SATORI

Ethics assessment and guidance in different types of organisations

Civil Society Organisations (CSOs)

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Annex 3.g
Ethical Assessment of Research and Innovation: A Comparative Analysis of Practices and Institutions in the EU and selected other countries
Deliverable 1.1

European Commission

Contents

1 Introduction

The aim of this report is to analyse and compare the way in which ethics assessment and ethical guidance of research and innovation is performed by Civil Society Organisations in the European Union, the United States and China. The report is based on online and offline documentation, previous published reports, and interviews with representatives of organisations in ten different countries and at the EU and global international level. Eight representative European countries have been singled out for in-depth study, including seven EU members and one candidate for EU membership: Austria, France, Germany, the Netherlands, Poland, Serbia (EU candidate country), Spain and the United Kingdom. The report describes how Civil Society Organisations are organised in these countries, in China, the US and, where relevant, at the EU and global levels. The situation in other EU member states and candidate countries will be considered as well. The report offers insights into the ways in which organisations of this type are institutionally embedded, how they perform ethics assessment and guidance and with what aims, and what are the perceived strengths and weaknesses of their participation in ethics assessment and guidance.

Ethics assessment, in the context of this report, is any kind of assessment, evaluation, review, appraisal or valuation of research or innovation that makes use of ethical principles and criteria. Ethical principles are criteria that aim to determine whether certain actions or developments are right or wrong. They define individual rights like rights to freedom and privacy, and include principles of justice and principles that say that harms to individuals and society should be avoided and benefits promoted. Ethical guidance is different from ethics assessment in that it does not concern an evaluation of practices and products of research and innovation that have already occurred, but rather presents rules, codes, and recommendations to which future scientific practices, innovation practices, and developments in science and technology are expected or recommended to adhere.

1.1 CSOs: definition

There is no one agreed definition of the term "Civil Society Organisation." It is often used interchangeably with the notion "Non-Governmental Organisation,"[1] which came into use in 1945, after the UN differentiated between participation rights for intergovernmental specialised agencies and rights for international private organisations in its Charter.

According to the European Commission's Communication of September 2012 "the EU considers CSOs to include non-State, not-for-profit structures, non-partisan and non-violent, through which people organise to pursue shared objectives and ideals, whether political, cultural, social or economic"[2] (emphasis added). Not-for-profit structures include membership based, cause-based and service oriented CSOs including community-based organisations, non-governmental organisations, foundations, research institutions, gender and Lesbian, Gay, Bisexual, Transgender (LGBT) organisations, cooperatives, professional and business

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[1] Compare, for example, the nomenclature of the UN Department of Economic and Social Affairs, http://esango.un.org/civilsociety/login.do

[2] European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, COM(2012) 492 final, Brussels, 12.9.2012. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2012:0492:FIN:EN:PDF

associations, and the not-for-profit media. Trade unions and employers' organisations, the so-called social partners, constitute a specific category of CSOs.

Another commonly used definition of a CSO is that of the World Bank. According to the World Bank "civil society" covers a wide array of non-governmental and not-for-profit organisations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil Society Organisations (CSOs) therefore refer to a wide array of organisations: community groups, non-governmental organisations (NGOs), labour unions, indigenous groups, charitable organisations, faith-based organisations, professional associations, and foundations.[3]

EU-funded projects that focus on CSOs' involvement in research governance often coin their own working definitions, e.g. according to the Seventh Framework Programme (FP&) CONSIDER project "CSOs are organisations that are non-governmental, generally not-for-profit and that pursue a *common purpose for the public interest*" (emphasis added). The authors of this definition point out that its drawback is the contested meaning of "public interest".[4] However this is exactly where the issue of ethical principles and values that inspires the activities of a given CSO comes into play. According to the SATORI Basic Concepts document, CSOs are "non-governmental, non-industry organisations that represent the interest and will of citizens."[5]

2   CSOs: basic characteristics

According to Etzioni, the third sector refers to a societal sphere, which is located between the state and the market.[6] However, it is impossible to divide it into universal categories, because they are dependent on the institutional as well as the socio-cultural context of a particular country and will thus vary between regions.[7]

The Augur Project[8] proposes the following types of CSOs: religious, community based, philanthropic, expert groups and trade unions.[9] Additionally, it distinguishes two types of

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[3]World Bank, "Defining Civil Society".
http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/CSO/0,,contentMDK:20101499~menuPK:244752~pagePK:220503~piPK:220476~theSitePK:228717,00.html
[4] CONSIDER Civil Society Organisations in Designing Research and Governance, Policy Brief: Optimising Civil Society Participation in Research.
http://ec.europa.eu/research/science-society/document_library/pdf_06/optimising_civil_society_participation.pdf
[5] SATORI, "Basic Concepts", v. 2, p. 6.
[6] Etzioni, Amitai, "The Third Sector and Domestic Missions", *Public Administration Review*, Vol. 33, No. 4, August 1973, pp. 314-323.
[7] Central Statistical Office, *The third sector in Poland,* 2014. http://stat.gov.pl/obszary-tematyczne/gospodarka-spoleczna-wolontariat/gospodarka-spoleczna-trzeci-sektor/trzeci-sektor-w-polsce-stowarzyszenia-fundacje-spoleczne-podmioty-wyznaniowe-samorzad-zawodowy-i-gospodarczy-oraz-organisacje-pracodawcow-w-2012-r-,1,3.html
[8] http://www.augurproject.eu/
[9] AUGUR, *The Role and Structure of Civil Society Organisations in National and Global Governance. Evolution between now and 2030,* 2012.
http://www.augurproject.eu/IMG/pdf/cso_note_provisional_draft5_june_2012.pdf

hybrid organisations: business CSOs and government orientated CSOs. Religious organisations are those associated with moral standards of a given religion. These organisations do not necessarily promote moral standards or religion as their main objective (take the Red Cross as an example), but "[t]heir primary fields of intervention are education, health, emergency relief and basic assistance (food, clothing, shelter etc.)".[10]

The community based CSOs are local ones based on personal initiatives taken by individuals in the community.[11] Their fields of operation include social services (for example, child welfare and services for the elderly), civic and legal assistance, and culture and recreation.[12] The third type include the philanthropic CSOs, which "serve a cause without any religious affiliation and are based on values such as generosity and humanism".[13] Examples of this type of organisation are Amnesty International and Doctors without Borders. As far as expert CSOs are concerned, they are organisations which use their broad knowledge in a specific area to prepare technical reports, for instance Greenpeace. Trade unions are CSOs promoting the interests of the employees.

As for hybrid organisations, they are CSOs, which are linked with either the Government or particular firms. Government oriented NGOs are those controlled by national authorities (this type can by seen especially in developed Asian countries, in China in particular). The last type is the Business and Industry NGOs, which defend interests of specific firms.[14]

Another example of the subdivision of CSOs was proposed in SATORI's Work Package 1 and is based on their societal role. It includes the following categories: religious, environmental, civil liberties, consumer, developmental, animal rights, disease charity, patient/disabled rights organisations and labour unions.

The concept of civil society encompasses thus a wide range of organisations, including all non-market and non-state organisations and structures in which people organise to pursue shared objectives and ideals. These include NGOs, cooperatives, associations, grass-roots, not-for profits, foundations, think tanks, research institutes, faith-based initiatives, umbrella organisations networks, networks as well as less-formalised groups of activists. CSOs operate on different levels – local, national, regional and international. Until the early 1990s, most NGOs did not engage in transnational activities. However, the cooperation between local groups and their activism on global issues is viewed as the root and source of current NGO involvement in policy-making.[15] In general, the activities of CSOs are viewed as a form of societal engagement and an organised public voice. Their common feature is the fact that they pursue a value-oriented goal. Consequently, all CSO activities are potentially viewed as an expression of a set of values and a specific understanding of what constitutes public interest. The following chart represents the CSO workforce as a percentage of the economically active

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[10] Ibid.

[11] Lawry, Lynn, Guide *to Nongovernmental Organisations for the Military*, 2009.

[12] AUGUR, *The Role and Structure of Civil Society Organisations in National and Global Governance. Evolution between now and 2030,* 2012.
http://www.augurproject.eu/IMG/pdf/cso_note_provisional_draft5_june_2012.pdf

[13] Ibid.

[14] Ibid.

[15] GEST global ethics in science and technology, Ethics State of the Art: EU Debate. http://www.uclan.ac.uk/research/environment/projects/assets/cpe_gest_D1_1.pdf, p. 108

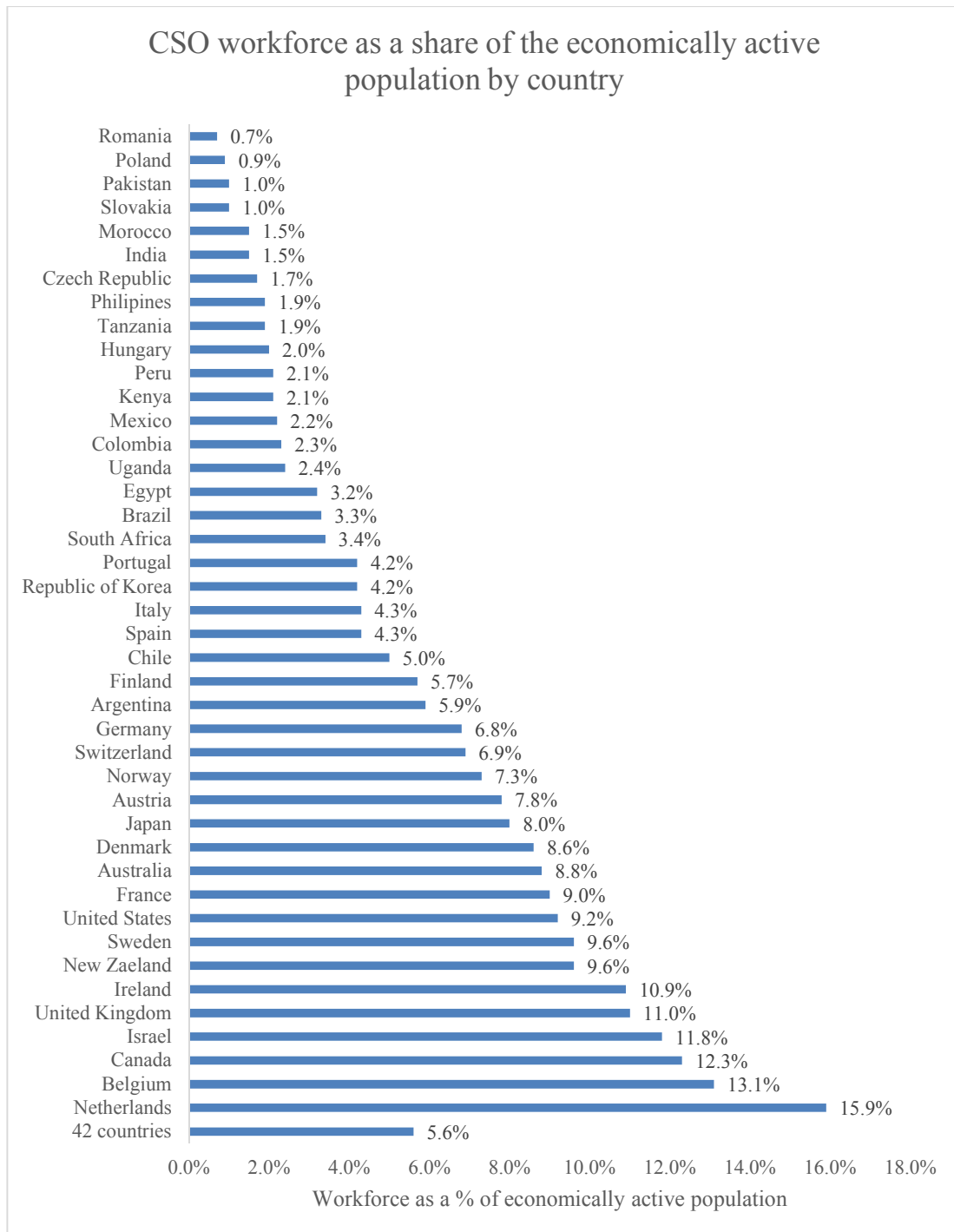population in 42 selected countries and the average percentage of all analysed countries (bottom line of the chart).[16]

CSO workforce as a share of the economically active population by country

Country	%
Romania	0.7%
Poland	0.9%
Pakistan	1.0%
Slovakia	1.0%
Morocco	1.5%
India	1.5%
Czech Republic	1.7%
Philipines	1.9%
Tanzania	1.9%
Hungary	2.0%
Peru	2.1%
Kenya	2.1%
Mexico	2.2%
Colombia	2.3%
Uganda	2.4%
Egypt	3.2%
Brazil	3.3%
South Africa	3.4%
Portugal	4.2%
Republic of Korea	4.2%
Italy	4.3%
Spain	4.3%
Chile	5.0%
Finland	5.7%
Argentina	5.9%
Germany	6.8%
Switzerland	6.9%
Norway	7.3%
Austria	7.8%
Japan	8.0%
Denmark	8.6%
Australia	8.8%
France	9.0%
United States	9.2%
Sweden	9.6%
New Zaeland	9.6%
Ireland	10.9%
United Kingdom	11.0%
Israel	11.8%
Canada	12.3%
Belgium	13.1%
Netherlands	15.9%
42 countries	5.6%

Workforce as a % of economically active population

Figure 1: CSO workforce as a share of the economically active population by country[17]

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[16] Salamon, Lester, and Wojciech Sokolowski, *Global Civil Society, 3rd edition*, 2010.

