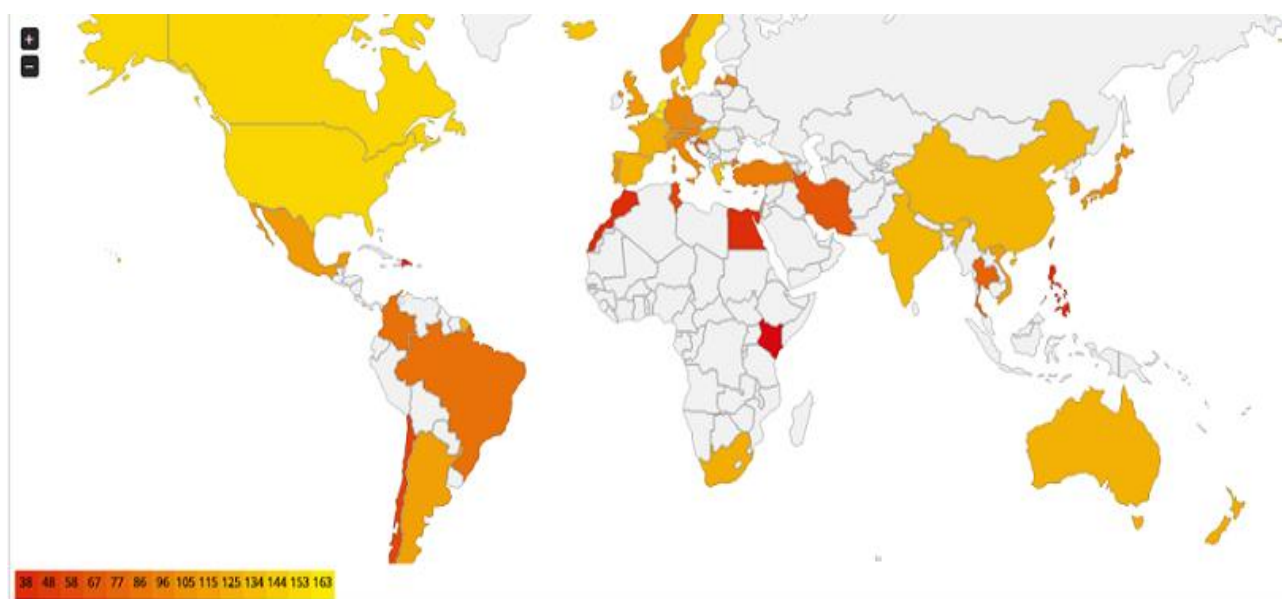


## *Research and Self Determination Index*

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. Their freedom to translate these aspirations in actual results is contained by the regulatory environments in which researchers, health care professionals and patients live. Regulatory environments differ from nation to nation: some support freedom of researchers, health care professionals and patients; some limit it. Aiming to raise awareness of such differences and to foster an evidence-based dialogue between policymakers, patients, the medical community and society, we created the Research and Self Determination Index as a tool for comparative assessment of the degree of freedom that researchers, health care professionals and patients enjoy around the globe. Researching and measuring "freedom" is an important task as it allows understanding the context in which science and medicine advance so that we can further expand freedom.



## Approach:

To truly advance freedom of research and treatment, we must learn how to measure it comprehensively and rigorously. In this spirit we build a multi-dimension grid of issues and sub-issues that enabled us to clarify and operationalized freedom in particularly contested areas of policy.

## Measurement questions:

### Monitoring and measuring freedom

Thinking about freedom as a matter of degree facilitates measurement. Actions are thus “free” on a scale from absolute prohibition to complete absence of constraints. Since law and other regulatory instruments constitute key sources of constraints in modern societies, we can monitor and measure freedom by reviewing the regulatory environment in which researchers, health care professionals and patients do research, provide health care, and seek treatment. This review allows us determine the degree to which we can say that actors are “free” to pursue the aspirations to expanding medical knowledge, foster patients’ well being and choose the best treatment.

### Methodology

We adopted a multi-step methodology that is inspired by other efforts to build indexes and ranking in other domains of social life (human development, freedom of press, social progress, happiness, corruption, and economic freedoms).

