



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

## Policy developments in the ethics of research and innovation

### SATORI Newsletter Issue 6

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

### **SATORI workshop: Ethics assessment in R&I: policy encounters**

SATORI will host a policy workshop at UNESCO, in Brussels on 23 May 2017 to discuss its ethics assessment policy recommendations, how policy decisions can nurture or restrict ethics in research and innovation (R&I), and how policymakers can further support and optimise ethics. *Register your interest: few spaces left!*

Source: <http://satoriproject.eu/events/event/ethics-assessment-in-research-innovation-policy-encounters/>

### **ALLEA publishes revised edition of the European Code of Conduct for Research Integrity**

ALLEA, the European Federation of Academies of Sciences and Humanities, has published the revised edition of the European Code of Conduct for Research Integrity, a document that serves the European research community as a framework for self-regulation across all scientific and scholarly disciplines and for all research settings.

Source: <http://www.allea.org/wp-content/uploads/2017/03/ALLEA-European-Code-of-Conduct-for-Research-Integrity-2017-1.pdf>

### **RRI in the health industry: joint conference**

The [European Economic and Social Committee \(EESC\)](#), the [European Institute of Innovation and Technology](#) and the [EU project Responsible-Industry](#) will organise a conference on "RRI in the Health Industry" (Brussels, 18-19 May 2017). It will explore topics such as RRI in ICT, biomedicine and health, integration of social values and needs, drivers and obstacles to implementation of RRI. The [Responsible Industry project](#) will present its final results, including its [guide](#) to implement RRI in the ICT industry, complemented by testing and feedbacks collected in real industry cases.

Source: <http://www.eesc.europa.eu/?i=portal.en.events-and-activities-responsible-research>

### **HEIRRI project calls on HEIs to test its training programs and materials**

The [HEIRRI project](#) has invited higher education institutions (HEIs) interested in Responsible Research & Innovation (RRI) and its integration into their curricula to apply to test its training programs and materials. The pilots will take place between June 2017 and April 2018. Participants will actively participate in the learning process, and give feedback on the materials and their use. Deadline for applications: 30 April 2017.

Source: <http://heirri.eu/news/call-for-applications-to-test-the-heirri-training-materials-is-now-open/>

## France

### **A new, centralized, office for scientific integrity**

The French Office for Scientific Integrity (OFIS) was created on 20 March 2017 by the Haut conseil de l'évaluation de la Recherche et de l'enseignement supérieur (HCERES), the administrative independent authority in charge of the evaluation of procedures in all universities and research centers. It will contribute to the development of national policy for scientific integrity and monitor the implementation of the national chart on scientific integrity.

Source:

[http://www.cnrs.fr/comets/IMG/pdf/20170320\\_cp\\_hceres\\_creationofis.pdf](http://www.cnrs.fr/comets/IMG/pdf/20170320_cp_hceres_creationofis.pdf)

## Italy

### **Responsible innovation, precautionary principle and quality of life: new guidance developed in Italy**

UNI, the Italian Standard Body, has recently published the UNI/PdR 27:2017 "Guidance for management and processes development for responsible innovation", designed for organisations active in defining, developing, producing, implementing, exploiting or disseminating any kind of innovation (products, services, processes, systems, etc.). The precautionary principle and the value of quality of life, defined according to stakeholders' expectations, are two key criteria taken into account by the document. The document has been developed with the collaboration of AIRI and CISE/Chamber of Commerce of Forlì.

Source:

[http://www.uni.com/index.php?option=com\\_content&view=article&id=5845:innovazione-responsabile-pubblicata-la-nuova-prassi-di-riferimento-uni-pdr-27&catid=171:istituzionale&Itemid=2612](http://www.uni.com/index.php?option=com_content&view=article&id=5845:innovazione-responsabile-pubblicata-la-nuova-prassi-di-riferimento-uni-pdr-27&catid=171:istituzionale&Itemid=2612)

### **Approval of Bill on Living Will**

With 326 assenting votes, the majority of members of the Italian Chamber of Deputies approved a bill on Living Will. It is the result of years of debate and compromises with the Catholic part of the country which is still against the regulation of end-of-life decisions. The bill has now to be approved by the Italian Senate to become law, but opposition is expected.