The institutional structure of CSOs varies considerably. As there is no single definition of a CSO, CSOs can function in different legal forms. Depending on the legal structure, different laws govern their operations. The following offers a brief description of CSOs operating in different regions. It is based on country reports prepared for the SATORI Work Package 1.

2.1.1   France[18]

In France, the establishment of associations is regulated by the "*Waldeck-Rousseau law*" dated 1884. Below are examples of CSOs:

- Religious organisations - Jérôme-Lejuene Foundation (supports research aimed at developing treatments for Down syndrome);
- Environmental organisations – France Nature Environment (organisation aimed at educating on environmental issues);[19]
- Civil liberties/human rights organisations – Amnesty International (French branch of the international organisation preventing abuse of human rights);
- Consumer organisations - Léo Lagrange pour la Défense des Consommateurs (provides consumers with information and legal aid);
- Animal rights organisations – National Council for Animal Protection (helps to address/change legislation with regard to animal protection);
- Disease charity and patient/disabled rights organisations – Association of Patients (provide for moral, legal and financial support for patients);

2.1.2   Germany[20]

The main legal documents regarding CSOs are the Constitution (*Grudgesetz*), German Federal Civil Code (*Bürgerliches Gesetzbuch) and the Law on Associations (Vereinsgesetz). These are the most important examples of CSOs in Germany:*

- Religious organisations – Protestant Church;
- Environmental organisations – Naturschutzbund Deutschland (one of the biggest German organisations dealing with environment protection)
- Civil liberties/human rights organisations – European Centre for Constitutional and Human Rights (organisation engaged in strategic litigation);
- Development organisations – Association of German development non-governmental organisations (association of 120 NGOs working in the fields of advocacy, development education, emergency assistance and development cooperation);
- Animal rights organisations – German Animal Welfare Organisation (association of German animal rights organisations)
- Labour unions – *Deutsche Gewerkschaftsbund* (the biggest German trade union);

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[17] Ibid.
[18] SATORI, France Country Report", D1.1, June 2015.
[19] http://www.fne.asso.fr/fr/nos-missions/plaidoyer/
[20] SATORI, Germany Country Report", D1.1, June 2015.

2.1.3 Netherlands[21]

The following regulations are of particular importance for the CSOs in the Netherlands: Medefinancieringsstelstel II and Mensenrechtenfonds, which specify subsidies granting. The following are examples of CSOs operating in Netherlands:

- Religious organisations – Roman Catholic Church;
- Environmental organisations – Wadden Association (organisation aimed at protecting the Wadden Sea region);
- Civil liberties/human rights organisations – the Dutch Council for Refugees (defends the rights of refugees);
- Consumer organisations – Consumer Association (organisation defending the rights of Dutch consumers);
- Development organisations – Max Havelaar Foundation (licenses the use of the Faitrade Certification Mark)
- Animal rights organisations – the Dutch Society for the Replacement of Animal Testing (works towards stopping the animal experimentations)
- Disease charity and patient/disabled rights organisations – the Federation of Patients and Consumer Organisations in the Netherlands (association of organisations defending patients' rights);
- Labour unions – the Federation Dutch Labour Movement (federation of Dutch trade unions).

2.1.4 United Kingdom[22]

In the United Kingdom, the following bodies are of particular importance with regard to CSOs: Minister for Civil Society, the Commission on Civil Society and Democratic Engagement and the Independent Commission for Aid Impact. The major CSOs in the UK are as follows:

- Religious organisations – the Church of England;
- Environmental organisations – GeneWatch UK ("*a not-for profit-group that monitors developments in genetic technologies from a public interest, human rights, environmental protection and animal welfare protection*");[23]
- Civil liberties/human rights organisations – StateWatch UK (its aim is to monitor civil liberties in Europe);
- Animal rights organisations – Gene Watch UK
- Disease charity and patient/disabled rights organisations – Cancer Research UK (its aim is to eradicate cancer through research);[24]

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[21] SATORI, "Netherlands Country Report", D1.1, June 2015.
[22] SATORI, "UK Country Report", D1.1, June 2015.
[23] Please compare: http://www.genewatch.org/
[24] http://www.cancerresearchuk.org/our-research/our-research-by-cancer-type

2.1.5 Spain[25]

The activities of CSOs are regulated by the Law on Associations. These are the most important examples of Spanish CSOs:

- Religious organisations – Spanish Episcopal Conference;
- Environmental and animal rights organisations – Ecologists in Action;
- Civil liberties/human rights organisations – Spanish Romani Union (deals with the integration of the Gypsy community);
- Consumer organisations – Consumers in Action;
- Development organisations – Help in Action (organisation aimed at improving the living conditions of children, their families and communities);
- Labour unions – General Workers' Union.

2.1.6 Austria[26]

The most important provisions concerning CSOs are laid down in the Act on the Associations (*Vereinsgesetz*). The following are examples of organisations operating in Austria:

- Religious organisations – Catholic Church;
- Environmental organisations – Greenpeace (Austrian branch of the international organisation dealing with environmental protection);
- Civil liberties/human rights organisations – Amnesty International Austria (Austrian branch of the organisation preventing abuse of human rights);
- Consumer organisations – Austrian Consumer Protection Association (focuses on providing information regarding consumer protection);[27]
- Animal rights organisations – WWF Austria (Austrian branch of international organisation protecting the environment from degradation);
- Disease charity and patient/disabled rights organisations - Lebenshilfe Österreich (the largest organisation protecting the interests of the intellectually disabled in Austria);[28]

2.1.7 Poland[29]

National legislation relating specifically to CSOs in Poland includes the following:

- The act on public benefit activity and volunteerism of April 24, 2003. The law contains the legal definition of a non-governmental organisation, which states that non-governmental organisations are corporate and non-corporate entities, which according to separate legal provisions have the capacity to perform acts in law, such as foundations and associations, but neither form part of the public finance sector as defined in the Act on Public Finance nor operate for profit;
- The act on foundations of 6 April 1984;

[25] SATORI, "Spain Country Report", D1.1, June 2015.
[26] SATORI, "Austria Country Report", D1.1, June 2015.
[27] http://www.konsumenten-schutz.at/
[28] http://www.lebenshilfe.at/index.php?/de/Ueber-uns
[29] SATORI, "Poland Country Report", D1.1, June 2015.

- The law on associations of 7 April 1989.

The most important CSOs in Poland include:

- Religious organisations – the Roman Catholic Church;
- Environmental organisations – the Polish Climate Coalition (an association of 23 organisations dealing with climate protection);
- Civil liberties/human rights organisations – Helsinki Foundation for Human Rights (organisation promoting development of culture based on freedom and human rights both in Poland and abroad);
- Consumer organisations – the Federation of Consumers (focuses on consumer protection and provision of legal aid);
- Development organisations – Foundation for Small and Medium Sized Enterprises (a foundation aimed at promoting small and medium sized enterprises both in Poland and abroad);
- Animal rights organisations – Gaja Club (organisation aimed at raising the awareness of the public with regard to protection of animals and the environment);
- Disease charity and patient/disabled rights organisations – Polish Society for the Visually Impaired (protects the rights of visually impaired people);
- Trade unions – the Independent and Self-Governing Trade Union Solidarność (organisation aimed at defending the rights and dignity of the employees).

2.1.8   Serbia[30]

CSOs' activities are mostly stipulated in the Law on Association. Other relevant legal documents include: Law on churches and religious organisations, Law on political parties and Law on volunteering. The major Serbian CSOs are as follows:

- Religious organisations – Serbian Orthodox Church
- Environmental organisations – the Ecological society "ENDEMIT" (provides advocacy with regard to sustainable development);
- Civil liberties/human rights organisations – Equal Opportunities (aims to facilitate equal access for men and women to Info-Communication Technology);
- Consumer organisations – the National Organisation of Consumers in Serbia (association of 26 consumer organisations);
- Animal rights organisations – ORCA (oldest Serbian animal rights protection organisation);
- Disease charity and patient/disabled rights organisations – the National Organisation for Rear Diseases (association of organisation with the objective of helping patients with rare diseases);

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[30] SATORI, "Serbia Country Report", D1.1, June 2015.

2.1.9 United States[31]

The regulation concerning CSOs varies between different States. These are the most important examples of CSOs in USA:

- Religious organisations – the Catholic Church;
- Environmental organisations – WWF United States;
- Civil liberties/human rights organisations – American Association for the Advancement of Science (defends individual rights and liberties guaranteed by the Constitution);
- Consumer organisations – Consumer Federation of America (focuses on the advancement of consumer interests);
- Development organisations – Food for the Poor (organisation helping the poor in the Caribbean and Latin America);[32]
- Animal rights organisations – the Humane Society of the United States (the largest animal rights organisation in USA);
- Disease charity and patient/disabled rights organisations – American Cancer Society (it focuses on eradicating cancer);

2.1.10 China[33]

In China the most-well developed CSOs are often controlled or supported by the government. In other words, they are an example of hybrid organisations (discussed above). The relevant national regulation regarding CSO include Interim Regulations on Registration Administration of Private Non-enterprise Unites, Regulation on Foundation Administration and Regulation on Registration and Administration of Social Organisations. Below you can find some examples of CSOs operating in China:

- Environmental organisations – International Fund for China's Environment (Chinese branch of an international organisation focusing on ensuring healthy environment);
- Civil liberties/human rights organisations – The Cultural Development Centre for Rural Women (focuses on promoting the development of rural women);
- Development organisations – Non-Profit Incubator (an association of organisations supporting the third sector in China);
- Animal rights organisations – Beijing Human and Animal Environmental Education Centre (organisation focusing on protection of pets);
- Disease charity and patient/disabled rights organisations – The Cancer Foundation of China (dedicated to cancer control in China);
- Trade unions – the Little Bird Hotline (organisation providing legal aid for migrant workers).

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[31] SATORI, "USA Country Report", D1.1, June 2015.
[32] http://www.foodforthepoor.org/about/
[33] SATORI, "China Country Report", D1.1, June 2015.

Research carried out for SATORI confirmed that in the 10 analysed countries CSOs are active in spheres either directly or indirectly linked with ethical issues related to R&I. These spheres, or aspects of social life, include: religion, health, environment, human rights, consumer protection, animal rights, or development.

CSO represent thus interests of different groups of people (vulnerable groups, particularly patients, but also consumers, women, children), as well as act to protect the well being of animals or the state of the environment. In this sense, they may represent and give voice to those, whose interests may be missing or overlooked in reaching decisions concerning research, e.g. in setting research agendas or assessing concrete projects.

3   Ethics Assessment by Civil Society Organisations

Although activities carried out by CSOs are rarely termed as ethics assessment, many CSOs perform (informal) ethics assessment or guidance in the course of their activities, e.g. advocacy work.

The following chart illustrates the practices of CSOs interviewed for the purpose of SATORI. These organisations either directly or indirectly do ethics assessment or guidance.

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
Forschungswende	Germany	Policy oriented ethical guidance	According to Forschungwende, there should be broader stakeholder involvement in research and innovation agenda setting and budget planning. The process of research agendas' setting should be more transparent.
INKOTA	Germany	Informal policy oriented ethics assessment, followed by recommendations	INKOTA does not directly engage in ethics assessment. At the same time, when it publishes position papers on certain technological innovations (e.g. biofuels) or issues lobbying letters concerning some new laws, the paper or the letter consist of elements of ethical assessment of the innovation. INKOTA seeks to find the real sources of a given problem and often proposes solutions alternative to technology.
Royal Dutch Society of	The	Ethical guidance for professional	KIVI facilitates discussion on ethical issues among its members. KIVI also promotes ethical

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
Engineers (KIVI)	Netherlands	conduct by engineers	behaviour among its members. It brings together engineers from a wide variety of disciplines and professional roles to support them in their work. KIVI offers guidance and a platform for exchange. It has authored a Code of conduct for their members.
Federation of Patients and Consumers Organisations (NPCF)	The Netherlands	Ethical assessment of projects	NCPF was involved in assessing research grant applications for medicines (of ZonMw/NWO), to bring in the experience and perspective of patients
The Citizens of Academia	Poland	Ethical guidance for professional conduct by scientists	Initially, CA concentrated on issues related to scientific integrity. One of the main goals of CA is to ensure high quality of research. The interest in ethics is a result of that focus. CA understands ethics of research and innovation broadly -this understanding also covers issues related to the mission of the scientist. It includes the belief that scientists should contribute to ensuring a better future for society.
Polish Ethics Society	Poland	Informal policy oriented ethics assessment and ethical guidance	The mission of the Society consists of, among others, disseminating knowledge of and promoting research in ethics, raising awareness about ethical issues, initiating public debate on ethical and moral dilemmas. Representatives of the section of animal welfare assess draft laws on animal experimentation.
Panoptykon Foundation	Poland	Informal policy oriented ethics	The Foundation does not consider its work to be "ethics assessment", however assessment of the ways in which the implementation of a given

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
		assessment	technology may affect the rights of an individual is an element of many of its activities.
Equal Opportunities	Serbia	Informal policy oriented ethics assessment	The organisation does not directly engage in ethics assessment. It does, however, address several ethical questions implicitly in its activities related to the societal role of ICT and its use and gender equality. EO is especially interested in social implications of innovation: who has access to it, what stereotypes are linked with it, for what purposes is it used by different groups, etc.
Consumers in Action	Spain	Informal policy oriented ethics assessment	Consumers in Action analyse the behaviour of companies, not only if they violate the law, but also with regard to whether their practices respond to ethical principles. Ethics is closely linked to legal practice in the market, business relationships, health services, etc.
Genetic Alliance UK	UK	Informal policy oriented ethics assessment	Consideration of ethical issues is a part of the organisation's policy work; advocating research that would benefit patients: voicing patients' stake in ethics assessment process.
American Association for the Advancement of Science (AAAS)	US	Policy oriented ethical guidance Ethical guidance for professional conduct by scientists Ethics assessment (e.g. stem cell research)	The *Scientific Responsibility, Human Rights and Law Program* (SRHRLP) is part of the Center for Science, Policy and Society Programs under AAAS. The program "*addresses ethical, legal and human rights issues related to the conduct and application of science and technology.[34]*" Some of the reports by SRHRLP are aimed as policy or legal recommendations, while some reports reflect an attempt to educate and explain issues to. SRHRLP has further assisted the Government in developing new regulations.

