

# RESEARCH AND SELF DETERMINATION INDEX (SDI)

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**June 30, 2017, 11am-1pm**  
**Conference Room XXVII**  
**Palais des Nations**

## What is it?

The Index is a **tool for comparative assessment** of the degree to which the right to science is realized around the globe

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## **Background (1)**

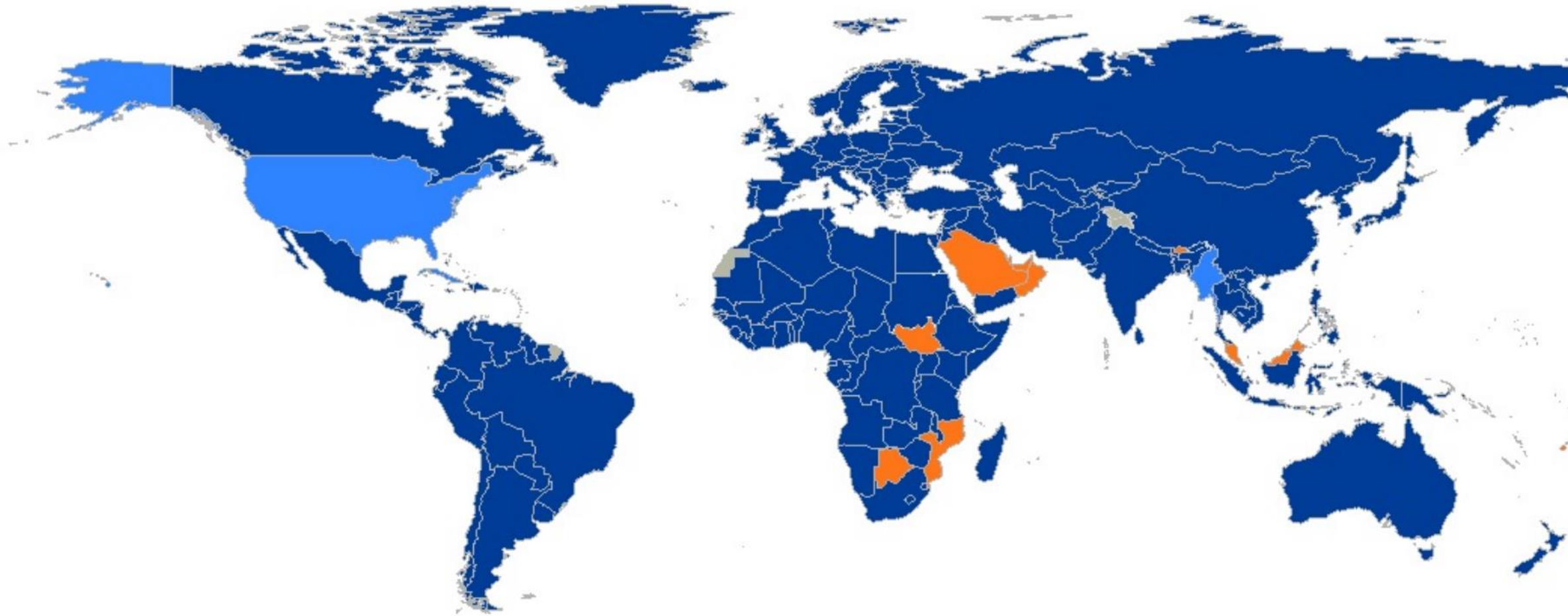
Science as a human right under international law (right to “enjoy the benefits of scientific progress and its applications” under Article 15 of the ICESCR)



UNITED NATIONS  
**HUMAN RIGHTS**  
OFFICE OF THE HIGH COMMISSIONER

## International Covenant on Economic, Social and Cultural Rights

Last Updated: 24 Mar 2017



Country Status

 State Party (165)  Signatory (5)  No Action (27)

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Science as a human right under international law (right to “enjoy the benefits of scientific progress and its applications” under Article 15 of the ICESCR)

Central role that member **states** play in the realization of human rights

Progressive realization : the human right to science is

- yet to be fully realized
- not equally realized around the globe (resources)