### Identification key areas of medical research and treatment that raise important questions of freedom

Four areas that raise important questions of freedom, and thus can lead to key insights as to the degree of freedom that researchers, health care professionals and patients enjoy, were selected. These four areas are:

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

### Operationalization of the meaning of “freedom” in each of these key areas

To operationalize ‘freedom’ in each of the four areas of medical research and treatment, key regulatory conditions that constrain actors to some degree were identified. Furthermore, a list of questions was prepared for each of the areas. These questions capture the nature of these conditions and the degree to which the regulatory framework limits actors’ freedom to pursue the proper goal of each area of inquiry

## Measurement

Points (from 0 to 12) are assigned for each answer of each question. The highest score is allotted to the regulation that recognizes the highest degree of freedom. Progressively lower scores are assigned to less free environments, that is, regulatory environments that limit freedom moderately, severely, or entirely. The score 0 was assigned to blank prohibitions. If data are not available, the answer is not included in the calculation. For each country, we report the level of completion of data collection.

## Data collection

To assign the points, each question needed to be answered. To this end, data were collected from various sources including primary sources (statutes and other regulatory documents) and secondary sources (scientific papers and policy reports). As of March 2014, we have completed data collection for 42 countries.

## Ranking

Points were then added to a total. The result quantifies the degree of freedom that key actors enjoy while acting in each of the areas of medical research and treatment selected. The points of each area were then added and their total represents the score of each country. Countries were then ranked based on the overall score.

## Data sources:

### Literature

- Ian Carter, “Positive and Negative Liberty”, The Stanford Encyclopedia of Philosophy (Winter 2003 Edition), Edward N. Zalta (ed.), <http://plato.stanford.edu/entries/liberty-positive-negative/>
- Gerald MacCallum, “Negative and Positive Freedom”, Philosophical Review, Vol. 76 (1967), pp.312-34

### Selected Indexes (Organization, Source):

- Human Development, UNDP, <http://hdr.undp.org/en/countries>
- Your Better Life Index, OECD, [www.oecdbetterlifeindex.org/](http://www.oecdbetterlifeindex.org/)
- Freedom in the World , Freedom House, <http://freedomhouse.org/reports#.UxUIoVeZixI>
- Press Freedom, Reporters without Borders, <http://en.rsf.org/press-freedom-index-2013,1054.html>
- Economic Freedom, Heritage Foundation, <http://www.heritage.org/index/ranking>
- Happy planet, New Economics Foundation (NEF) , <http://www.happyplanetindex.org/>
- Social Progress, MIT, <http://www.socialprogressimperative.org/data/spi>
- Corruption Perceptions, Transparency International, <http://cpi.transparency.org/cpi2013/>
- Open Markets Index, Int'l Chamber of Commerce, <http://www.iccwbo.org/Global-influence/G20/Reports-and-Products/Open-Markets-Index/>

<b>Rank</b>		<b>Total (out of 194)</b>	<b>POINTS ON 100 SCALE</b>
1	<b>Belgium</b>	163	95
2	<b>Netherlands</b>	159	94
3	<b>United States</b>	151	92
4	<b>Canada</b>	150	92
5	<b>Sweden</b>	143	90
6	<b>Iceland</b>	139	89
7	<b>Denmark</b>	137	88
8	<b>Greece</b>	135	88
10	<b>China</b>	129	86
10	<b>India</b>	129	86
11	<b>Spain</b>	127	86
12	<b>Australia</b>	126	86
14	<b>France</b>	125	85
14	<b>Singapore</b>	125	85
16	<b>New Zealand</b>	124	85
16	<b>South Africa</b>	124	85
17	<b>Hungary</b>	121	84
18	<b>Israel</b>	120	84
20	<b>Argentina</b>	115	83
20	<b>Vietnam</b>	115	83
21	<b>United Kingdom</b>	113	82
23	<b>Mexico</b>	112	82
23	<b>Switzerland</b>	112	82
24	<b>Portugal</b>	109	81
26	<b>Japan</b>	104	80
26	<b>South Korea</b>	104	80
27	<b>Czech Republic</b>	101	79
29	<b>Germany</b>	99	79
29	<b>Norway</b>	99	79
30	<b>Italy</b>	98	79
32	<b>Austria</b>	96	78
32	<b>Taiwan</b>	96	78
33	<b>Latvia</b>	94	78
34	<b>Turkey</b>	91	77
36	<b>Brazil</b>	83	75
36	<b>Colombia</b>	83	75
37	<b>Thailand</b>	74	73

<b>Rank</b>		<b>Total (out of 194)</b>	<b>POINTS ON 100 SCALE</b>
38	<b>Croatia</b>	72	72
39	<b>Iran</b>	66	71
40	<b>Tunisia</b>	56	68
41	<b>Chile</b>	55	68
44	<b>Egypt</b>	38	64
44	<b>Morocco</b>	38	64
44	<b>Philippines</b>	38	64
45	<b>Dominican Republic</b>	31	62
46	<b>Kenya</b>	12	57