECAL) and the regional government, has sought a meeting with Iberia to explore possible solutions to the problem.

Source: [http://elpais.com/elpais/2016/10/25/ciencia/1477392195\\_420271.html](http://elpais.com/elpais/2016/10/25/ciencia/1477392195_420271.html)

## **Switzerland**

### **The National Advisory Commission on Biomedical Ethics (NCE) social egg freezing and non-invasive prenatal tests**

The NCE is working on two position papers - one related to the non-invasive prenatal tests (NIPT) and another on social egg freezing. The papers are being discussed in the Commission and will be published (in German) in 2017.

Source: <http://www.nek-cne.ch/de/die-kommission/news/news-details/aus-der-letzten-nek-sitzung-arbeit-an-stellungnahmen-zum-social-egg-freezing-und-zu-nicht-invasive/>

## **Creating equal partnerships between the global north and south is in the interest of funders and researchers**

A news item on the Swiss National Science Foundation by Ochieng' Ogodo (*Sub-Saharan African English Edition Regional Coordinator and News Editor at SciDev.net*) suggests "Western researchers should share more responsibilities with their colleagues from the South". The article discusses the changing international research landscape and the inequality that exists at many levels.

Source: <http://www.snf.ch/en/researchinFocus/newsroom/Pages/news-161130-horizons-the-quest-for-fair-research.aspx>

## **United Kingdom**

### **Human cryogenic freezing raises ethical issues: is it time to regulate?**

In Ireland and the UK, some people are choosing to have their bodies frozen to be preserved for a future in which it is possible to be regenerated. In the UK, a judge backed the right of a 14-year-old girl who died of cancer to be cryogenically frozen. The ethical concerns of this practice include dignity, health risks, misleading assumptions about cheating death, consent (of preserved individuals, parents, guardians), human autonomy, etc. How will policy makers and regulators rise to the call for the "proper regulation" of cryonic preservation?

Sources:

(Ireland): <http://www.rte.ie/news/2016/1118/832787-frozen-girl-analysis/>

(UK) <http://www.telegraph.co.uk/news/2016/11/18/cancer-girl-14-is-cryogenically-frozen-after-telling-judge-she-w/>

### **POSTnote issued covering current and future uses of genome editing, its regulation, and potential concerns**

A POSTnote (issued November 2016) by the UK Parliamentary Office of Science and Technology (POST) covers current and future uses of genome editing, its regulation, and the potential concerns it raises.

Source: <http://researchbriefings.files.parliament.uk/documents/POST-PN-0541/POST-PN-0541.pdf>

### **UK court rules parliamentary approval required before Brexit can happen**

In *R (Miller) v Secretary of State for Exiting the European Union*, a divisional court held that the UK government did not have the power under the Crown's prerogative to give notice pursuant to Article 50 for the UK to withdraw from the European Union. [Media reports](#) suggest that the UK government will appeal the ruling, and the UK Supreme Court set aside 7 and 8 December 2016 to hear the appeal.

Source (judgment summary): <https://www.judiciary.gov.uk/wp-content/uploads/2016/11/summary-r-miller-v-secretary-of-state-for-exiting-the-eu-20161103.pdf>

### **UK Science and Technology Committee holds its fourth evidence session on science communication**

The UK Science and Technology Committee held its fourth evidence session on science communication on 16 November 2016. In this final session, the committee examined the 'consultation' process in engaging the public, 'responsible research and innovation', the use of scientific advice and the social sciences in policy making.

Source: <http://www.parliament.uk/business/committees/committees-a-z/commons-select/science-and-technology-committee/news-parliament-2015/science-communication-ev4/>

### **Alan Turing Institute offers to lead a 'Commission on Artificial Intelligence'**

In a letter to the UK government, the Alan Turing Institute has offered to lead a Standing Commission on AI (were it to be set up based on the recommendations of the report on Robotics and AI) that would examine the social, ethical and legal implications of recent and potential developments in AI.

Source (letter): <http://www.parliament.uk/documents/commons-committees/science-technology/Correspondence/161021-letter-from-Alan-Turing-Institute-to-Stephen-Metcalf-artificial-intelligence.pdf>

### **Research integrity concordat progress report published**

Universities UK has published a progress report on *the concordat to support research integrity* (originally published in 2012 and was developed by Universities UK, Research Councils UK, the higher education funding councils, the Wellcome Trust, and the government). The progress report examines the dissemination and awareness of the concordat, the nature of its reception, the manner and extent to which universities have responded to meet the five commitments, and makes recommendations.

Source: <http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Pages/concordat-research-integrity-progress-report.aspx>

## **Global News**

### **Fourth version of the CIOMS international ethical guidelines published**

The Council for International Organizations of Medical Sciences (CIOMS) has released a new version of its International Ethical Guidelines for Health-Related Research Involving Humans (developed in collaboration with WHO and based on authoritative ethical guidance documents, such as the World Medical Association's Declaration of Helsinki and UNESCO's Universal Declaration on Bioethics and Human Rights). The guidelines aim to provide internationally vetted ethical

principles and detailed commentary on how these principles should be applied, with particular attention to research in low and middle income countries.

Source: <http://www.cioms.ch/ethical-guidelines-2016/>

### **WHO to develop new policy on dealing with suspected research misconduct**

An independent review commissioned by WHO (World Health Organization) has found that research ethics misconduct occurred in a study on foetal growth standards. In light of this incident, and the fact that several departments across WHO are involved in research in different capacities, WHO is developing its own policy on dealing with suspected research misconduct. The new WHO policy is expected to be published before 2017.

Source:

[http://www.who.int/reproductivehealth/topics/maternal\\_perinatal/research-dispute/en/](http://www.who.int/reproductivehealth/topics/maternal_perinatal/research-dispute/en/)

### **ACM Code of Ethics and Professional Conduct solicits feedback**

The ACM Committee on Professional Ethics (COPE) has invited feedback on the first draft of the 2018 version of the ACM Code of Ethics and Professional Conduct. The public comments period runs from 1 December 2016 to 15 January 2017.

Source: <http://ethics.acm.org/code-of-ethics/code-2018/>

## **China**

### **China tests CRISPR gene-editing in a human for the first time**

News reports reveal that a Chinese group has become the first to inject a person with cells that contain genes edited using the revolutionary CRISPR–Cas9 technique. On 28 October 2016, a team led by oncologist Lu You at Sichuan University in Chengdu, China delivered modified cells into a patient with aggressive lung cancer as part of a clinical trial at the West China Hospital, also in Chengdu.

Source: <http://www.nature.com/news/crispr-gene-editing-tested-in-a-person-for-the-first-time-1.20988>

SATORI invites suggestions for policy items to include in future issues of the newsletter. To send suggestions and feedback, please email Rowena Rodrigues: [rowena.rodriques@trilateralresearch.com](mailto:rowena.rodriques@trilateralresearch.com) or visit our blog: <http://satoriproject.eu/blog/>

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