Source: <http://www.lastampa.it/2017/04/21/esteri/lastampa-in-english/living-will-the-battle-begins-oChaykrJaRa7dBRJrf1ugK/pagina.html>

## Netherlands

### **Green light for the creation of human embryos for research**

In a move to make embryo gene editing research possible, the Dutch Health Council has recommended that scientists be allowed to create embryos specifically for research purposes. While the exact ethical framework is yet to be developed,

the Council has suggested that the government should move away from the current regulation that only allow research scientists to use embryos left from procedures such as in vitro fertilisation (IVF).

Source: <https://www.bioedge.org/bioethics/dutch-health-council-authorises-the-creation-of-human-embryos-for-research/12249>

## **Poland**

### **A National Biobanking Network to be established**

The Ministry of Science and Higher Education has invested 40 million zlotys (approximately EUR 94,58,592.68) for establishment of the National Biobanking Network. One of the goals of the Network is to set common standards for storing, transporting and processing samples in Poland. The project will finish by the end of 2021. The National Biobanking Network will form a part of the Biobanking and Biomolecular Resources Research Infrastructure - European Research Infrastructure Consortium (BBMRI-ERIC).

Source: <http://naukawpolsce.pap.pl/aktualnosci/news,413065,wroclaw-resort-nauki-przyznal-40-mln-zl-na-utworzenie-sieci-biobankow-w-polsce.html>

## **Sweden**

### **CARe symposium: Ethics and Value Challenges in Antibiotic Resistance Management, Policy and Research**

The Centre for Antibiotic Resistance Research (CARe), University of Gothenburg will hold a two-day symposium on 'Ethics and Value Challenges in Antibiotic Resistance Management, Policy and Research', 15-16 November 2017. The symposium will bring together speakers in ethics, law, public health and related areas engaged on this topic – including leaders of recently started major research projects (from Australia, Canada, the Netherlands, Germany, Sweden, the UK, and the USA).

Source: <http://care.gu.se/news-events/n//care-presents-a-2-day-symposium-on-the-theme-of-ethics-and-value-challenges-in-antibiotic-resistance-management--policy-and-research--november-15-16--2017.-.cid1429970>

### **First HBP curriculum workshop series: research ethics & societal impact**

The Human Brain Project (HBP) [workshop](#) scheduled for 10-12 July 2017 aims to provide the participants with insights on ethical aspects of the use of ICT and animals in science and research.

Source: <https://education.humanbrainproject.eu/web/1st-hbp-curriculum-ethics>

## Switzerland

### **A new funding scheme aims at supporting women in academia**

The Swiss National Science Foundation has introduced a new funding schema, PRIMA (Promoting Women in Academia), aiming to contribute to the appointment of female professors in Switzerland.

Source: <http://www.snf.ch/en/researchinFocus/newsroom/Pages/news-170413-prima-supports-excellent-women-researchers.aspx>

## United Kingdom

### **UKRIO responds to House of Commons research integrity inquiry**

The UK Research Integrity Office (UKRIO) has responded to the House of Commons research integrity inquiry. One of the points the submission makes is that “It is unclear whether regulation would be an effective tool to address many of the existing concerns about research integrity”.

Source: <http://ukrio.org/wp-content/uploads/Research-integrity-inquiry-submission-from-the-UK-Research-Integrity-Office-March-2017.pdf>

### **Discussion on Brexit: the impact on science & innovation in the UK and Europe**

EuroScience, Academia Europaea, and the Royal Institution with support from Elsevier are organising a debate on “Brexit: the facts behind opportunities & challenges for both the UK & European Science Establishments” on 8 May 2017 at the Royal Institution, London, UK.

Source: <http://www.euroscience.org/news/a-discussion-on-brexit/>

### **ICO: Big data, artificial intelligence, machine learning, and data protection**

The UK Information Commissioner’s Office (ICO) has updated its paper on big data, considering the advances made since its last publication and the imminent implementation of the General Data Protection Regulation (GDPR). The paper examines the implications of big data, artificial intelligence (AI) and machine learning for data protection, and explains the ICO’s views on these.

Source: <https://ico.org.uk/media/for-organisations/documents/2013559/big-data-ai-ml-and-data-protection.pdf>

## Global

### **WHO issues ethics guidance to protect rights of TB patients**

The World Health Organization (WHO) new ethics guidance addresses contentious issues such as, the isolation of contagious patients, the rights of tuberculosis (TB) patients in prison, discriminatory policies against migrants affected by TB, etc. It emphasizes five key ethical obligations for governments, health workers, care providers, non-governmental organisations, researchers, and other stakeholders.

