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Research and Self Determination Index

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INTRO

Expanding medical knowledge through research, enhancing patients' well-being through medical treatment, and securing the best available treatment are universal aspirations shared by researchers, health care professionals and patients around the globe.

The pursuit of scientific knowledge is a social good as well as a matter of rights. In fact, people have the right to benefit from the advancement of science and its applications as promulgated in article 27 of the Universal Declaration of Human Rights and article 15(b) of the International Covenant on Economic, Social and Cultural Rights, which many countries have signed and ratified.

The human right to science is unfortunately not fully realized and not equally realized around the globe. Domestic laws constrain researchers, health care professionals and patients. Further, cross-national variation of legal regimes is significant: some countries support the rights of researchers, health care professionals and patients more than others.

The Research and Self Determination Index (SDI) is a tool for comparative assessment of the degree to which researchers, health care professionals and patients enjoy the right to science around the globe.

Researching and measuring the "freedom" to pursue scientific knowledge and enjoy its benefits is an important task as it allows understanding the context in which science and medicine advance so that we can further expand the right to science.

The intent is to raise awareness of such differences and to foster an evidence-based dialogue among policymakers, scientists, patients, and society.

METHODOLOGY

The SDI is based on a five-step process:

1. Selection of key areas of medical research and treatment that raise important questions of freedom
2. Identification of key legal and regulatory indicators of freedom in each of the four areas
3. Point allocation for each legal and regulatory indicator with highest score allotted to legal environments with highest degree of freedom (If data are not available, the answer is not included in the calculation)
4. Data collection
5. Visualization of results on maps and ranking of countries based on the overall score and area scores

Countries that appear on the SDI have at least 80% of data completed.

SDI FEATURES

Presents overall ranking of 46 countries based on data on the laws and regulations pertaining to four areas of policy:

1. Assisted reproduction technologies (ART)
2. Research with human embryonic stem cells (hESC)
3. End-of-life decisions
4. Abortion and contraception

Presents separate analyses and ranking for each of the four areas.

Databases was updated in 2014, 2016, and 2017.

32 comprehensive country reports discussing current issues in the four areas of policy.

Court-specific news published with regularity on the website and on twitter @Free2research.

TIMELINE

2009 – Concept and pilot study presented at the Second World Congress for Freedom of Scientific Research

2014 – SDI is launched at the Third World Congress for Freedom of Scientific Research Website goes live with data collected for 42 countries.

2015 – Three countries added (Iceland, Dominica Republic, and Thailand)

2017 – Kenya is added. Netherlands goes up and occupies first place

SNAPTSHOT 1 – MOVERS AND SHAKERS

2017

- The Dutch Health Council has recommended that scientists in **The Netherlands** be allowed to create embryos specifically for research purposes,
- **Britain** granted its first research license to genetically modify human embryos for therapeutic purposes (assisted reproduction)
- **Japanese** government is considering limiting human embryo modification and prohibiting both the implantation of embryos with altered genes

2016

- **Japanese** government authorizes the modification of fertilized human eggs
- The Supreme Court of **Brazil** ruled that "abortion should not be a crime when performed in the first three months of pregnancy." Case was brought in response to fetal defects from Zika virus
- Non-commercial surrogacy agreements were legalized in **Vietnam** in 2016

2015

- **British** law is amended to permit mitochondrial transfer thus allowing using biological material from three different people in IVF to help prevent women from passing on genetic diseases to their children
- The Supreme Court of **Canada** struck down Canadian law prohibiting assisted suicide, giving Canadian adults who are mentally competent and suffering intolerably and enduring the right to a doctor's help in dying.
- Terminally-ill patients in **France** can now be put in a "deep sleep" until they die
- First case of physician-assisted suicide is performed in **Colombia** despite it has been legal since the 1990s
- Physician assisted suicide was legalized in **Germany** in 2015