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[34] http://www.aaas.org/page/srhrl-about

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
PRIM&R	US	Ethical guidance for projects and practices Policy oriented ethics assessment (by the Public Policy Committee)	Advancing highest standards by providing education to people who oversee research on human subjects and animals. PRIM&R engages in ethics guidance by providing and organising courses related to ethical conduct of biomedical, social science and behavioral research. They comment on particular policies
COHRED	International	Informal ethical guidance	"COHRED, the Council on Health Research for Development, is a global, non-profit organisation whose singular goal is to maximise the potential of research and innovation(R&I) to deliver sustainable solutions to the health and development problems of people living in low and middle-income countries. Its Mission is: To provide leadership and effective solutions to support low and middle income countries to build their own research and innovation systems for health and development."
SciDev.Net	UK (international activities)	Informal ethics assessment	SciDev does not do ethical assessment as such but it could be said many of their stories are ethics assessments of R&I implicitly. The organisation is not likely to use the word "ethics". SciDev.net is committed to bringing scientific evidence and technological innovation to development policy and practice.
Greenpeace	International	Informal policy oriented ethics assessment	Greenpeace assesses innovation in terms of its environmental impact and risk. The organisation also depends on science and technology to provide solutions to environmental threats. Greenpeace assess technologies in relation to issues relating to environment protection, quality of life and care for health.
EURORDIS	EU level	Informal policy oriented ethical	EURORDIS seeks to improve the quality of life of people living with rare diseases in Europe

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
		guidance (They've assessed the new clinical trials legislation)	through advocacy at the European level, support for research and medicines development. EURORDIS also guides patient organisations that are interested in research projects.
Regional Environmental Centre	European (Hungary)	Informal ethical guidance	The REC as an independent, non-partisan, non-advocacy, not-for-profit body of international character that designs and implements programs to fulfil its mission. REC follows the progress of global environmental problems, among others; regularly assesses strategic environmental needs in Central and Eastern Europe and strives to identify solutions; promote public participation in environmental decision making; support cooperation between government, academic and nongovernmental organisations and members of the business community; gather and distribute environmental data for the countries in the region as well as for the region as a whole; offer opportunities for mutual exchange of experiences for interested countries, organisations and individuals.
Amnesty International	EU level (UK)	Ethical guidance for research projects on human rights	AI is not directly engaged in ethics assessment. In dealing with cases of human rights abuses, especially when selecting individual cases for campaign purposes, AI have very strict protocol how to use those data. The right to dignity, informed consent, privacy, and other human rights are guaranteed in their research techniques. They also expect other organisations to respect human dignity, right to privacy, informed consent and so on, when conducting research on human subjects

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
International Women's Forum in Science and Business	International	Informal policy oriented ethics assessment Ethical guidance in terms of promoting equality and involvement of women in research	IWF is engaged indirectly in ethics assessment, through investigating or commenting on gender related issues. IWF is not primarily oriented towards R&I, but is currently a partner in a project about gender innovation and sustainable development in the Baltic Sea region. They analyse the innovation process, the involvement of women in research area and the distribution of resources and general assessment of this process. In this project IWF does not address ethical issues in particular but they will touch upon issues like distribution of opportunities and resources in a process of innovation.
European consumer voice in standardisation (ANEC)	EU-level	Informal policy oriented ethical guidance	ANEC defends consumers' interests in the development of standards. It has principles according to which it operates. ANEC always works to achieve the highest level of consumer protection in standards possible. Without effective consumer representation in the writing of standards, products will not be as safe, as interoperable, as accessible or as sustainable as they could be. ANEC's experience is that business tends to focus on the needs of the mainstream or "average" consumer - where costs are often lowest and profits highest - to the detriment of vulnerable consumers: those who are young, old or disabled. When standards are used for legislation or other public policy objectives, it is essential they take account of the needs of all consumers.
European civil society organisation	UK	Policy oriented ethics assessment	Ethical issues are examined as part of its investigative and critical research work. The organisation's work involves the examination of, for instance, new technologies,

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
			and effects of the development of new technologies. It looks at issues such as surveillance, privacy, data protection, border security, right to claim asylum.
Patient association « Vaincre les Maladies Lysosomales » (VML) "Defeat Lysosomal Diseases"	France	Ethical guidance for projects and practices	VLM is solicited to proofread information such as consent forms and to provide guidance in the recruitment of patients' process. VML analyses the content of information given to patients, the quality of this information and the way in which this information is provided.
EUSJA (European Union of Science Journalists Association)	EU	Informal ethics assessment	The interest in ethics is driven by the need for a code of conduct for science journalists and by the focus on the social role of journalists. It takes the form of public comment and discussion, particularly of emerging science.
EFSJ (European Federation for Science Journalism)	EU	Informal ethics assessment and guidance	They have a strong focus on ethics. Their aim is not only to build a professional code of conduct but also to foster the reflection about the role of science journalists in shaping the public perception of controversial topics and innovations They are also interested in investigative journalism and in building a professional ethical framework for science journalists that will merge some values from general journalism and some values from science.
EANL (European Association for Neuroscience and	EU-Italy	Informal ethics assessment	A scientific association devoted to the development of the dialogue between law and neuroscience. It groups lawyers, judges, neuroscientists, philosophers and ethicists. Its

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
Law)			aim is to develop a common framework and language that will help the law when it has to deal with neuroscientific evidences in courts and in writing the new norms and laws. Many members of the scientific association take part in ethical committees because of their expertise in the field.
BEUC- Altroconsumo	EU-Italy	CSR assessment	They do not define themselves as ethical assessors but in fact they have a division devoted to the evaluation of the "ethicity" of the industries. They noticed in recent years that the public is asking more and more about the way products are produced, so they had to move from their previous approach (that was based essentially on the evaluation of the cost-effectiveness of a product) to a more general evaluation that takes into account also the ethical aspects (working conditions, environmental and social impact and so on). All the national associations that are part of BEUC share the same general guideline to evaluate corporate social responsibility and industry impact.
CEC (Conference of European Churches)	EU	Ethical assessment and guidance	They consider ethics to be at the core of their mission and entrenched in all their activities. There are however some units dealing with fields directly related to R+I, such as bioethics, environmental issues and economic and human rights. While acknowledging the freedom of research, they consider it to be inextricably linked to their consequences and how those are handled. So social, environmental and ethical consequences of research are considered of utmost importance, and a great emphasis is thus placed in the dialogue and ethical deliberation between politics, science, ethics and religion.
Israel Medical Association Worlds Fellowship	International	Religious oriented ethics assessment	They are very active in the field of bioethics, trying to apply the principles of the Jewish religion to a modern approach to medicine and

Name of the CSO	Country (region)	Classification of the practice (Classifications have been decided upon within the project and not by the respondents themselves)	Excerpt from the interview table/summary to support the choice of the kind of practice
(IMA-WF)			ethics. It has a special commission devoted to the study of bioethical controversies and they publish guidelines both for the national members of the IMA and for the foreign members.
Green Choice Alliance (GCA)	China	National Civil Society Organisation	GCA uses market-based independent auditors to do the ethics assessment and the assessment involves the participation of NGOs.

Table 1: Practices of CSOs

When it comes to the CSOs' attitude towards the terms "ethics", few organisations explicitly use it. When they do, they do so in the context of referring to professional codes of conduct. However even in those cases, there are CSOs that decide to use the term "good practices", since some stakeholders perceive promoting ethics as "moralising" and the organisations wish to avoid that label.

Other NGOs describe their activities as "political action", "advice", "lobbing" which have the elements of ethical assessment or guidance. Ethical issues may also be an element of environmental impact and risk assessment.

The word "ethics" is explicitly used by organisations that represent or act on behalf of patients when referring to the work of ethics committees that oversee clinical trials.

Assessment by CSOs is carried out at different stages of the R&I process and focuses on various elements. The objects of assessment/guidance range from the conduct of scientists, professionals, or companies, to the involvement of particular groups in research and innovation and the impacts of particular technologies. In order to influence policy making on a larger scale, CSOs offer guidance in the course of setting research agendas. CSOs that conduct research make sure that it adheres to ethical standards.

The objects of assessment or guidance are numerous. The following were identified in the course of interviewing CSOs for the SATORI project:

- Research and innovation agendas
- Technological innovations, e.g. biofuels
- Scientific conduct of professionals
- Research grant applications for medicines
- Principles of research ethics, draft laws

- Technologies enabling health surveillance, phone surveillance, law enforcement, urban surveillance, internet surveillance, and video surveillance and legal acts that concern their use or implementation
- Societal role of ICT and its use, social implications of innovation, issues of access and use by different groups
- The conduct of companies
- Medical research
- Professional conduct, conduct of scientists, scientific freedom, scientists in the service of human rights, particular types of research e.g. stem cell research
- Guidance - biomedical, social sciences and behavioural research, assessment - particular policies
- Research and innovation that may deliver solutions for people in developing countries
- Societal impacts of R&I, ethics of journalistic practice
- Innovation in terms of its environmental impact and risk, quality of life and care for health
- Research and policy in rare diseases, clinical trial legislation
- Strategic environmental needs in Central and Eastern Europe
- Research projects in human rights
- The innovation process, the involvement of women in research area and the distribution of resources and general assessment of this process
- Research and innovation, in particular new technologies, and effects of the development of new technologies related to surveillance, privacy, data protection, border security, right to claim asylum
- Information given to patients, consent forms
- The process of developing standards
- Research in general, particularly emerging science
- Intersections of neuroscience and law
- Science in general, innovation and its impacts, professional conduct
- Corporate social responsibility, the impact of industry on society and environment
- Ethical issues related to bioethics (concerning the human body) and the environment
- Ethical issues related to medicine

For the majority of CSOs here, ethical reflection is perceived as a crosscutting issue. Thus assessment or guidance is closely related to the overall mission of the organisation which is value-based.

The following aims of assessment/guidance were identified by the interviewees:

- To influence agendas and budget plans to ensure compatibility with environmental goals, ethics, justice;
- Watchdog function and advocacy activities for fair rules for international trade and a sustainable agricultural policy in addition to accountability of international corporations

- To promote ethical behaviour among members of society (engineers), to promote the importance of technology in society;
- To introduce the experience and perspectives of patients in the process of ethical assessment, to ensure patient organisations speak with one voice;
- To ensure high quality of research and professional conduct;
- To influence the process of introducing new or amending existing laws so that they correspond with the standards of animal protection;
- To ensure that surveillance technologies do not violate rights and freedoms;
- To defend the rights of consumers, to demand improvements in market regulation and quality, labelling and advertising of products and services, to empower citizens, organise and inform them about the possible abuses of the market;
- To advocate for research that would benefit patients, to voice patients' stake in ethics assessment process;
- To promote responsible science, to increase public engagement with science and technology and to protect the integrity of science;
- To advance high standards by providing education to people who oversee research on human subjects and animals and by organising courses related to ethical conduct of biomedical, social sciences and behavioural research;
- To maximise the potential of R&I to deliver sustainable solutions for the health and development problems of people living in low and middle-income countries
- To ensure dialogue between research and global development practices;
- To make an assessment from the viewpoint of public interest and environment protection;
- To improve the quality of life of people living with rare diseases in Europe through advocacy at the European level, to provide support for research and medicines development, to facilitate networking amongst patient groups, raise awareness, and many other actions designed to reduce the impact of rare diseases on the lives of patients and family;
- To promote public participation in environmental decision making, to promote cooperation among governments, non-governmental organisations, businesses and other environmental stakeholders, and support the free exchange of information and public participation in environmental decision making, to gather and distribute environmental data for the countries in the region as well as for the region as a whole;
- To ensure dignity, informed consent, privacy, and other human rights in research;
- To promote gender equality with regard to building an innovative economy; to research, examine, investigate and critically analyse technologies and their application;
- To provide a service for civil society to encourage informed discussion and debate, (ethical issues are examined as part of investigative and critical work);
- to put the patient at the centre of ethical reflection, to ensure the quality of information given to patients and the way in which this information is given;
- To represent the European consumer interest in the creation of technical standards, especially those developed to support the implementation of European laws and

public policies, to defend consumers' interests in the development of standards, to ensure the highest level of consumer protection in standards;

- To promote a faith based - approach to research and innovation;
- To improve the skills of science journalists
- To improve the quality and scientific reliability of evidence brought into court

As regards beneficiaries, as the name suggests, CSO usually act on behalf of (civil) society in general. Some CSOs act on behalf of certain (vulnerable) groups (e.g. patients with rare diseases, women, consumers). The results of the assessment are often addressed to political decision makers.

