

# Enhancing ethics assessment in R&I at the national level

Rowena Rodrigues, Trilateral Research

SATORI policy workshop UNESCO, Brussels 23 May 2017





### SATORI countries of analysis: EA inventory

Austria	
China	
Denmark	
France	
Germany	
The Netherlands	
Poland	
Serbia	
Spain	
United Kingdom	
United States	TR





#### Conclusions from SATORI country analysis

- Countries are currently expanding ethics assessment and guidance infrastructure
- The expansion of ethics assessment in non-medical areas is especially noteworthy.
- Greater efforts are being made to address ethical issues by governments, universities, research funding organisations, CSOs, and industry.
- Significant differences in the extent to which ethics of R&I is institutionalised ranging from limited (China, Poland, Serbia) to extensive (Austria, Germany, Netherlands).

Source: WP1/D1.1





#### Conclusions from SATORI country analysis

- There are national differences in the types of ethical principles and R&I issues that receive attention.
- Role of government in ethics assessment and guidance is different, ranging from strong (China) to little (US) regulation.
- Governments stimulate corporate social responsibility (CSR) for industry to different degrees and with different means.
- The role of CSOs in government policy, representation in ethics assessment panels and committees, and in conducting ethics assessment varies considerably.

Source: WP1/D1.1





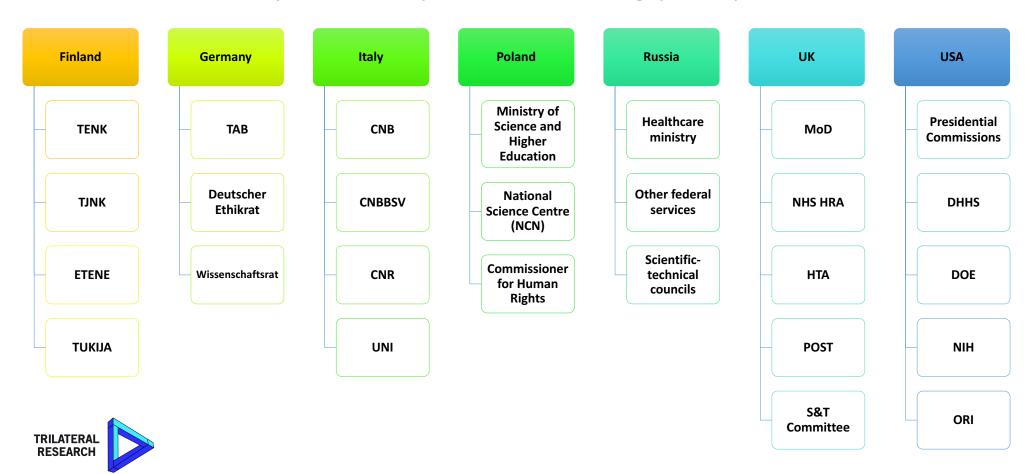
### WP9 country policy developments scan

Australia	Austria	Canada	Chile	China	Denmark	Finland
France	Germany	Hungary	India	Ireland	Italy	Netherlands
Norway	Poland	Qatar	Serbia	Singapore	Slovenia	South Africa
Spain	Sweden	Switzerland	Taiwan	Tanzania	UK	USA





#### Examples of key actors driving policy





# **July 2016**

Privacy framework (US)

Treatment of intersex children (Finland)

Treatment of intersex children (i iniana)

**Whistleblower protection (Netherlands)** 

**Research misconduct (Netherlands)** 

**Public engagement (New Zealand)** 

Genome editing (UK)

**Human embryos - genetic modification (UK)** 

**Human subject research (Poland)** 

**Animal welfare (Poland)** 

**Gender bias in research (Switzerland)** 





## Aug 2016

Leaking of results of psychological tests by researchers (Finland)

Simplification of reporting of data processing in health research projects (France)

New guidelines for research ethics (Norway)

New ethical framework for the counselling professions (UK)

Independent Review of Research Excellence Framework (REF) (UK)

**New Ethical Guidelines for Biomedical Research (India)** 

Importance of ICT Code of Ethics (Tanzania)





## Oct 2016

Citizen science; Integration of European research initiatives (Germany)

Policy recommendations to enhance R&I (Hungary)

**Ethics, policy and society (Ireland)** 

RRI and ethical guidelines; ISO 26000 guidance (Italy)

Ethical review boards for informatics research; organ donation; in vitro meat (Netherlands)

**Ethics in research (Slovenia)** 

Clinical trials; genetic engineering (Switzerland)

Impacts of ethics officers; robotics (UK)





### Dec 2016

Meeting of NECs (Austria)

Debate on whether private research should be exempt from scrutiny (Denmark)

