



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

## Policy developments in the ethics of research and innovation

SATORI Newsletter Issue 1:

29 July 2016

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

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## Global News

### Global code of ethics for chemists

The American Chemical Society has drafted a global code of ethics based on the Hague Ethical Guidelines from 2015. The code includes guidelines for accessing dual-use chemicals, and it focuses on environmental issues and sustainability. The intention behind the code is that it can be used as a basis for establishing ethical codes in chemistry for scientists in their home countries.

Source: <http://www.rsc.org/chemistryworld/2016/05/global-ethics-code-chemists-safety-conduct-sustainability>

## Europe

### Changes in the rules for approving new medical devices

The Netherlands Presidency of the Council and representatives of the European Parliament agreed upon new rules for medical devices and in vitro diagnostic medical devices on 25 May. The new rules seek to make the approval of new devices easier while simultaneously increasing the safety of those devices. The rules introduce a central database for the purpose of better tracing new medical devices on the market.

Source: <http://www.euractiv.com/section/health-consumers/news/new-medical-devices-rules-should-avoid-unnecessary-red-tape-industry-says/>

Discussion: <https://wellcome.ac.uk/news/eu-ruling-medical-devices>

### Public call for membership in the European Group on Ethics in Science and New Technologies (EGE)

The European Commission launched a public call on 30 May for candidacies for membership in the European Group on Ethics in Science and New Technologies (EGE). The group will be devoted to ethical questions in Research, Science and Innovation and will comprise 15 members representing a range of perspectives and disciplinary backgrounds. The call closed on 26 June 2016.

Source: <http://ec.europa.eu/research/index.cfm?pg=newsalert&year=2016&na=na-300516>

## **An open source toolbox for pure mathematics**

With the intention of facilitating collaboration for researchers in Europe, a group of 50 researchers spread over 15 sites in Europe are developing an open-source platform for mathematics software. The EU-funded OPENDREAMKIT project aims to improve and unify existing software with the goal of allowing researchers to easily set up customized collaborative Virtual Research Environments.

Source: [http://cordis.europa.eu/news/rcn/125362\\_en.html](http://cordis.europa.eu/news/rcn/125362_en.html)

Project website: <http://opendreamkit.org/>

## **European Commission adopts the EU-U.S. Privacy Shield**

The EC has adopted a new framework that is intended to protect the rights of those in the EU whose personal data is transferred to the United States. The framework should also bring legal clarity for businesses that rely on transatlantic data transfers. The Privacy Shield is based on a number of principles, such as obligations for companies handling data, safeguards and transparency obligations on U.S. government access, effective protection of individual rights and an annual joint review mechanism.

Source: [http://europa.eu/rapid/press-release\\_IP-16-2461\\_en.htm](http://europa.eu/rapid/press-release_IP-16-2461_en.htm)

Article 29 Working Party Statement on the decision:

[http://ec.europa.eu/justice/data-protection/article-29/press-material/press-release/art29\\_press\\_material/2016/20160726\\_wp29\\_wp\\_statement\\_eu\\_us\\_privacy\\_shield\\_en.pdf](http://ec.europa.eu/justice/data-protection/article-29/press-material/press-release/art29_press_material/2016/20160726_wp29_wp_statement_eu_us_privacy_shield_en.pdf)

## **Finland**

### **The National Advisory Board on Social Welfare and Health Care Ethics (ETENE) issues position statement on the treatment of intersex children**

Intersex is a rare condition of six to eight children born annually in Finland in which the sex of the child cannot be determined on the basis of physical characteristics. ETENE has issued a position statement on the treatment of such children. The statement recommends that measures should be taken to modify the person's external gender characteristics when the child is able to define their own gender and form an opinion about their own sexuality.

Source: [http://etene.fi/en/article/-/asset\\_publisher/etene-ja-intersukupuolisten-lastenhoito](http://etene.fi/en/article/-/asset_publisher/etene-ja-intersukupuolisten-lastenhoito)

## **Netherlands**

### **New Dutch legislation to protect whistleblowers**

The Netherlands has recently adopted new legislation, the "house of whistleblowers" act, which aims at increasing the protection for whistleblowers. This act applies to the public as well as to the private sector (any company with more than 50 employees).

Source: <https://zoek.officielebekendmakingen.nl/dossier/34105/kst-34105-7?resultIndex=27&sorttype=1&sortorder=4>

## **Netherlands to survey every researcher on misconduct**

The Dutch government is investing eight million Euro to identify the reasons for scientific misconduct in the country and to find possible solutions to the problem. Part of this program will be a mass survey of researchers in the country, which will try to establish how many researchers are involved in misconduct or “sloppy science”.

Source: <https://www.timeshighereducation.com/news/netherlands-to-survey-every-researcher-on-misconduct>

## **New Zealand**

### **New guidelines to support public engagement for researchers**

The Royal Society of New Zealand has released new guidelines with the goal of promoting engagement between researchers and society. The guidelines are meant to increase public awareness of new knowledge and how it might be applied. They also seek to build and maintain public trust through professionalism and transparency from researchers.