The following beneficiaries and addressees of the assessments/guidance were identified in the course of the SATORI interviews with representatives of CSOs:

- Policy makers, governments
- Other CSOs/NGOs
- Private companies, individual businesses, industry
- Society in general/the public/civil society
- Indigenous people
- Engineers who are members of a CSO
- Patients with rare diseases
- Scientists, researchers
- Politicians, political decision makers
- Consumers
- Business schools, universities
- Media
- Scientific societies
- Institutional review boards, ethics committees, institutional animal care and use committees
- People living in low and middle-income countries
- European medicine agency
- Environmental stakeholders
- Victims of human rights abuses, vulnerable groups
- Women in science and business

The vast majority of CSOs undertake ethics assessment and/or guidance voluntarily out of a sense of responsibility.

In the case of some countries, the inclusion of representatives of patients is ensured in the assessment of clinical trials. In those cases, CSOs may facilitate the involvement of patients.

In most cases, recommendations provided by CSOs are not binding in nature.[35]

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[35] The role of CSOs in policy-making has been recognized, however, in environmental matters. The 1998 UNECE (UN Economic Commission for Europe) Convention on Access to Information, Public Participation in Decision-making and Access to Justice in Environmental Matters (the so-called Aarhus Convention),[35] to which the EU is party, established rights of the public, both individuals and associations, with regard to the

CSOs in general are not involved in formal assessment or guidance, and would not describe their activities in these terms. Moreover, they rarely use the word "ethics" and, in some cases, deliberately avoid it.

CSOs participate in assessment and guidance on a voluntary basis. These processes are not separate from other activities performed by the organisation, and since ethics is considered a cross cutting issue, the aims of informal assessment and/or guidance are closely related to the overall mission of the organisation. As regards the object of assessment, it can be a specific innovation and its application, the conduct of scientists or professionals, as well as decision-making processes. CSOs act as an interface between society and political decision makers, thus both of these groups should be considered the beneficiaries of their activities.

4   Institutional Setup of Ethics Assessment

There are rarely separate structures or divisions responsible solely for ethics tasks. The exceptions are those CSOs for which ethical guidance (even if not explicitly labelled as "ethical") is, in fact, the main mission of the organisation. In these cases, ethical guidance is performed by the CSO as a whole.

The following structures involved in (informal) assessment/guidance have been set up in the CSOs investigated for the SATORI project:

- An informal group that focuses on "good practices" (The Citizens of Academia)
- A specific program (Scientific Responsibility, Human Rights and Law Program - SRHRL) that "addresses ethical, legal and human rights issues related to the conduct and application of science and technology" - the work is done by a committee and in some cases by researchers. Two to three persons are involved in ethical assessments, with the same number of people covering legal assessments.
- A sub-group of the board that sits on the Public Policy Committee that comments on particular policies (PRIM&R);
- Greenpeace Science Unit that carries the main responsibility for environmental impact and risk assessment;
- Community advisory boards created to act as interlocutor between child participants in clinical trials, the investigator and the sponsor (EURORDIS);
- Specific units that deal with fields directly related to R&I, such as bioethics, environmental issues and economic and human rights (Conference of European Churches).

The majority of CSOs that engage in informal ethics assessment or guidance do not include a specialised division or formal structure that undertakes these activities.

The research conducted for SATORI indicated that ethical reflection comprises an element within other activities (research, advocacy, lobbying). Some CSOs that become involved in

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environment. It is perceived as a landmark of so-called environmental democracy, since it establishes not only the right to obtain information but also the rights to participate in decision-making - the public should be able to comment on plans, programmes and proposals for projects affecting the environment; the public should be also able to review procedures and challenge public decisions.

informal ethics assessment may have programmes or projects that focus on the assessment of innovation.

5   Methods and activities of CSOs

As indicated above, ethics assessment carried out by CSOs is rarely termed as such. As ethics is perceived as a crosscutting issue, the way in which ethics assessment and/or guidance is performed and the procedures and protocols that are used, correspond, to a large extent, to the ways in which an organisation operates in other areas.

In the course of performing (informal) assessment or guidance, CSOs make use of different methods. The following are types of activities performed by CSOs interviewed for the purpose of SATORI:

- Gathering and analysing data;
- Writing reports, guidelines, recommendations;
- Participating in meetings with political decision makers, lobbying;
- Providing educational activities and raising awareness;
- Engaging people in the procedures of ethical assessment;
- Cooperating with other organisations, facilitating networking between different groups of stakeholders;
- Monitoring the activities of public institutions (acting as a watchdog);
- Establishing expert groups and forums for expert discussions;
- Promoting public participation in research and innovation.

6   Principles and Issues for Ethics Assessment

As already mentioned, CSOs usually pursue a defined set of objectives which are based on a concrete set of values. These guiding principles are often enshrined in the document establishing an organisation. In the case of non-religious CSOs, values and principles are often based on human rights. American CSO that act in the area of biomedical research refer to the Belmont report[36] as a point of reference with regards to ethical principles.

The main values recognised in European political decision-making are human-rights based – they refer mainly to individual rights. They are described in the Charter and the Treaty. The Charter lists six values – justice, dignity, freedom, citizens' rights, solidarity and equality. In addition, the Treaty identifies the value of sustainability. In order to influence policy-making, CSOs refer to those values. CSOs have recourse to international legal instruments to further justify and legitimise their activities.

In the course of (informal) ethical assessment of research and innovation, religious organisations rely on values inherent to a given religion.

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[36] National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, Department of Health, "Education and Welfare", *The Belmont Report,* 30 September 1978.

The following are ethical principles and issues listed by CSOs interviewed for the purpose of SATORI:

- Justice/fairness
- Common good
- Biodiversity
- Sustainability
- Engagement for future generations
- Food security
- Corporate social responsibility
- Scientific integrity
- Professional integrity
- Human subject research,
- Treatment of animals
- Human dignity
- Equality/non-discrimination
- Autonomy/freedom
- Implications for civil rights
- Implications for privacy (data protection)
- Social responsibility
- Implications for health/safety
- Implications for quality of life
- Environmental impacts
- Social impacts
- Outsourcing of R&I to developing countries
- Dual use
- Openness
- Transparency
- Popularisation of science and research results
- "Three Rs" in animal testing (reduce, replace, refine)
- Respecting lives and interests of all individuals (ethical individualism)
- Human rights
- Wellbeing
- Distribution of opportunities and resources
- Benefit sharing, distributive justice

Some CSOs establish their own frameworks referred to in the course of assessment or guidance. Depending on the type of CSO, it may take the form of:

- Formalised key claims;
- A code of conduct, a charter of good practice or practical guides for members or scientists and researchers in general;
- An assessment framework for the interests of patients in order to improve the assessment of clinical trials; a charter for clinical trials for patient organisations interested in research projects

7   Problems and developments

Some problems faced by CSOs that perform (informal) ethics assessment and guidance is common to CSOs in general and is linked with the way in which these organisations are financed (CSOs act on the basis of project grants and receive little institutional support)[37]. As a result, many CSO employees only work on projects and do not have spare time to participate in other long-term activities. The lack of resources is a serious obstacle.

The problem is that a lot of staff are working only on projects and they don't have spare time to participate in the research agenda setting process. The lack of resources in the organisations is a serious obstacle. It is a question of organisational development. It would be helpful to have an independent organisation that would focus on research and innovation and cooperate with other specialised CSOs in developing agendas and strategies of their own. Governments or big foundations could support this core organisation. (Forschungswende)

In general the involvement of CSOs in the ethics assessment of research and innovation is often a question of resources. It is possible only in the case of bigger organisations with a lot of resources or really small ones that specialise and focus on particular topics. (INKOTA)

One of the main challenges is the fact that the Society has limited resources. (Polish Ethics Society)

As regards the impact of recommendations made by CSOs, CSOs point out that politicians are often only superficially interested in ethics:

The presence of ethical issues in politics of research and innovation is still more of a 'window-dressing'. Politicians are changing their language and they are more open to the participation of CSOs in research agenda setting, but the goals of research remain the same. CSOs are now at a critical point – civil society needs to get more powerful and be strong to bring new values into research agendas. (…)The impact on the environment is formally taken into consideration, but there is no meaning behind it or real engagement (Forschungswende)

The activities undertaken by the Ministry of Science and other collegial bodies are unsatisfactory. They do publish some guidelines and organise meetings, however it has little impact on reality. In addition there are still problems with how the process of public consultations functions - CSOs do not feel the authorities hear and take into considerations their opinions. (Citizens of the Academia)

Despite the limitations:

Lobbying by the Society does have impact on politicians. Even though the results are not always satisfactory, one can assume that if the Society did not take any action, the situation could be even worse. (Polish Ethics Society)

In some cases the impact is unknown to the organisations themselves:

The impact of the work of SRHRLP is unknown to the interviewee. (AAAS)

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[37] This aspect was mentioned during the interview for example by Dr Steffi Ober of Forschungswende.

Still, many CSOs see the added value of their involvement in the process of ethics assessment/guidance:

The major role of civil society and civil society organisations is that of a watchdog. CSOs can keep an eye on the activities of the authorities. (Citizens of Academia)

Since this is a consumer organisation, they have the perspective of the recipient of the product, the final consumer. (…) Consumer organisations represent the whole society, for that reason he believes that they should participate in ethics committees, so that in the evaluation of research projects the opinion of society (users, patients) is heard. (FACUA)

There is a role for CSOs who can do translation work between more formal, academic ethics assessment and act as a bridge between researchers and practitioners. (PRIM&R)

CSOs offer third-view and are more creative than international institutions that may represent Members States. (COHRED)

Leaving ethical considerations to the public sector and research funders alone would be risky. (SciDev.Net)

The role of CSOs is to act as guardians of public interest, since what is presented as public interest is often only a mask for a partial private interest. Environmental CSOs emphasise the protection of environment as a public interest. Climate change is not a popular topic and tends to be swept away from public discussions – the role of CSOs is to keep these discussions in the spotlight of public discourse. CSOs are often responsible for introducing and popularising new aspects or ways of thinking, e. g. animal rights (in contrast to the old Cartesian tradition of separating man from nature), transition to renewable energy (even though there is plenty of cheap coal that can be used instead). (Greenpeace)

When it comes to the ethics assessment of research in general, AI can be useful in protecting rights and dignity of people who are the subjects of research, especially vulnerable groups. (Amnesty International)

CSOs that act as (informal) ethics assessors deal with different types of obstacles. The first group of challenges is closely related to the ways in which independent CSOs operate in general. Their activities, in terms of financing, are mostly project-based, which may often undermine the continuity of work. On the other hand, due to weak institutional or structural "anchorage", it may be problematic for CSOs to influence the decision making process, as politicians and stakeholders are rarely formally obliged to follow their recommendations.

In spite of these challenges, however, representatives of CSO interviewed for SATORI often express the opinion that they have an important role to play in R&I process as guardians of public interest and in their presence as an "interface" between different groups of stakeholders.

8   Annex: Ethics Assessment and Guidance in Specific Civil Society Organisations

This Annex contains 30 reports on civil society organisations that were surveyed for SATORI. For each CSO that was surveyed, basic data is provided about the organisation, its mission, structure, and role in ethics assessment and/or ethical guidance, in addition to its procedures for assessment and guidance.

The following organisations were surveyed:

1. China – Green Choice Alliance (GCA)

2. European Union – Amnesty International

3. European Union – European Consumer Organisation (BEUC)

4. European Union – Conference of European Churches (CEC)

5. European Union – European Association for Neuroscience and Law (EANL)

6. European Union – European Consumer Voice in Standardisation (ANEC)

7. European Union – European Federation for Science Journalism (EFSJ)[38]

8. European Union – The European Organisation for Rare Diseases (EURORDIS)

9. European Union – European Union of Science Journalists' Associations (EUSJA)

10. European Union – Regional Environmental Centre (REC)

11. France – Defeat Lysosomal Diseases (VML)

12. Germany – Forschungswende

13. Germany – INKOTA

14. Global International – Council on Health Research for Development (COHRED)

15. Global International – Greenpeace

16. Global International - International Women's Forum in Science and Business

17. Global International – Israel Medical Association Worlds Fellowship (IMA-WF)

18. Poland – Panoptykon Foundation

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[38] Disclosure of potential conflict of interest: EUSJA SATORI expert Daniela Ovadia declares a potential conflict of interest here. Ovadia's husband Fabio Turone was interviewed by the EUSJA team in his role as an initiator for a non-registered network EFSJ. Turone and Ovadia own Agenzia Zoe, a science journalism and science communication company that works for many publishers and companies fully listed on the Agency website (http://www.agenziazoe.it). In 2012 Agenzia Zoe started a project called Center for Ethical Science Journalism http://www.cesj.eu/.