Decree on research involving the human person (France)

In utero germline editing (Italy)

**Death & healthcare ethics (Netherlands)** 

Consultation on responsibility and hierarchy in science (Slovenia)

**Animal welfare (Spain)** 

Prenatal tests, social egg freezing; north-south research partnerships (Switzerland)

Human cryogenic freezing; genome editing; Brexit, RRI, AI (UK)

**CRISPR** gene-editing (China)





### Feb 2017

**Ethical guidelines for organs cultivated in vitro (Austria)** 

Plagiarism scandal; weakening of ethics committee powers (Croatia)

Board to deal with serious cases of scientific dishonesty (Denmark)

**Genome editing (Germany)** 

New regulations to promote innovation (Poland)

Transplantation of human organs; Draft law on application of human cells and tissue; Code of medical ethics (Serbia)

**Civil Society Monitor of Ethics in Science (Slovenia)** 

**Open government data (Switzerland)** 

Parliamentary inquiry on research integrity (UK)

Public consultation: Australian Code for Responsible Conduct of Research (Australia)



NAS & NAM Report: Human Genome Editing; government guidance on scientific integrity for its researchers (USA)



## **April 2017**

A new, centralized, office for scientific integrity (France)

Responsible innovation: new guidance (Italy)

**Green light for the creation of human embryos for research (Netherlands)** 

**Establishment of a National Biobanking Network (Poland)** 

Symposium: Ethics and Value Challenges in Antibiotic Resistance Management, Policy and Research (Sweden)

PRIMA (Promoting Women in Academia) (Switzerland)

UKRIO responds to House of Commons research integrity inquiry; Brexit impact on R&I; ICO report on big data (UK)

Update of guidelines on assisted reproductive technology (Australia)

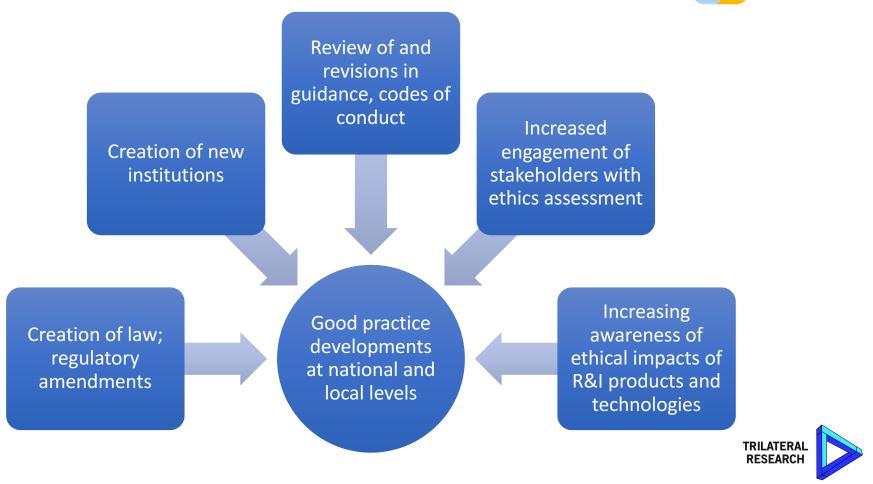
**Genetic Non-Discrimination Act (Canada)** 

Data protection amendment bill (Chile)

Discussion of social and ethical implications of genome editing (India)









#### But, there are challenges and barriers...

**Cultures of ethics** 

Lack of shared understanding

Differences in approaches within scientific fields

**Parallel developments** 

Lack of good practice sharing – closed door effect The bitter pill effect of 'ethics' assessment in R&I The levels of ethics assessment – highly developed, developing and under-developed structures

**Resource constraints** 





#### Yet, there are opportunities...







#### What can we do?

Identify the right opportunities

Time it right

Allocate adequate resources for the use of the Framework

Get EU and national level bodies to advocate the use of the Framework

Capture the attention of national level key players





#### Questions for reflection & discussion

- What can you/your organisation do in your country to support the dissemination and use of the SATORI Framework at the national level? List two or three key actions.
- 2. What scientific fields and areas should the SATORI framework (recommendations for ethics committees and ethical impact assessment) be promoted in?
- 3. Identify challenges to implementing the Framework (in your country) and suggest how these could be overcome?





## Rowena Rodrigues, Trilateral Research www.trilateralresearch.com

rowena.rodrigues@trilateralresearch.com

Twitter: @RRodriguesTRI; Trilateral\_UK



www.satoriproject.eu

Stakeholders Acting Together on the Ethical Impact Assessment of Research and Innovation - SATORI received funding from the European Commission's Seventh Framework Programme (FP7/2007-2013) under Grant Agreement n° 612231