**Domestic laws** constrain (in some cases these are unnecessary obstacles) to researchers, health care professionals and patients

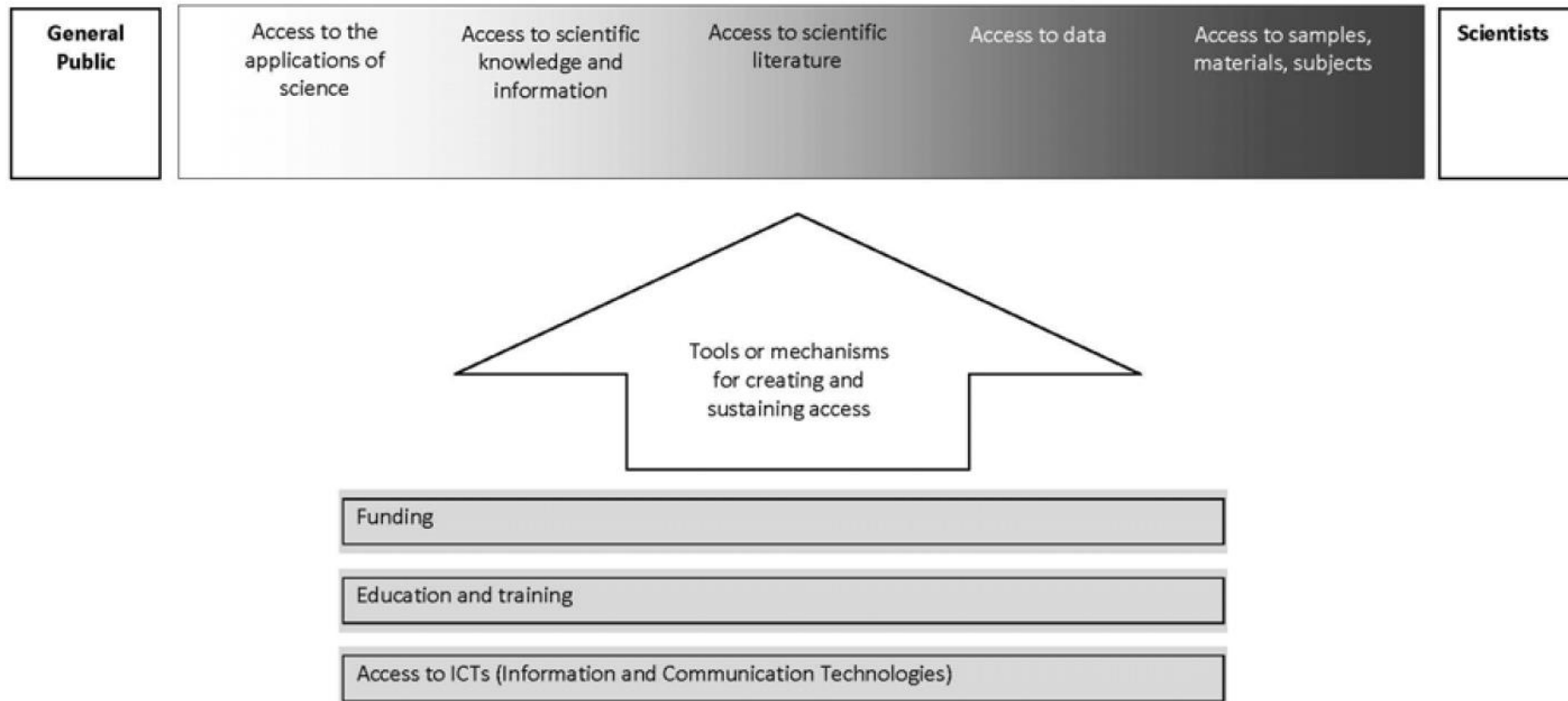
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## **Background (2)**