Source: <http://www.who.int/mediacentre/news/releases/2017/world-tb-day/en/>

### **Scientists call for new ethical guidelines for 'synthetic embryos'**

'Synthetic' structures – such as organoids or embryos assembled from stem cells in the lab – are increasingly being used in cutting-edge research. Currently, there are no specific ethical guidelines or regulatory bodies covering the use of these structures. There are concerns amongst scientists that the current lack of ethical guidelines for these structures could lead to ethically problematic cases.

Source: [http://www.bionews.org.uk/page.asp?obj\\_id=808573](http://www.bionews.org.uk/page.asp?obj_id=808573)

## Australia

### **Update of Guidelines on assisted reproductive technology**

The National Health and Medical Research Council (NHMRC) has updated its guidelines on assisted reproductive technology (ART). The Council's *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2017 (ART Guidelines)* replaces the *2007 ART Guidelines* and provides new ethical guidance for the conduct of ART in the clinical setting.

Source: <http://www.psnews.com.au/aps/548/news/ivf-guidelines-update-state-of-the-art>

## Canada

### **Genetic Non-Discrimination Act**

Parliament has passed the Genetic Non-Discrimination Act which aims to prohibit and prevent genetic discrimination. As of 8 March 2017, it is awaiting royal assent.

Source: <https://openparliament.ca/bills/42-1/S-201/>

## Chile

### **Data protection amendment bill**

The President of Chile, Michelle Bachelet, signed, on 13 March 2017, a Bill to regulate the protection and processing of personal data and create the Personal

Data Protection Agency ('the Government's Bill'), which would amend Law No. 19.628 on the Protection of Private Life 1999. The Bill is an attempt to reform the current law.

Source: <https://www.dataguidance.com/chile-data-protection-amendment-bill-fulfils-governments-commitment-oecd/>

## **India**

### **Discussion of social and ethical implications of genome editing**

A news report states the department of biotechnology and Indian Council of Medical Research (ICMR) will meet with Inserm, the French National Institute of Health and Medical Research, this month to discuss the social and ethical implications of genome editing in India, after which the government plans to issue broad guidelines for researchers.

Source: <http://indianexpress.com/article/technology/science/india-prepares-to-discuss-breakthrough-technology-designer-humans-science-ethics-of-germline-editing-4569430/>

## **Qatar**

### **MOHP research ethics workshop**

The Ministry of Public Health (MoPH) organised a workshop on research ethics with participation of more than 150 individuals, including members of research review committees, physicians, and allied health practitioners. The event addressed important topics including an overview of the criteria for research approval, paediatric research, conflicts of interest, informed consent, Internet research, clinical trials, adverse events, research on biological specimens, genomic sequencing, and case studies in biomedical research and social, behavioural, and educational research.

Source: <http://www.gulf-times.com/story/542190/Ministry-holds-research-ethics-workshop>

## **South Africa**

### **San code of research ethics**

The South African San Council has launched a [code of ethics](#) to guide researchers to stop intrusive and sometimes exploitative research in San communities. The code of ethics was launched in Cape Town on 2 March 2017 during a [TRUST project](#) conference (TRUST is funded by the European Union's Horizon 2020 Programme).

Source: <https://mg.co.za/article/2017-03-06-san-council-launches-code-of-ethics-for-researchers>

## Taiwan

### Ministry of Science and Technology sets up integrity office

On 15 March 2017, the Ministry of Science and Technology announced the establishment of an Office of Research Integrity to collect data on breaches of academic integrity and provide a reference for future academic studies.

Source:

<http://www.taipeitimes.com/News/taiwan/archives/2017/03/16/2003666873?src=ilaw>

## USA

### Bills introduced to promote preserve integrity scientific review process

In March 2017 two bills were introduced: [Honest and Open New EPA Science Treatment Act of 2017 \(HONEST Act\)](#) and the [EPA Science Advisory Board Reform Act of 2017](#). Both bills aim to promote an open and honest Environmental Protection Agency (EPA) and preserve the integrity of the scientific review process.

Source: <https://science.house.gov/news/press-releases/sst-committee-members-introduce-honest-and-open-new-epa-science-treatment-act-0>

To send suggestions and feedback on the SATORI newsletter or to engage with SATORI policy work, please email Rowena Rodrigues:

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