Source: <http://www.royalsociety.org.nz/2016/07/21/new-guidelines-support-researchers-to-engage-with-the-public/>

## **Poland**

### **NCN Council recommendations on research ethics**

The Council of the National Science Centre (NCN) has prepared recommendations for research involving human subjects. The goal is to ensure that scientific research funded by the NCN complies with high ethical standards and to support researchers in resolving ethical dilemmas related to the design and conduct of research. The Council recommends that applicants that are planning to conduct types of research specified in the recommendation obtain a positive opinion of a Research Ethics Committee. NCN is a government agency, supervised by the Ministry of Science and Higher Education, set up in 2011 to support basic research in Poland.

Source: <https://www.ncn.gov.pl/aktualnosci/2016-03-24-zalecenia-dot-etyki-badan>

### **The situation of laboratory animals will be monitored by the Supreme Audit Office**

The Supreme Audit Office (NIK) will check whether the existing regulations, adopted last year, have improved the protection of animals used in laboratory research. Experts invited to NIK pointed to a number of deficiencies in the new law. According to some experts, the law that passed in order to implement the EU directive had a negative impact on the situation and well-being of laboratory animals. NIK wants to examine how the new law works in practice. A report summarizing the situation of laboratory animals can be expected in the first quarter of 2017.

Source: <https://www.nik.gov.pl/aktualnosci/nik-przyjrzy-sie-doswiadczeniom-na-zwierzetach-panel-ekspertow.html>

## Switzerland

### **Second SNSF conference on Gender and Excellence discusses the latest challenges for equal opportunities in research funding**

The Swiss National Science Foundation organized its second conference on Gender and Excellence on 21 June 2016. With around 130 people attending, the discussion focused on potential gender bias in the perception and evaluation of excellence as well as on the inclusion of the gender dimension in specific research areas. Based on the outcomes of the conference, the Gender Equality Commission of the SNSF will elaborate recommendations that it will share with the National Research Council.

Source: <http://www.snf.ch/en/researchinFocus/newsroom/Pages/news-160705-conference-gender-and-excellence.aspx>

## United Kingdom

### **UK legal entities still eligible to participate and receive funding in Horizon 2020 actions**

In a statement on the UK referendum to leave the EU, the Heads of State or Government of 27 Member States, as well as the Presidents of the European Council and the European Commission confirmed that until the UK leaves the EU, EU law continues to apply to and within the UK. This includes the eligibility of UK legal entities to participate and receive funding in Horizon 2020 actions.

Source: <http://ec.europa.eu/research/index.cfm?pg=ukref>

### **British scientists gain permission for genetic modification of human embryos**

The Cambridge Central Research Ethics Committee has approved genetic modification of human embryos by the Francis Crick Institute. The approved work will investigate possible genetic causes of infertility and miscarriage. The study is intended for research purposes only, not for clinical application. The embryos will be donated by parents undergoing fertility treatment who have given informed consent. The ethical approval of this research has met criticism from those who claim that it is not necessary because it addresses issues that are already well-understood.

Source: <https://www.crick.ac.uk/research/a-z-researchers/researchers-k-o/kathy-niakan/hfea-licence/>

Discussion: <http://www.telegraph.co.uk/news/2016/05/27/british-scientist-can-genetically-modify-human-embryos-ethics-co/>

<http://www.ibtimes.com.au/ethics-committee-allows-british-scientists-genetically-modify-human-embryo-1517362>

<http://www.christianconcern.com/our-concerns/abortion/ethics-committee-greenlights-uk-gene-editing>

## New report on genome editing and public dialogue published

The Nuffield Council on Bioethics has published a report on public concerns over genome editing technology. The report is based on a workshop hosted by the Council and Sciencewise. It addresses questions of the effectiveness of public dialogue and the role of public dialogue as a part of the larger conversation. An interim report on moral questions raised by genome editing is planned for later in 2016.

Sources: <http://nuffieldbioethics.org/news/2016/why-when-who-report-of-workshop-on-genome/>; <http://nuffieldbioethics.org/wp-content/uploads/Public-Dialogue-on-Genome-Editing-workshop-report.pdf>

## United States

### American Medical Association issues ethical guidelines for telemedicine

The American Medical Association has adopted new guidelines for doctors interacting with patients through telemedicine. The guidelines include recommendations for physicians to inform patients about the limitations of telemedicine, to tailor informed consent to include information about the distinctive nature of telehealth, to strive to promote continuity of care and to monitor the telemedicine landscape for positive and negative consequences of technologies.

Source: <http://www.healthcarediver.com/news/ama-guidelines-offer-roadmap-for-ethical-use-of-telemedicine/422641/>

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

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