The right to science as continuum

**Diagram 1: Continuum of Access**



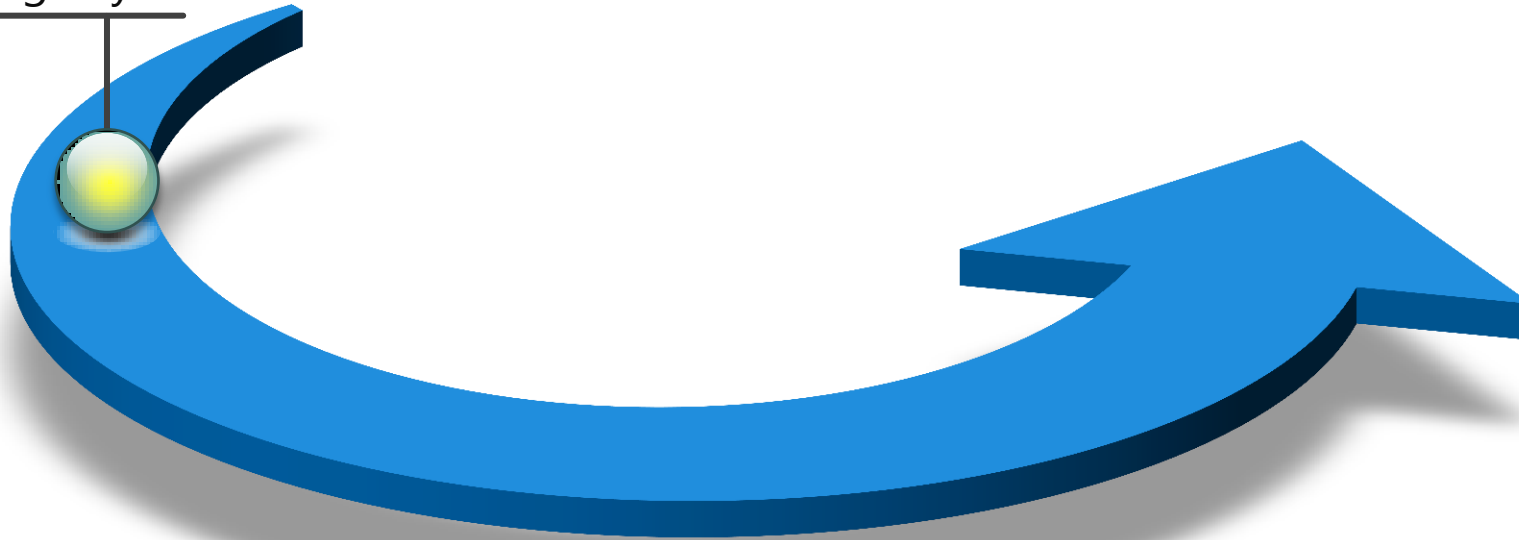
AAAS Science and Human Rights Coalition Defining the Right to Enjoy the Benefits of Scientific Progress and Its Applications: American Scientists' Perspectives (AAAS, October 2013)