19. Poland – Polish Ethics Society

20. Poland – The Citizens of Academia

21. Serbia – Equal Opportunities

22. Spain – Consumers in Action

23. The Netherlands – Federation of Patients and Consumers Organisations (NPCF)

24. The Netherlands – Royal Dutch Society of Engineers (KIVI)

25. The Netherlands - Partos

26. United Kingdom – Genetic Alliance UK

27. United Kingdom – SciDev.Net

28. United Kingdom – European civil society organisation

29. United States - American Association for the Advancement of Science (AAAS)

30. United States – Public Responsibility in Medicine and Research **(**PRIM&R)

Name of organisation	**Green Choice Alliance (GCA)** (绿色选择联盟)
Type of organisation	National civil society organisation
Country	China
Website address	General: http://www.ipe.org.cn/alliance/gca.aspx Main page(s) on ethics assessment: same as general address
Basic description (organisation and mission)	The *Green Choice Alliance* is a coalition of NGOs throughout China. It promotes a global green supply chain by pushing large corporations to concentrate on procurement and the environmental performance of their suppliers. It also encouraging consumers to takes the environmental performance of manufacturing enterprises into consideration while exercising their purchasing power to make green choices.
Interest in research and innovation	The main executive body of GCA, the *Institute of Public and Environmental Affairs (IPE)* has developed a Chinese pollution database to monitor corporate environmental performance since its establishment in 2006. This database is a research project in environmental protection. Corporations with any environmental violation are recorded in the database and will only be removed after an assessment conducted by GCA.
Ethics assessment and/or guidance	Assessment ☒ Guidance ☐ Other ☐ None ☐ If assessment/guidance is undertaken: In-house ☐ Outsourced ☒ Other ☐ Commentary: GCA uses market-based independent auditors to do the ethics assessment and the assessment involves the participation of NGOs.
Terminology for ethics assessment / guidance	GCA uses the GC Audit (绿色选择审核), a third-party audit, as the ethics assessment. It follows a GC Auditing Protocol which is developed on the basis of protocols widely used by some recognised environmental consulting firms.
Name and description of ethics unit(s)	The GC Audit is performed by accredited auditing entities and observed by NGO members to ensure external validity and enhance transparency. The auditing bodies accredited by GCA include: British Standards Institution, GOLDER, Greenment, SGS-CSTC, SOIL (Shanghai) Environmental Technology Co., Ltd, TUV-Rheinland, and URS. In the assessment, the assessed body is required to financially support the whole process.
Aims and motivation for ethics assessment	The GCA program aims for facilitating public-private collaboration on environmental aspects of supply chain management. By the third-party auditing

	with the participation of environmental protection NGOs, the GC Audit assesses the comprehensiveness, effectiveness and regulatory compliance of the environmental pollution control of corporations. The results of the assessment are publicised to the society and thus affect the choices of consumers.
Objects and scope of assessment	As a GCA member, a corporation needs to openly commit not to use polluters as suppliers in China and engage in a process that identifies polluting companies, and allows these companies to resolve their environmental management problems. For the assessment, corporate members are requested to draft an Action Plan which addresses how they intend to fulfil this commitment. The assessment focuses on whether the pollution produced in all the work of corporations meets the demand of relevant laws and regulations and technology standards.
Beneficiaries of assessment	The general public and the environment of China.
Ethics assessment unit: appointment process	The ethics assessment is only carried out by an accredited auditing entity. To be accredited by the GCA, an auditing entity is first checked and evaluated by GCA. This evaluation is conducted by Green Choice Alliance Technical Working Group (GCA-TWG) and Green Choice Assessment Team (GC-AT). GCA-TWG adopts a process in order to evaluate the auditing bodies to ascertain that the auditing entity meets the demand of GC Auditing. GCA-AT does the major evaluating work. Auditors in auditing entities are also accredited after being evaluated by GCA-AT. In addition, GCA-TWG oversees the work of accredited auditing organisations regularly.
Procedure for ethics assessment: before	To remove the environmental violation record from the IPE database, the enterprise submits relevant documents explaining the violation record and relevant documents for the assessment. Then the off-site document review can be carried out. The enterprise also needs to choose an auditing company according to the GCA regulations. When the participant of the audit is coordinated, the on-site audit is carried out.
Procedure for ethics assessment: during	The audit has an on-site part and an off-site part. The off-site part is the document review, in which the enterprise submits relevant documents and the auditing company provided by NGOs audits the documents and writes the document review report. Afterwards the on-site audit is carried out. The auditing company chosen by the enterprise will lead the onsite document audit, on-site investigation and interviews and if necessary some sampling work. During this process, NGOs take part in all auditing activities by informing the auditing company of anything that could affect the normal auditing procedures. The auditing company will report on-site audit findings and NGOs will check the findings. The auditing company will write the preliminary audit report and NGOs check this audit report.
Procedure for ethics assessment: after	After the assessment, the enterprise carries out corrective actions related to non-compliances discovered during the audit and this process will be traced by NGOs. The auditing body needs to clarify the nature of the enterprise's environmental record and also track the progress of the follow-up actions of the enterprise. The

	auditing body also needs to write the final report of this assessment and send to NGOs to check and then the final audit report will be sent to the audited enterprise. The NGOs prepare an audit conclusions report within 7 days based on the audit conclusions and the on-site circumstances. This report will be made public among GCA NGOs. Given good results, the environmental violation record of the corporation will be removed from the IPE database, which is made public to the whole society.
Principles and issues in assessment / guidance	[ ]scientific integrity [ ]justice / fairness [ ]professional integrity [x]implications for health and/or safety [ ]human subjects research [x]implications for quality of life [ ]treatment of animals in R&I [x]environmental impacts [ ]human dignity [x]social impacts [ ]equality / non-discrimination [ ]outsourcing of R&I to developing [ ]autonomy / freedom countries with lower ethics standards [ ]implications for civil rights [ ]dual use (possible military uses) [ ]implications for privacy [ ]other, specify: [x]social responsibility Commentary: As part of the Chinese government's initiative to strengthen environmental enforcement, legal and policy measures have been established to facilitate public participation. The laws and regulations used by the GC Audit include (but not limited to) national laws concerning environmental protection such as: Law of People's Republic of China on Environmental Protection, Law of People's Republic of China on the Prevention and Control of Atmospheric Pollution, Law of People's Republic of China on the Prevention and Control of Atmospheric Pollution, Law of People's Republic of China on Environmental Impact Assessment, and so forth. The audit also uses relevant technology standards on fields related to environmental protection such as wastewater, air emissions, hazardous waste, and so forth.
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**Amnesty International**

Type of organisation	CSO
Country	EU level (UK)
Website address	*General:* http://www.amnesty.eu/ *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	Amnesty International (AI) is a global movement of more than 3m supporters, members and activists in over 150 countries and territories who campaign to end grave abuses of human rights. AI vision is for everyone to enjoy all the rights enshrined in the United Nations' Universal Declaration of Human Rights and other international human rights standards. AI is dedicated to promoting all human rights for all people and campaigning to stop serious violations of those rights whenever and wherever they occur. AI claims to be independent of any government, political ideology, economic interest or religion, and is funded mainly by their membership and public donations.
Interest in research and innovation	AI work is based primarily on research not so much on innovation. They try to be as much factual as it is possible, so they document human rights abuse cases. Having their own research ensures their independence. It is fair to say that their research is not the same as in scientific filed but rather directed towards campaigns and advocacy for the right of individuals.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	AI doesn't have specific unit within organisation that deals with ethical issues, but ethics is very important for AI, in particular when they are dealing with individual cases of human rights abuse. AI is not directly engaged in ethics assessment. They do lot of campaigns to stop serious violations of human rights whenever and wherever they occur. When they are dealing with cases of human rights abuses especially when selecting individual cases for campaign purposes AI have very strict protocol how to use those data. Right on dignity, informed consent, privacy, and other human rights are guaranteed in their research techniques. They also expect from other organisation to respect human dignity, right to privacy, informed consent and so on, when conducting researches on human subjects.
Aims and motivation for ethics assessment	N/A
Objects and scope of	N/A

assessment	
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [x] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [x] human dignity [ ] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [ ] dual use (possible military uses) [x] implications for privacy [ ] other, specify: [ ] social responsibility
Self-assessments, strengths and weaknesses	AI is satisfied how ethical issues are dealt with, at least for an organisation. Sometimes it would be even better to have more active participation of people subjected to the research, particularly when we document human rights abuse. However, this is not always possible.
Other	N/A

Name of organisation	**European Consumer Organisation – Italian Chapter (BEUC-Altroconsumo)**

Type of organisation	CSO
Country	EU Level (Italy)
Website address	General: http://www.beuc.org/beuc-network/members/altroconsumo
Basic description (organisation and mission)	BEUC acts as the umbrella group in Brussels for its members and its main task is to represent them at European level and defend the interests of all Europe's consumers. BEUC investigates EU decisions and developments likely to affect consumers, with a special focus on eight areas identified as priorities by the members: Financial Services, Food, Digital Rights, Consumer Rights, Sustainability, Safety, Health and Energy. Just like the EU itself, BEUC's membership has grown, and its members now include 41 independent national consumer organisations from 31 European countries (EU, EEA and applicant countries). Altroconsumo is its Italian representative.
Interest in research and innovation	They work to ensure that consumer policy at EU level is sustainable for all; 'sustainability' not only meaning respect and protection of the environment, including climate change, but also reduction of negative social and economic impacts of innovation, while improving well-being for all, without compromising the needs of future generations. This means that vulnerable groups, such as children, the elderly and low income consumers, are taken into account when designing policy. The concept of sustainability underpins all their campaigns and is also reflected in the day-to-day running of their Secretariat in Brussels. At local level they have divisions dealing with the evaluation of industry and products campaigns and with the assessment of corporate social responsibility. They are interested both in research and in innovation, especially in technology and its impact on the society or the environment.
Ethics assessment and/or guidance	Assessment [X] Guidance [ ] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [X] Outsourced [ ] Other [ ] Commentary: They are interested in social and environmental issues, even if in recent years they focused more on the working conditions of people involved in the production of the goods they evaluate.
Terminology for ethics assessment / guidance	They are involved in CSR assessment, but they don't do it in a formal way, even if they have some general guidelines issued by their central office in Brussels. They rely to the official documents by the EU Commission and the EU norms on products and commerce.
Name and description of ethics unit(s)	They don't have a unit devoted specifically to ethics assessment.
Aims and motivation for ethics assessment	They ideally refer to the concept of "ethical consumerism" (or ethical consumption and purchasing), a type of consumer activism that is based on the concept that the way we spend our money is an indirect form of voting, and

	influencing the society. If we practice a 'positive buying' we can change the rules of our productive system and protect both the consumer and the society. They also focus their activity in publishing reports and magazines for the consumers, because they believe in information as a tool for empowering the consumer and helping him to do a better choice.
Objects and scope of assessment	They adapt their evaluation to the changing requests of the public: actually they focus also on human rights and pollution, because this is something that people perceive as valuable.
Beneficiaries of assessment	The consumers.
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	When they obtain information about ethical issues related to the production of a new product, they publish it on their review or on their website to influence they consumer. They also try to lobby to influence the norms and policies at European level.
Principles and issues in assessment / guidance	[ ]scientific integrity [ ]justice / fairness [ ]professional integrity [X]implications for health and/or safety [ ]human subjects research [X]implications for quality of life [ ]treatment of animals in R&I [X]environmental impacts [X]human dignity [X]social impacts [X]equality / non-discrimination [ ]outsourcing of R&I to developing [ ]autonomy / freedom countries with lower ethics standards [X]implications for civil rights [ ]dual use (possible military uses) [ ]implications for privacy [ ]other, specify: [x]social responsibility
Self-assessments, strengths and	N/A

weaknesses	
Other	N/A

Name of organisation	**Conference of European Churches - CEC**
Type of organisation	CSO
Country	EU level (Belgium)
Website address	*General:* http://www.ceceurope.org/ *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	CEC is an ecumenical organisation for churches in European countries (but also beyond). It groups about 120 churches. Because of its ecumenical and religious character, they consider ethics to be at the core of their mission and entrenched in all their activities. There are however some units dealing with fields directly related to R&I, such as bioethics, environmental issues and economic and human rights.
Interest in research and innovation	R&I should be linked with the ideas of common good, stability and wellbeing within the community. So they address ethics focusing not only in research practices, but on the general wellbeing of the community. While acknowledging the freedom of research, they consider it to be inextricably linked to their consequences and how those are handled. So social, environmental and ethical consequences of research are consider of utmost importance (i.e. conflicts between growth and sustainability, inequality, dignity of the human being…) and a great emphasis is thus placed in the dialogue and ethical deliberation between politics, science, ethics and religion.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [X] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ] Commentary:
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	They don't do ethic assessment on their own, but have publications for their members where they deal with ethical issues (i.e. publications on environmental issues or on the ethical aspects of human enhancement). They are an observer member of the Council of Europe steering group for bioethics. They stress their

	will of engaging in discussion and exchange with different actors of civil society, academia and political institutions.
Aims and motivation for ethics assessment	They promote a faith based approach. Concerned about wellbeing of the community, justice, inequality, growth, dignity of the human being.
Objects and scope of assessment	Two particular areas of interest can be noted: Bioethics: everything related to the human body, including medicine and especially referring to "the frontiers of life": beginning and end of life, human enhancement, nanotechnologies. They consider especially the implications for dignity and justice. Environment: limits and development not just as a "green issue" but indeed about justice, growth and inequality.

