

## Annex I

### List of recommendations concerning the Universal Periodic Review of Italy submitted by Associazione Luca Coscioni and Science for Democracy

#### **1. Assisted reproduction technologies (ART) and research with human embryonic stem cells (hESC)**

- a) Italy should remove the remaining prohibitions of Law 40/2004, also in light of the many decisions made by the Constitutional Court, to avoid that judicial interventions remain the only effective way to obtain access to PMA techniques, i.e. allow same-sex couples and single persons to access PMA.
- b) Italy should regulate the donation of human blastocysts not suitable or intended for reproductive purposes to national research.

#### **2. Maternal surrogacy in Italy**

- a) Italy should adopt norms to fill the lack of regulation concerning surrogacy to: protect the rights of children born from surrogacy abroad, regulate altruistic surrogacy at the national level, end discrimination and protect individuals' fundamental rights, including reproductive rights and self-determination.

#### **3. Abortion and contraception**

- a) Italy should guarantee access to emergency contraception without medical prescription to all women and girls, including underage girls.
- b) Italy should include any means of contraception among the expenses reimbursed by the National Health Service.

#### **4. Provisions for informed consent and advance health directives**

- a) Italy should take immediate action to provide clear guidance for the recording and collection of citizens' advanced directives, together with the possibility to access those information when needed.

#### **5. Assisted suicide and euthanasia**

- a) Italy should consider end-of-life care and rights as a priority issue in the institutional agenda and take immediate action towards the adoption of proper legislation in compliance with international human rights standards and order 207/2018 of the national Constitutional Court.

#### **6. Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR), New Plant Breeding Techniques and "old" Genetically Modified Organisms (GMOs)**

- a) Italy should review the implementation of the 2001 EU GMO directive to regulate the product rather than the technique used to make it.

- b) Italy should allow experimentation of CRISPR plants in open fields selecting land under the direct jurisdiction of the Ministry of Agriculture.
- c) Italy should clarify how she intends to implement the decision of the European Court of Justice on mutagenesis of July 2018.

#### **7. The Legislative Decree 26/2016 on the use of animals for scientific purposes**

- a) Italy should consistently respect the law allowing the use of animals in medical research by issuing the decision, whether positive or negative, in 40 working days and a better transparency and communication in the evaluation of the projects.
- b) Italy should review her animal research law to ensure proper balance between biomedical progress and the protection of the welfare of all animals used in research, including the possibility of allowing breeding of dogs, cats and non-human primates for research purposes.

#### **8. Mental health**

- a) Italy should convene the National Conference on Mental Health.

#### **9. The Convention on the Rights of Persons with Disabilities**

- a) Italy should guarantee the full application of the UN Convention on the rights of persons with disabilities, starting from reviewing the mechanisms to compose the National Observatory for persons with disabilities.
- b) Italy should reform the national health system to promote the respect of the principle of equal access to treatment.
- c) Italy should remove architectural barriers all over the country starting from public building through to fully allow an independent life for all;
- d) Italy should update the list of Essential Levels of Assistance (LEA) and the tariff list of aids and prosthesis.
- e) Italy should review its legislation to ensure the “right to a signature” for people who cannot do it manually.

#### **10. Medical research on controlled narcotic and psychotropic substances**

- a) Italy should improve her data collection system to assess the real national need of therapeutic cannabinoids, the conditions for which it is prescribed, the type of products prepared and/or imported and the eventual adverse effects.
- b) Italy should increase its national production, including through public-private partnerships, and improve the system to import products she does not produce.
- c) Italy should support studies on cannabis-based products starting from the varieties that she produces and promote clinical trials with the plant and its derivatives.
- d) Italy should promote studies and clinical trials on other controlled narcotic substances aimed at introducing benefits from a wider range of therapies for various conditions including treatment for problematic drug users.

#### **11. Investment in scientific research and Gross Domestic Product (GDP)**

- a) Italy should significantly fund national research institutes and universities to meet her commitment to invest 3% of national GDP.

## **12. Gender equality in the workplace and science**

- a) Italy should make Science, Technology, Engineering and Mathematics (STEM) more attractive for women and reduce the gender gap in employment.
- b) Italy should capitalize on the benefits of progress of women in STEM to stimulate innovation and business development.
- c) Italy should exploit new technologies to offer the opportunity to promote flexible working hours that help both men and women in STEM to reconcile the time devoted to work and that dedicated to the family, with potential positive effects on the balance of gender in the activities of domestic work and care of members of family.

## **13. Embedding evidence-based evaluations of the living environment in the Italian institutional practices**

- a) Italy should establish an independent “science-policy” agency with the mandate of elaborating evidence-based evaluations of the impacts of plans and projects on human health and the environment irrespective of any contingent political mandate. Such independent body could be better suited to establish a trustworthy dialogue with citizens and informing public debates on the living environment based on accessible evidence-based evaluations, therefore responding to UN recommendations.

## **14. Evaluation of scientific research**

- a) Italy should review the governance and the structure of the National Agency for the Evaluation of University System, ANVUR, to make it become a fully independent body with a complete disclosure of its evaluation practices and methods used.

## **15. Research funding policies for rare diseases**

- a) Italy should consider rare diseases within her research priorities and include academic research centres for the allocation of available resources.
- b) Italy should establish a national research agency responsible for the monitoring of the allocation of resources.