## Four areas

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

## Methodology – a five-step process

1. Identifying key areas



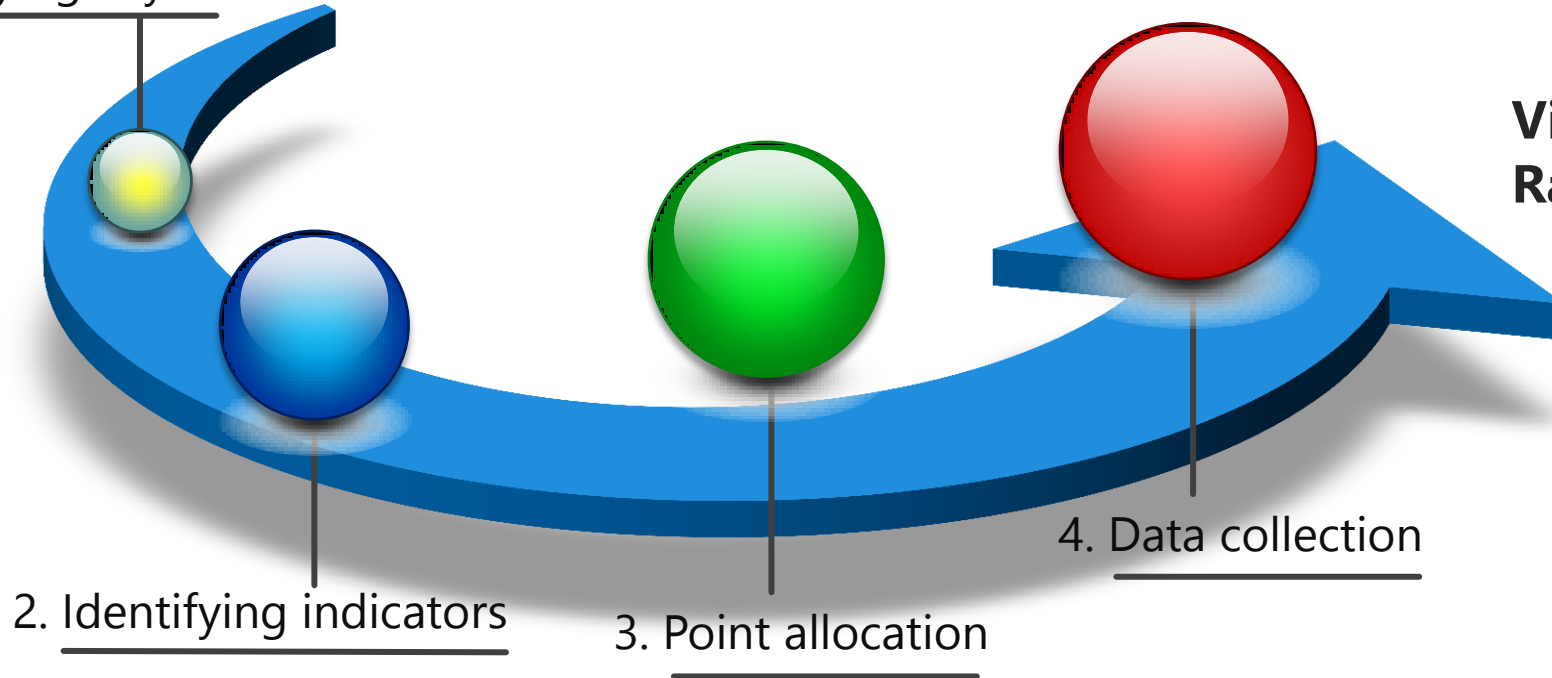


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**2009** Concept and pilot study presented at the Second World Congress for Freedom of Scientific Research

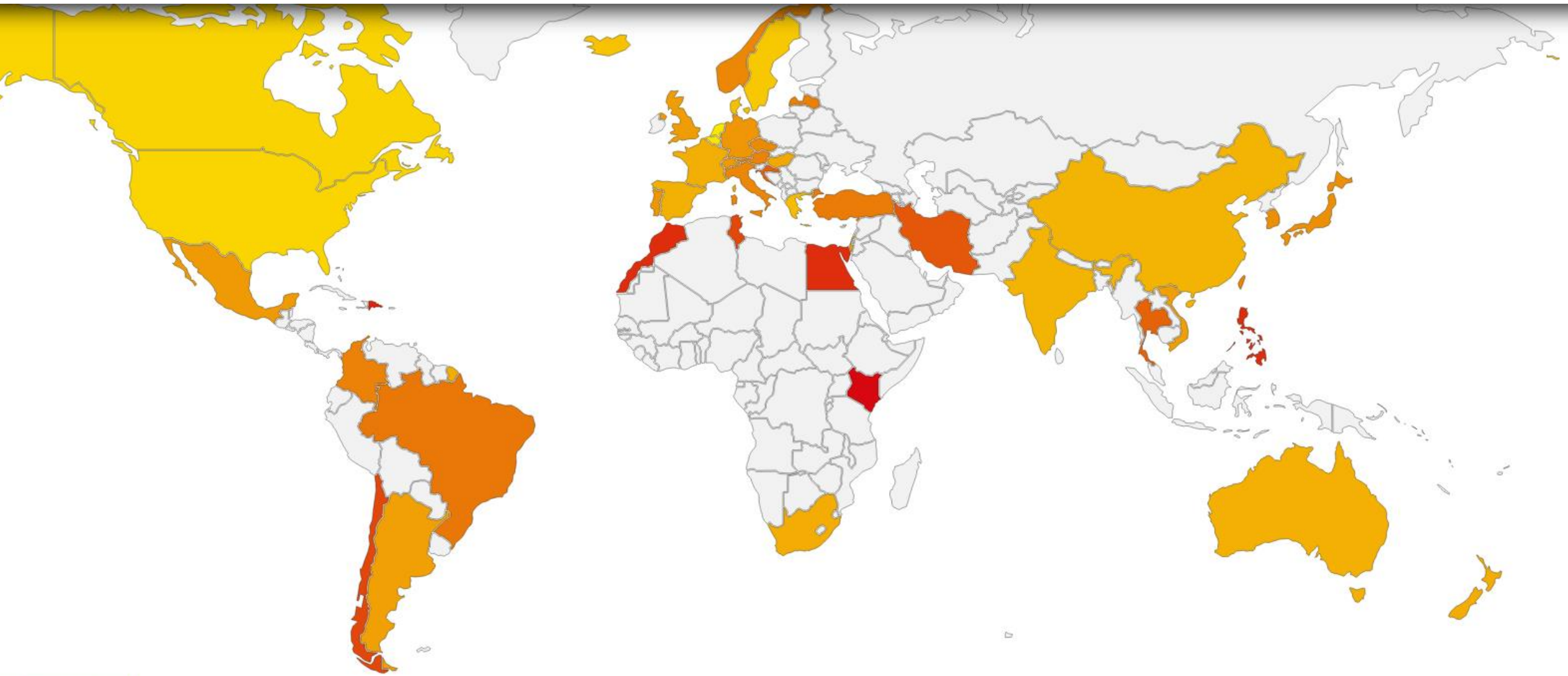
**2014** SDI is launched  
Website goes live with data collected for 42 countries