Name of organisation	**European Association for Neuroscience and Law (EANL)**
Type of organisation	CSO
Country	EU level (Italy)
Website address	*General:* http://www.neurolaw-eanl.org/
Basic description (organisation and mission)	In 2010 legal scholars, experts in the field of neuroscience and behavioural genetics, ethicists, psychologists and media representatives met in University of Pavia (Italy) and established a consortium to exam the emerging use of neuroscience in legal setting**.** Participants were from Italy, Belgium, France, Switzerland, Germany, The Netherlands, UK, Spain, USA and Australia. The association promotes the discussion between different experts in the field of neuroscience and law (judges, lawyers, jurists, researchers, neurologists, psychiatrists, psychologists…) but also representatives of the civil society and of the media. Their interest is extended to all the legal implications of new technologies. They are mainly involved in education, they organise an annual PhD students winter school on the topic at University of Pavia and many seminars and workshops all over Europe.
Interest in research and innovation	They are interested in every new research or innovation that has an impact in courts, especially in determining the capacity of the defendant in a trial. In recent years they approached the field in a broader way, including the research on artificial intelligence and the legal rights of the intelligent machines and the

	Internet of things.
Ethics assessment and/or guidance	Assessment [] Guidance [x] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ] Commentary: EANL develops the interdisciplinary dialogue between different experts and stakeholders. They also issue scientific publications on this topic to guide the experts and the jurists.
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	They don't have a specialised unit, but their steering committee often deals with ethical issues in evaluating cases that are discussed in courts all over Europe, and when someone asks us for an official statement on a single case or technique.
Aims and motivation for ethics assessment	EANL don't deal directly with formal ethical evaluations but the analysis of the ethical framework of the new neurotechniques is an important part of their methodological approach to the field. They represent a large part of the European judicial system that has to deal on a daily basis with new discoveries and techniques brought into the courts by the defendants and by their lawyers and many neurologists, neuroscientists and psychiatrists that are called as experts in courts. They also have representatives of the media in their steering committee because they are aware of the fact that many judges and lawyers are informed about scientific topics through the lay press and other media.
Objects and scope of assessment	They are very concerned with ethical issues related with civil and individual rights that can be threatened by the new neurotechnologies (like lie detection machines, predictive fMRI etc.) but also by the use of behavioural genetics. They also deal with non-discrimination issues (especially in the field of predictive criminology and juvenile justice). They try to foster the professional integrity of the judges, lawyers but also of the scientific experts in courts.
Beneficiaries of assessment	Academy, legal and scientific community

Name of organisation	**European consumer voice in standardisation (ANEC)**
Type of organisation	Non-assessor /CSO
Country	EU

Website address	*General:* http://anec.org/anec.asp
Basic description (organisation and mission)	ANEC is the European consumer voice in standardisation. ANEC represents the European consumer interest in the creation of technical standards, especially those developed to support the implementation of European laws and public policies.
Interest in research and innovation	Standards are bearers of knowledge and share knowledge as widely as possible. This is a base for innovation. Through conforming at certain standards innovations can prove that they are e.g. safe.
Ethics assessment and/or guidance	Assessment [] Guidance [x] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ] Commentary: ANEC defends consumers' interests in the development of standards. It has principles according to which they operate.
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	ANEC always works to achieve the highest level of consumer protection in standards possible. Without effective consumer representation in the writing of standards, products will not be as safe, as interoperable, as accessible or as sustainable as they could be. Of course, it is not the interests of business to ignore the needs of consumers if it wants to sell its products and services, but ANECs experience is that business tends to focus on the needs of the mainstream or "average" consumer - where costs are often lowest and profits highest - to the detriment of vulnerable consumers: those who are young, old or disabled. When standards are used for legislation or other public policy objectives, it is essential they take account of the needs of all consumers.
Objects and scope of assessment	In 2014, the ANEC budget allowed ANEC to operate in the following main areas of priority: • Child Safety; • Design for All (DfA); • Domestic Appliances (DOMAP); • Sustainability; • Information Society; • Services, Traffic; • Chemicals; • Smart Meters.

Beneficiaries of assessment	Consumers in Europe
Ethics assessment unit: appointment process	ANEC is not engaged in ethics assessment.
Procedure for (ethics) assessment: before	ANEC is not engaged in ethics assessment.
Procedure for ethics assessment: during	ANEC is not engaged in ethics assessment.
Procedure for (ethics) assessment: after	ANEC is not engaged in ethics assessment.
Principles and issues in assessment / guidance	[] scientific integrity [ ] justice / fairness [] professional integrity [x] implications for health and/or safety [] human subjects research [x] implications for quality of life [] treatment of animals in R&I [x] environmental impacts [] human dignity [x] social impacts [x] equality / non-discrimination [] outsourcing of R&I to developing [] autonomy / freedom countries with lower ethics standards [] implications for civil rights [] dual use (possible military uses) [] implications for privacy [] other, specify: [x] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	European Federation for Science Journalism (EFSJ)
Type of organisation	CSO – non-assessor

Country	EU level (Belgium, Italy)
Website address	*General:* http://www.efsj.eu/
Basic description (organisation and mission)	The EFSJ is the newly born umbrella association for science journalism in Europe. It regroups mainly the Western Europe national associations (France, The Netherlands, GB, Switzerland, Italy, Germany) but they also accept single journalists' affiliations. They are planning to evaluate the ethical aspects of science journalism in a very professional way, but they are newly born; they want to analyse the ethical issues from the point of view of a professional journalist dealing with them on a daily basis.
Interest in research and innovation	As science journalists, research and innovation, and even the policies for R&I, are their main area of interest and coverage.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [x] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ] Commentary:
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	None
Aims and motivation for ethics assessment	They have a strong focus on ethics not only to build a professional code of conducts but also to foster the reflection about the role of science journalists in shaping the public perception of controversial topics and innovations and for the role they could have in pushing the scientific community in a more ethical direction (i.e. by identifying frauds and misconducts or by analysing the impact of new research topics or technological applications). They are also interested in investigative journalism and in building a professional ethical framework for science journalists that will merge some values from general journalism and some values from science, avoiding a complete ethical overlapping between science journalists and the two other categories. Their approach to ethics assessment is nevertheless informal.
Objects and scope of assessment	N/A
Beneficiaries of assessment	The professional community of science journalists; the public.
Ethics assessment unit: appointment	N/A

process	
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[x] scientific integrity [x] justice / fairness [x] professional integrity [x] implications for health and/or safety [ ] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [x] environmental impacts [ ] human dignity [x] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [ ] dual use (possible military uses) [x] implications for privacy [ ] other, specify: [x] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**The European Organisation for Rare Diseases (EURORDIS)**
Type of organisation	CSO – non-assessor
Country	EU level (office in France)
Website address	*General:* www.eurordis.org *Main page(s) on ethics assessment:*

Basic description (organisation and mission)	The European Organisation for Rare Diseases (EURORDIS) is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe. Their mission is: 1) to build a strong pan-European community of patient organisations and people living with rare diseases, and 2) be their voice at the European level and to fight against the impact of rare diseases on their lives.
	EURORDIS seeks to improve the quality of life of people living with rare diseases in Europe through advocacy at the European level, support for research and medicines development, facilitating networking amongst patient groups, raising awareness, and many other actions designed to reduce the impact of rare diseases on the lives of patients and family.
Interest in research and innovation	Main activity of EURORDIS is to identify research projects with different research opportunities and build capacity among patient so that they can understand importance of scientific, especially lab work in the field of rear diseases. They are trying to foster patient organisation curiosity on fundamental research and to inform patient organisations which research exists for their diseases hopping that one day something will derive from this early day research.
	EURORDIS is also guiding patient organisations who are interested in research projects with development of the new medicines were they have created *Charter for clinical trials* and set up the *Community advisory board* as interlocutor between child participants in clinical trials, the investigators and the sponsor, public or private. They discuss all aspects of the clinical development in different stages, in terms of deciding on outcome measures, comparator or design. Among all, they also follow up the clinical trials from start until end, they contribute to the ethical discussion, advice the sponsors of the trial on the next step, how to communicate unexpected events in the trial.
	At the policy level, EURORDIS is participating in discussions with different stakeholder: such as *European medicines agency*, the *Welcome trust*, *National institute of medicine* in the USA and so forth, on issues related to personal data protection, confidentiality of clinical trial data, data publishing, consent forms. Furthermore, they also have contributed to the consultation on the new legislation on the clinical trials and they expect to play active role in the implementation of this legislation.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [x] Commentary:
	If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
	Commentary:
Terminology for ethics assessment / guidance	N/A
Name and description	EURORDIS doesn't have special unit within organisation that deals with ethical

of ethics unit(s)	issues.
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [x] justice / fairness [ ] professional integrity [x] implications for health and/or safety [x] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [x] human dignity [ ] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [x] implications for privacy [ ] other, specify: [ ] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**European Union of Science Journalist's Associations (EUSJA)**
Type of organisation	CSO – non-assessor
Country	EU level (France)
Website address	*General:* http://www.eusja.org/
Basic description (organisation and mission)	Founded in 1971 in Belgium by seven national associations of science journalists, EUSJA represents around 1800 science journalists from 19 countries. Following the collapse of the Berlin Wall in 1989 there was an upsurge of interest from Eastern European countries that now play a large role in EUSJA's activities. Member countries are (by February 2015) Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, Germany, Greece, Hungary, Ireland, Italy, Poland, Portugal, Romania, Russia, Slovenia, Spain, Sweden. The main goal of EUSJA is barrier-breaking by aiming to improve communication between the international scientific community and society and to promote contacts between journalists in the field of scientific and technical communication. EUSJA has its head office and secretariat in Strasbourg. An electronic mailing list only open to science writers who are members of a national association within EUSJA keeps the contacts between the members.
Interest in research and innovation	EUSJA is interested in questions posed by emerging science, and it believes that seasoned, critical and specialised journalists are needed to assess that. In their view, science journalists play an important role s independent and critical outsiders acting as knowledge brokers between scientists and the public, but also as ethics checkers, as they are attentive to misconduct and other ethical issues in research and have the advantage of being independent.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [x] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	There is no special unit within this organisation that deals with ethical issues in research and innovation.
Aims and motivation for ethics assessment	EUSJA involvement in ethics assessment is indirect and take the form of public comment and discussion: they usually comment on ethical questions from media perspective (how some scientific findings are explained) but also on ethical issues in research such as commercial motives of research, false interpretation, hype etc.
Objects and scope of	Particular interests, which are intertwined with the concerns of science journalism, are plagiarism, commercial interests as hidden agenda in research,

assessment	media hype over breakthroughs, science publishing mechanisms in general, framing scientific findings as unclear disputes /denialism, cherry-picking, i.e. exaggeration of nice findings, false balance. As EUSJA is composed by country associations, these concerns may change slightly from one member organisation to another according to national science policies and priorities.
Beneficiaries of assessment	The general public
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[x] scientific integrity [ ] justice / fairness [x] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [x] environmental impacts [ ] human dignity [x] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [x] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [x] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**Regional Environmental Centre (REC)**
Type of organisation	EU level CSO – non-assessor
Country	EU (Hungary)
Website address	*General:* http://www.rec.org/ *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	The Regional Environmental Centre for Central and Eastern Europe (REC) is an international organisation with a mission to assist in addressing environmental issues. The REC fulfils this mission by promoting cooperation among governments, non-governmental organisations, businesses and other environmental stakeholders, and by supporting the free exchange of information and public participation in environmental decision making. The United States, the European Commission and Hungary established the REC in 1990. Today, the REC is legally based on a charter with over 30 signatories. The REC has an office network in 17 countries; the head office is located in Szentendre, Hungary. The REC as an independent, non-partisan, non-advocacy, not-for-profit body of international character that designs and implements programs to fulfil its mission. Among other, REC follows the progress of global environmental problems; regularly assesses strategic environmental needs in Central and Eastern Europe and strives to identify solutions; promote public participation in environmental decision making; support cooperation between government, academic and nongovernmental organisations and members of the business community; gather and distribute environmental data for the countries in the region as well as for the region as a whole; offer opportunities for mutual exchange of experiences for interested countries, organisations and individuals.
Interest in research and innovation	Although REC supports research project it is not a research organisation. The fact that they are an environmental organisation defines research projects they support, and preserving environment is one of the key preconditions for the beginning of application procedure. REC does not deal with ethical issues in particular, but they see them as a very important subject since there is a possibility of misusing scientific research results.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	N/A
Name and description	There is no special unit within this organisation that deals with ethical issues in

of ethics unit(s)	research and innovation.
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [ ] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**Defeat Lysosomal Diseases Patient association** *Vaincre les Maladies Lysosomales* (VML)
Type of organisation	Patient association
Country	France
Website address	*General:* http://www.vml-asso.org/ *Main page(s) on ethics assessment:* /
Basic description (organisation and mission)	VML is an patient association that has 1.1000 members including people affected by lysosomal storage disease, relatives, physicians, supporters and volunteers. VML supports people with lysosomal storage diseases. However the association missions are also those of providing information for healthcare professionals and of encouraging public authorities to discuss rare diseases.
Interest in research and innovation	Funds research projects. (fundamental research, clinical research & SHS research)
Ethics assessment and/or guidance	Assessment [] Guidance [ ] Other [x] None [ ] Commentary: VLM is solicited to proofread information such as consent forms and to provide guidance in the recruitment of patients' process. If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	Guidance : free and informed consent & respect of the research
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A

Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[x] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [x] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [x] other, specify: Data protection. The VML analyses the content of information given to patients, the quality of this information and the way in which this information is given. [ ] social responsibility Commentary: Human dignity is a principle referred to by considering the ethical issues of free and informed consent.
Self-assessments, strengths and weaknesses	The association wants to put the patient at the center of the ethical reflection. "Our role is to ask the question: who is served by the ethics: the interests of the researchers or the interests of the patients?"

Other	A shared European approach to ethics assessment would be desirable. Indeed, given the low prevalence of rare diseases. "It is important to have the same research protocol for everyone, rather than defining shared values and principles, a task that can be difficult due to cultural differences.