2014

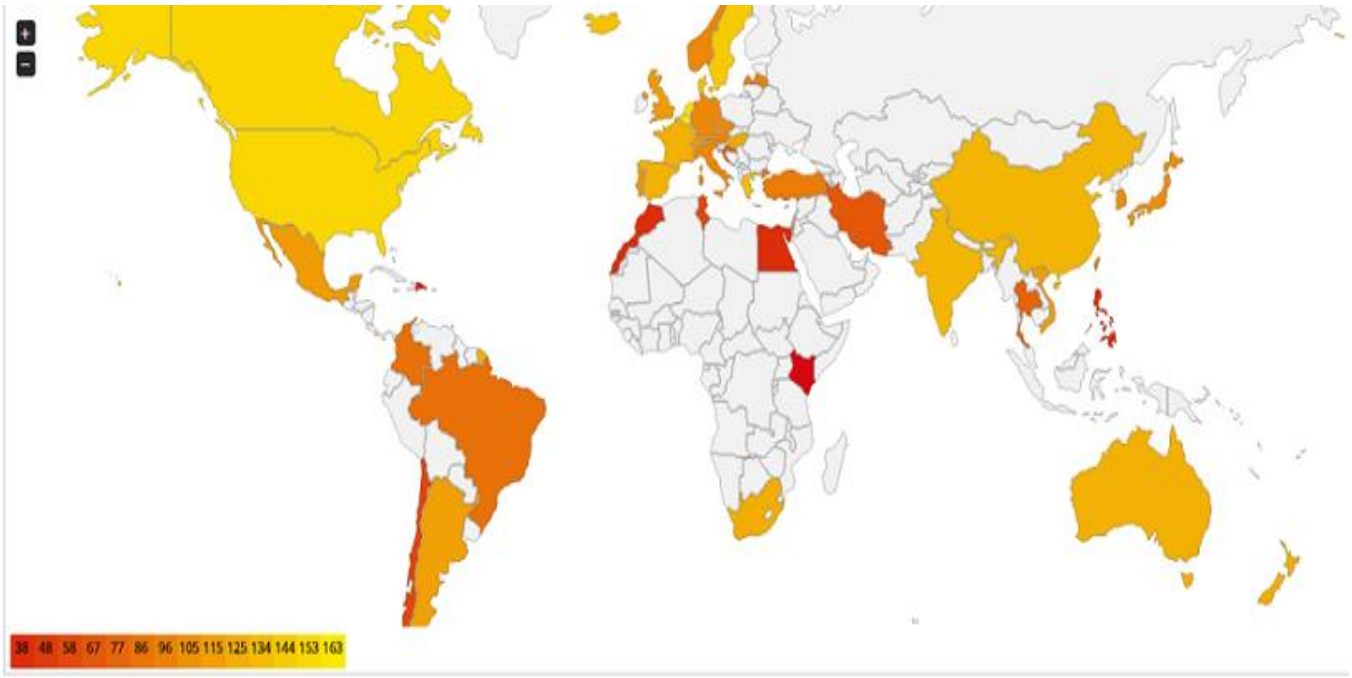
- The Supreme Court of **India** ruled to allow passive euthanasia for patients who are in a permanent vegetative state or are declared brain-dead
- An **Israeli court** approved passive euthanasia for patients with terminal ALS

SNAPSHOT 2 – RESEARCH WITH STEM CELLS AND EMBRYOS

Research with embryos and pre-embryos as well as therapeutic cloning concerns scientists' freedom to investigate human biology as well as patients' freedom to access regenerative medicine treatments that may be developed as a result of research with human embryonic stem cells. Since the early 2000s, research with stem cells and embryos has been at the center of an often-polarized debate about the nature and scope of scientific freedom. The advent of gene editing techniques puts restrictions on research with embryos at the forefront of policy again as many countries impose substantial restrictions to editing human germ line cells and embryos for clinical use. This is unfortunate because being able to genetically change stem cells offers an extraordinary tool to advance both basic research and therapy. Genetically modifying stem cells opens up new opportunities for researchers to discover the role of genes and the ways in which they may be involved in human development or the development of disease as well as to model diseases in the lab. It also present therapeutic opportunities if the genes causing disease in patients are repaired. Gene editing also opens new opportunities for research with embryos. For instance, further research may demonstrate the feasibility gene correction in embryos of high-risk parents carrying an inheritable genetic disease (such as Huntington's Disease) thus preventing the disease mutation from being passed down to the at-risk parent's future children. The SDI is a useful guide in navigating this filed.

Indicators:

1 Is the use of human pre-embryos for experimental purposes an acceptable procedure? If not, can imported stem cells be used?
2 Is derivation of new hESC lines from supernumerary IVF embryos lawful?
3 Is derivation of new hESC lines from somatic cell nuclear transfer (SCNT) lawful?
4 Is derivation of new hESC from somatic cell nuclear transfer (SCNT) using non-human animal eggs lawful?



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Website: **www.freedomofresearch.org**