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

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

## Index v1.0

- Open data system
- Overall ranking of 46 countries
- Analyses and ranking for each of the four areas
- Updates in 2014, 2016, and 2017
- 32 comprehensive country reports discussing current issues in the 4 areas of policy
- Country-specific news published with regularity on [freedomofresearch.org](http://freedomofresearch.org) and on twitter [@Free2research](https://twitter.com/Free2research).



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**WORLD CONGRESS** *for freedom of scientific research*

## Score-changing developments (1)

### 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

## Score-changing developments (2)

### 2014

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### 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 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 is legalized in **Germany**

## Score-changing developments (3)

### 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**

## Score-changing developments (4)

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### 2017

- The **Dutch** Health Council has recommended that scientists 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



## Research with embryos and stem cells

### 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 lawful?
4. Is derivation of new hESC from somatic cell nuclear transfer using non-human animal eggs lawful?

# Research with embryos and stem cells

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## Open questions

What about human genome editing?

- Laws often impose substantial restrictions to editing human germ line cells and manipulating embryos for clinical use (14-day rule)
- Laws are silent on other aspects of genome editing
- Uncertainty over whether already existing bans on genome editing in embryos and germ cells for clinical purposes (e.g. to induce a pregnancy) also encompass a prohibition to conduct research, including reproductive research

## Towards the Index v2.0

### **Adding policy issues involving the right to science**

- Human genome editing
- Animal genome editing
- Plant genome editing
- GMOs
- Research on controlled substances
- Public funding of research

## Towards the Index v2.0

### GMOs

#### Research

- Prior authorization required
- No authorization required
- Research prohibited

#### Production/Cultivation

- Prior authorization required
- No authorization required
- Prohibited

#### Commercialization (distribution/marketing)

- Prior authorization required
- No authorization required
- Prohibited

#### Release into the environment

- No restrictions
- Restrictions
- Mandatory technical requirements to limit the potential release of GMOs into non-GMO fields
- Prohibition

#### Information and transparency measures

- Required
- Not required

#### Import/foreign companies operations

- Free access to markets
- Restricted access to markets
- No access to markets

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## Funding

- Associazione Luca Coscioni
- Union of Methodist and Waldensian Churches

## Contacts

[www.freedomofresearch.org](http://www.freedomofresearch.org)



Free2Research



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