Name of organisation	**Forschungswende (FW)**
Type of organisation	Civil society organisation
Country	Germany
Website address	*General:* http://www.forschungswende.de/ *Main page(s) on ethics assessment:* N/A
Basic description (organisation and mission)	Forschungswende's main focus is the research and innovation agenda setting process. The goal of Forschunsgwende (English "Transition of Research") is to enable CSOs of all kinds – social organisations, environmental organisations, transparency (Germany), consumer protection organisations, religious groups, development groups to engage in research and innovation system and to be advocates for their special themes, such as biodiversity, climate change, consumer protection, etc. All these big themes are currently not appropriately addressed by the research agenda. There is no established institutional cooperation with other organisations. However there is interaction.
Interest in research and innovation	FW assesses research and innovation agendas.
Ethics assessment and/or guidance	Assessment [x] Guidance [x] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	The presence of ethical issues in politics of research and innovation is still more of a "window-dressing". Politicians are changing the language and they are more open to the participation of CSOs in research agenda setting, but the goals of research remain the same. CSOs are now in a critical point – civil society needs to get more powerful and be strong to bring new values into the research agendas.
Name and description of ethics unit(s)	There is no specific unit in FW that deals specifically with ethical issues.
Aims and motivation	Forschungwende assesses the budget planning for the upcoming year from the point of view of their priorities, e.g. assesses how much money is given to

for ethics assessment	renewable energy research. Forschungswende is giving feedback to the Parliament and to the Ministry of Education and Research and asks them to reshape the budget accordingly. The goal of these kinds of ethical assessment is to influence the agendas and budget plans so that they are compatible with environmental goals, ethics and justice.
Objects and scope of assessment	FW assesses research and innovation agendas, as well as budget planning.
Beneficiaries of assessment	It addresses its recommendations and gives feedback to policy makers (Parliament and the Ministry of Education and Research). CSOs are as well a user group for fact sheets and knowledge transfer.
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	Representatives of Forschungswende participate in meetings as well as send feedback to the policy makers. They also give advice to policymakers as regards which organisations should they contact with regard to specific topics. FW functions as an "interface" to give more capacity to CSO and at the same time it is a lobby group to bring more diversity to the research policy.
Procedure for ethics assessment: after	The recommendations are not binding. However for the first time in the coalition document (Vertrag) pieces from CSOs proposals about the need to involve CSO in research agenda setting process and research projects can be found. CSO monitor the compliance with the recommendations and are in an ongoing discussion with the government how to implement the new mode of participation of CSOs and what do the CSOs need in order to participate in the process of research agenda setting. Currently CSOs do not have the resources (money, staff) to participate fully in the research agenda setting processes that continue a long time.
Principles and issues in assessment / guidance	[ ] scientific integrity [X] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts

	[ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [X] other, specify: see commentary [ ] social responsibility Commentary: There is no formalised ethics assessment framework, only shared values such as justice, common good, biodiversity, sustainability, etc. Values that define the activities of FW are: engagement for public good/for common good, sustainability, engagement for more justice for this world and the following generations.
Self-assessments, strengths and weaknesses	Most of the staff and many members are scientists, so the lack of expertise is not a problem. The problem is that a lot of staff is working only in projects and they don't have spare time to participate in the research agenda setting process. The lack of the resources in the organisations is a serious obstacle. It is a question of organisational development. It would be helpful to have an independent organisation that would focus on research and innovation and cooperate with other specialised CSOs in developing agendas and strategies of their own. Governments or big foundations could support this core organisation.
Other	One of most important problems concerning research and innovation currently is the fact that the research agendas are very technical and too narrow in their focus. Research is not only about technology, but also about the social change and the change for society (lifestyle, consumer patterns, way of living). If the expert groups are dominated by industry, they won't look at the people and how to implement social transformation. The impact on the environment is formally taken into consideration but there is no meaning behind it or real engagement.

Name of organisation	**INKOTA**
Type of organisation	CSO
Country	Germany
Website address	*General:* http://www.inkota.de/ *Main page(s) on ethics assessment:*
Basic description	INKOTA is a small organisation, it is an NGO, a non-for-profit organisation.

(organisation and mission)	INKOTA has offices in Germany only, but it has been working with organisations from abroad for a very long time. The organisation has existed for ca. 40 years. It is one of the few organisations founded in the former GDR that has survived the unification of Germany.
	There are two main topics that INKOTA is working on:
	1. Work standards, e.g. the clean clothes campaign - INKOTA is coordinating the activities in Germany,
	2. Food and agriculture; the main issues concern: land grabbing and the investments by private sector in food and agriculture sector, the focus is on global south and rural development.
	INKOTA has about 700 individual members. Groups can also become members, currently ca. 20 smaller organisations and groups belong to INKOTA.
	There is no special unit that would deal with ethical issues. Ethics is a crosscutting question and people who work with different topics come across ethical questions in the course of their work.
Interest in research and innovation	In general INKOTA does not directly concentrate on research and innovation issues, it becomes interested in those topics when they concern fields that it focuses on in its everyday work (e.g. work conditions, food and agriculture policies).
	In spite of this, two specific aspects of research and innovation that are of interest to INKOTA could be distinguished:
	1. the problem of how research is sometimes used to conduct anti-campaigns - research may be used to undermine issues that the NGOs are advocating for and in such cases it serves private interests
	2. the situation when technical solutions are promoted instead of coming up with real structural solutions and reforms. There is a strong belief that technical solutions will tackle existing problems. They are promoted instead of changing the mind-sets e.g. in the case of climate change. While there are of course some good aspects of how technical innovation influences the field of food and agriculture, it is important to highlight that technical innovation can contribute to solving real problems only if the local context is taken into consideration, as well as the knowledge and experience that are already in place, and the participation of the local people and NGOs is ensured.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [ ] Commentary:
	If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
	Commentary: INKOTA does not directly engage in ethics assessment.

	At the same time, when it publishes position papers on certain technological innovations (e.g. biofuels) or issues lobbying letters concerning some new laws, the paper or the letter consist of elements of ethical assessment of the innovation. INKOTA seeks to find the real sources of a given problem and often proposes solutions alternative to technology. In general the involvement of CSOs in the ethics assessment of research and innovation is often a question of resources. It is possible only in the case of bigger organisations with a lot of resources or really small ones that specialise and focus on particular topics.
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts

	[ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [ ] social responsibility Commentary: INKOTA advocates for: fair rules for international trade and a sustainable agricultural policy, as well as accountability of international corporations to ensure that their factories and subcontractors comply with the minimum social standards. INKOTA is concerned with food security and social corporate responsibility.[39] The main point of reference are human rights and values such as anti-discrimination, dignity, and participation. Other crucial principles are environmental sustainability and social justice
Self-assessments, strengths and weaknesses	N/A
Other	INKOTA does not collaborate with organisations that systematically engage in ethics assessment or ethics guidance (e.g. national ethics committees). INKOTA cooperates with organisations that investigate how particular actions of a company influence local communities, e.g. regarding the concept of fortification (adding nutrition to food products).

Name of organisation	**Council on Health Research for Development Africa (COHRED Africa)**
Type of organisation	NGO
Country	Geneva (Switzerland)
Website address	*General:* http://www.cohred.org/ *Main page(s) on ethics assessment:* http://www.cohred.org/marc/

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[39] http://www.inkota.de/english/#c9723

Basic description (organisation and mission)	"COHRED, the Council on Health Research for Development, is a global, non-profit organisation whose singular goal is to maximise the potential of research and innovation (R&I) to deliver sustainable solutions to the health and development problems of people living in low and middle-income countries. It's Mission is: To provide leadership and effective solutions to support low and middle income countries to build their own research and innovation systems for health and development."
Interest in research and innovation	- Training and support of projects - Ethics Review tracking in COHRED-Africa - Fairness index (measure of good practices in health care research)
Ethics assessment and/or guidance	Assessment [] Guidance [ ] Other [x] None [ ] Commentary: COHRED does not engage in direct ethics assessment or guidance. If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [x]
Terminology for ethics assessment / guidance	- Ethical issues around partnerships and research collaborations for health (capacity building, transfer of skills, benefit sharing, transfer of technology) - Ethical principle such as distributive justice is used
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	Maximise the potential of R&I to deliver sustainable solutions to the health and development problems of people living in low and middle-income countries.
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A

Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [x] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [x] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [x] human dignity [ ] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [x] other, specify: partnerships and collaborations for health(capacity building, transfer of skills, benefit sharing, transfer of technology) [ ] social responsibility
Self-assessments, strengths and weaknesses	CSO as an advantage: third-view and more creative than international institutions that may represent Members States.
Other	Challenge for shared principles: harmonisation and standardisation can be difficult when committees within a country have different kinds of ethics review.

Name of organisation	**Greenpeace**
Type of organisation	Civil society organisation
Country	International organisation
Website address	*General:* http://www.greenpeace.org/ *Main page(s) on ethics assessment:* n/a

Basic description (organisation and mission)	Greenpeace is a global environmental organisation. Supported by a consultative international decision making process in which the National/Regional Offices are the main stakeholders, Greenpeace International co-ordinates worldwide campaigns. Its mission is to preserve the liveliness of the planet in its entirety, i.e., the ecosystems of oceans, air, forests, the arctic, etc., or in other words, to ensure the ability of the earth to nurture life in all its diversity. Greenpeace strives to achieve these goals by nonviolent confrontation, the practice of "bearing witness" (e. g. with its ships near oil platforms), conducting its own research and proposing and promoting alternative solutions and innovations.
Interest in research and innovation	Greenpeace assesses innovation in terms of its environmental impact and risk. The organisation also depends on science and technology to provide solutions to environmental threats. Internal and external, independent scientific research as informing the credibility of Greenpeace's positions.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [x] None [ ] Commentary: Environmental impact assessment If assessment/guidance is undertaken: In-house [x] Outsourced [x] Other [ ]
Terminology for ethics assessment / guidance	Environmental impact and risk assessment.
Name and description of ethics unit(s)	Greenpeace has no ethics unit. The main responsibility for environmental impact and risk assessment assessments goes to Greenpeace Science Unit. Based at the University of Exeter in the UK, the laboratories provide scientific advice and analytical support to Greenpeace offices worldwide, over a range of disciplines.
Aims and motivation for ethics assessment	Innovation is never bad (or good) in itself. It can, however, be designed to solve a particular problem and serve a specific interest. When faced with an innovation, Greenpeace makes its assessment from the viewpoint of the public interest and environment protection.
Objects and scope of assessment	Greenpeace assess technologies in relation to issues relating to environment protection, quality of life and care for health.
Beneficiaries of assessment	Environmental CSOs emphasise protection of environment as a public interest. Climate change is not a popular topic and tends to be swept away from public discussions – the role of CSOs is to keep these discussions in the spotlight of public discourse.
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A

Procedure for ethics assessment: during	The goal of this unit is to achieve up to date scientific knowledge of new technologies and emerging issues connected to these technologies. Their assessments are based on GP's values but also on their own research. The most experienced GP experts working on a campaign give their own assessments on specific issues within their domain. When faced with an innovation with a potential environmental impact, GP establishes an internal forum of its experts and researchers, where the discussion is held through which an assessment and thus an official GP standpoint on this innovation is formulated and made public. In these assessments, GP is concerned with many ethical dilemmas, when various ethical claims seem to contradict each other; e. g. the right to develop economically often contradicts the values of environment protection; renewable energy is often unaffordable to the poor, etc. Sometimes it touches on the issues of civil rights, e. g. when living conditions of people are directly threatened by climate change. The issues of professional ethics and integrity are also very important, when industries and governments turn to biased experts to assess environmental risks.
Procedure for ethics assessment: after	Reports and position statements are published.
Principles and issues in assessment / guidance	[x] scientific integrity [ ] justice / fairness [x] professional integrity [x] implications for health and/or safety [ ] human subjects research [x] implications for quality of life [x] treatment of animals in R&I [x] environmental impacts [ ] human dignity [x] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [x] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**International Women's Forum**

Type of organisation	CSO / non-assessor
Country	EU level
Website address	*General:* http://iwforum.org *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	International Women's Forum (IWF) was established on 3 June 1993, and for the first two years it operated as the scientific-research program affiliated with the Collegium of World Economy Warsaw School of Economics. In April 1995, the IWF was registered as the association of women involved in science and business. The IWF mission is to strengthen the women's role in the economy and promoting entrepreneurship by creating positive models of a businesswoman, initiating the research and studies on female entrepreneurship, organising regular discursive meetings, as well as conferences and training. Since 2013, the IWF has been included as the partner organisation in two international projects. One of them is the pilot project Baltic Sea Region Partnership Platform for Gender and Economic Growth carried out within the UE strategy for the Baltic Sea region by Winnet organisation from Sweden and University of Szczecin. The second project is titled Knowledge Networking Program on Engendering Macroeconomics and International Economics; its objective is enlargement of knowledge on the role of women in economic development in conditions of globalisation. In the last few years we are touching question of innovation and women place in this process. Members are women who are academics and also women run business (small and medium).
Interest in research and innovation	IWF in past was not primarily oriented on research and innovation but, at the moment they are one of the partners in the project about gender innovation and sustainable development in the Baltic sea region. The main idea of this project is to promote gender equality, which is par excellence ethical issue, in respect of building innovative economy. They analyse the innovation process, the involvement of women in research area and the distribution of resources and general assessment of this process. Gender and innovation is almost completely blank area. In this project IWF does not address ethical issues in particular but they will touch upon issues like distribution of opportunities and resources in a process of innovation. IWF also research academic equality in gender terms and perform other studies. Gender research can be seen from the two sides. One is ethical side where gender equality is the core value for constitutions and other legal document frameworks – this is an individual right of women for equality. Usually, this issue is addressed by sociologist, philosophers, political scientist but not by economists. On the other side there is economics perspective with perspective of effectiveness, how good is gender equality for economy, its functioning, and so on. These two sides come together, when there is a view that gender inequality is bad as such based on argument of not using half of talents or knowledge on the market. So this is matter of ethics but it is also matter of economics, efficiency.

Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ] Commentary:
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	IWF doesn't have special unit within organisation that deals with ethical issues. IWF is engaged indirectly in ethics assessment, through investigating or commenting gender related issues.
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards

	[ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [ ] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**Israel Medical Association World Fellowship (IMA-WF)**
Type of organisation	CSO-religious
Country	EU Level (Israel)
Website address	*General:* http://www.ima.org.il/ENG/ViewCategory.aspx?CategoryId=4152 *Main page on ethics*: http://www.ima.org.il/ENG/ViewCategory.aspx?CategoryId=4531
Basic description (organisation and mission)	Established in 1912, it regroups Jewish doctors and medical professionals that are not resident in Israel. The objectives of the IMA-WF are to create and enhance mutual bonds between Israeli health professionals (including physicians, residents, fellows, medical students and allied health professionals) and their counterparts in other countries. Actually IMA-WF has 15 national chapters.
Interest in research and innovation	IMA-WF is interested in research and innovation in the fields of medicine, biology and human health.
Ethics assessment and/or guidance	Assessment [x] Guidance [x] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	The Israeli Medical Association (national professional association of Israeli's physicians) has an Ethics Bureau that prepares documents on bioethics and guidelines that are mandatory for Israeli members but constitute an important source of information for Jewish doctors all over the world.
Aims and motivation	The main motivation for ethics assessment in IMA-WF is the possible

for ethics assessment	applications of Jewish norms, values and laws in the context of a multi-religious and modern society.
Objects and scope of assessment	They are mainly focused on bioethical issues such as end of life decisions, embryo and stem cell research, human subjects' research etc. Thy also deal, for political reasons, with the topic of the role of physicians in conflicts and on the duties of doctors during wars, terroristic attacks, occupation.
Beneficiaries of assessment	Medical professionals and physicians
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[x] scientific integrity [x] justice / fairness [x] professional integrity [x] implications for health and/or safety [x] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [x] human dignity [ ] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [x] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: see commentary [ ] social responsibility Commentary: There is no formalised ethics assessment framework, only shared values related to religious Jewish sources and debates.
Self-assessments, strengths and weaknesses	N/A

Name of organisation	**Panoptykon Foundation** *Fundacja Panoptykon*
Type of organisation	Civil Society Organisation
Country	Poland
Website address	*General:* https://en.panoptykon.org/ *Main page(s) on ethics assessment:* N/A
Basic description (organisation and mission)	The Panoptykon Foundation was established in April 2009 upon the initiative of a group of lawyers, to express their opposition one surveillance. Currently the Panoptykon Foundation employs ca. nine professionals. The aim of the organisation is to protect freedom and human rights in the surveillance society[40]. The Foundation does not collaborate with organisations that systematically engage in ethics assessment. The Foundation stays in contact with the Inspector General for Personal Data Protection, as well as experts in IT. It is a member of umbrella organisations, such as EDRI[41].
Interest in research and innovation	In the Foundation's scope of interest are different types of surveillance, in which technological innovation plays a significant part (e.g. medical databases, mobile phones and tracking techniques, CCTV cameras, Internet applications, GPS etc.).
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [x] None [ ] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [X]
Terminology for ethics assessment / guidance	The Foundation does not consider its work to be "ethics assessment", however the element of assessing how the implementation of a given technology may affect the rights of an individual is an element of many of its activities.
Name and description of ethics unit(s)	The Foundation does not have a special unit that would deal with ethical issues.
Aims and motivation for ethics assessment	The basic issue of concern is the problem of surveillance that leads to the violations of rights and freedoms.

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[40] https://en.panoptykon.org/about
[41] https://edri.org/

	The Foundation is also concerned about the current situation in which public discourse is dominated by the blind faith that technology is a proper solution to complicated, social problems[42].
Objects and scope of assessment	The Foundation works on the following topics: health surveillance, phone surveillance, law enforcement, urban surveillance, internet surveillance, and video surveillance[43]. Moreover, in one of the new projects the Foundation is taking a closer look at public investments in the surveillance technologies. The aim of the project is to develop a catalogue of surveillance technologies purchased by Polish public institutions and a list of companies delivering them[44]. The Foundation also considers taking a closer look at research projects financed by the public funds. Some of them, e.g. the INDECT[45] project, raised ethical doubts in the past.
Beneficiaries of assessment	The public
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	The Foundation uses different methods. With regard to gathering data – it makes use of freedom of information requests, monitors the institutions, and participates in meetings with representatives of institutions and business. It also receives information from individuals about certain unsettling situations or practices.
Procedure for ethics assessment: during	At the level of advocacy – the Foundation prepares opinions on legal or administrative acts, lobbies at the government or parliamentary level. At times it also initiates court proceedings. The Foundation addresses issues both at the national and European levels – although more focus is put on the domestic activities. The Foundation becomes increasingly involved in educational activities – the aim is to make people realise what the dangers of certain technologies are, and what they can do to avoid them – including by means of technical solutions, such as encryption. The Foundation does not focus on assessing particular technologies but rather on the legal act that concerns their use or implementation. This is partly due to the fact that in some cases the Foundation lacks the necessary expertise to assess the

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[42] http://www.panoptykon.org/wiadomosc/komu-oplaca-sie-inwigilacja

[43] https://en.panoptykon.org/topics

[44] https://en.panoptykon.org/articles/new-project-public-institutions%E2%80%99-surveillance-practices, http://www.panoptykon.org/wiadomosc/komu-oplaca-sie-inwigilacja

[45] http://www.telegraph.co.uk/news/uknews/6210255/EU-funding-Orwellian-artificial-intelligence-plan-to-monitor-public-for-abnormal-behaviour.html

	technology itself. One example is the discussion on smart meters – the lawyers from the Foundation could not verify the technical aspects of the functioning of the meters. This is the reason why they choose to focus on the guarantees provided for by the law.
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [X] implications for privacy [ ] other, specify: [ ] social responsibility Commentary: In its activities the Foundation uses the human rights based approach - the aim of the organisation is to protect freedom and human rights in the surveillance society. The Foundation pays attention not only to privacy but also other rights and freedoms. Privacy is often the starting point for further reflection.
Self-assessments, strengths and weaknesses	N/A
Other	The main problem regarding ethical issues is that, in fact, nobody asks the question about the impact of some technologies on the society, for example the impact on children of the CCTV cameras installed at schools. Politicians, when faced with a problem, try to do something – anything, and introducing technological solutions is the easiest way to go. People tend to believe that technology will solve difficult societal problems – such as the violence at schools. Politicians do not pay attention to the negative effects of some technologies on social relations - for example how cameras impact mutual trust among the society. This is one of the problems related to the issue of surveillance state. Investigating the negative impacts of technologies on the society is something beyond looking at the impact on fundamental rights and freedoms. This issue is a

	question of ethical relevance.

Name of organisation	**Polish Ethics Society** *Polskie Towarzystwo Etyczne*
Type of organisation	Ethics association
Country	Poland
Website address	*General:* www.pte.hekko.pl *Main page(s) on ethics assessment:* same as general address
Basic description (organisation and mission)	Polish Ethics Society was founded in November 2010 upon the initiative of philosophers working at the Institute of Philosophy and Sociology at the Pedagogical University. The mission of the Society consists of, among others, disseminating knowledge of and promoting research in ethics, raising awareness about ethical issues, initiating public debate on ethical and moral dilemmas. There are seven sections within the Society.
Interest in research and innovation	The Society participates to some extent in the process of assessment of research ethics; particularly the Animal Welfare Section assesses the ethics of animal experiments.
Ethics assessment and/or guidance	Assessment [x] Guidance [x] Other [x] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ] Commentary: The Society participates to some extent in the process of assessment of research ethics. Representatives of the section of animal welfare take political action and intervene in cases of greatest significance. They provide advice, draft opinions and lobby in the course of the legislative process.
Terminology for ethics assessment / guidance	The term "ethics assessment" is not used, the activities of the Society are referred to as political action, advice, lobbying.
Name and description of ethics unit(s)	Animal Welfare Section. It is one of the thematic sections of the Society.
Aims and motivation for ethics assessment	The assessment performed corresponds with the mission of the Society. The aim of these activities is to influence the process of introducing new of amending existing laws so that they correspond with the standards of animal protection.
Objects and scope of	Typically the Society assesses draft laws.

assessment	
Beneficiaries of assessment	The Society addresses their activities to politicians, political decision makers.
Ethics assessment unit: appointment process	The membership is open to everyone with appropriate credentials; currently most members are university professors.
Procedure for ethics assessment: before	The Society decides on its own when to take action.
Procedure for ethics assessment: during	The Society cooperates with animal protection organisations. Its role is to channel and make their activities more rational and effective. The organisations have a lot of good will, however in some cases they lack the necessary knowledge. At times it is difficult for them to adopt a constructive and rational position. They limit themselves to protesting against the animal experimentation. The role of the Society is to channel the enthusiasm and turn it into something constructive. The Society catalyses political action and encourages the public to take a stand and express their opinion. It helps in setting realistic goals. It is "the voice of reason". This has a broader social relevance – the Society "prevents explosions" – it makes the process less radical. Thanks to the cooperation in the field of animal experiments the situation in Poland has been relatively calm in comparison to the UK or Germany. The cooperation with organisations is mutually beneficial. The membership of the Society is limited - it consists of several dozens of professors. The organisations have the necessary political power. There would be no success without "the joining of forces". Except for the organisations for the protection of animals, the section of animal welfare does not cooperate with other organisations in the area of ethics assessment.
Procedure for ethics assessment: after	Lobbying by the Society does have impact on politicians. Even though the results are not always satisfactory, one can assume that if the Society did not take any action, the situation could be even worse.
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [x] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards

	[ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: Three Rs (*reduce, replace, refine*) [ ] social responsibility Commentary: The most common guiding principles in animal experimentation are Three Rs (*reduce, replace, refine*). With regard to animal experimentation the Society relies on the principle of respecting lives and interests of all individual subjects (the co-called ethical individualism).
Self-assessments, strengths and weaknesses	One of the main challenges is the fact that the Society has limited resources. Moreover politicians do not have enough good will and some of them are against the very idea of raising the moral status of animals ("animal rights").
Other	N/A

Name of organisation	**The Citizens of Academia (CA)** *Obywatele Nauki*
Type of organisation	National civil society organisation (civic movement)
Country	Poland
Website address	*General:* *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	The Citizens of Academia (CA) civic movement originated to draw attention to the importance of academia for society and the country. The movement originated among members of the academic community representing various disciplines, who are joined by their conviction of the need for change in academia and related areas. The movement is based on the voluntary efforts of academics and those who support academia. Ca. 2000 people signed the manifesto of the movement.
Interest in research and innovation	Initially, CA concentrated on issues related to scientific integrity. One of the main goals of CA is ensuring high quality of research. The interest in ethics is a result of that focus. CA understand ethics of research and innovation broadly. This understanding also covers issues related to the mission of the scientist. It includes the belief that scientists should contribute to ensuring a better future for the society.
Ethics assessment	Assessment [ ] Guidance [x] Other [x] None [ ] Commentary:

and/or guidance	If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ] Commentary: CA does not engage directly in the ethical assessment of research and innovation, however ethical issues lie at the heart of the movement.
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[x] scientific integrity [ ] justice / fairness [x] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [x] other, specify: openness,

	transparency
	[ ] social responsibility
	Commentary: The main values CA advocate for are: openness, transparency, popularisation of science and research results, non-discrimination.
Self-assessments, strengths and weaknesses	The activities undertaken by the Ministry of Science and other collegial bodies are unsatisfactory. They do publish some guidelines and organise meetings, however it has little impact on reality. In addition there are still problems with how the process of public consultations functions - CSOs do not feel the authorities hear and take into considerations their opinions.
Other	The major role of civil society and civil society organisations is that of a watchdog. CSOs can keep an eye on the activities of the authorities. One of the problems faced by civil society that promote research ethics is a rather negative approach towards the very subject of ethics. Many stakeholders perceive promoting ethics as "moralising". The respondent said that in order to avoid such a label CA chooses to use the term "good practices" when referring to ethical issues.

Name of organisation	**Equal opportunities** *Jednake mogučnosti*
Type of organisation	Civil society organisation
Country	Serbia
Website address	*General:* http://www.e-jednakost.org.rs/en *Main page(s) on ethics assessment:* n/a
Basic description (organisation and mission)	The general goal of Equal opportunities (EO) is to strive for equal opportunities (gender equality) with a special focus on modern information and communication technologies. Its aim is to facilitate equal access for both women and men in using modern information and communication technologies (ICT); to bring awareness of gender digital divide and promote bridging the digital gap; to encourage the use of ICT in empowering women and their daily lives. To achieve these aims, EO is building ICT capacity of marginalised groups and does research on gender participation in using of ICT and women in ICT industry.
Interest in research and innovation	New technology motivates the organisation to make it accessible to those that would ordinarily have less chance of making use of it. EO is especially interested in social implications of innovation: who has access to it, what stereotypes are linked with it, for what purposes is it used by different groups, etc.

Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [x] Commentary: If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ] Commentary:
Terminology for ethics assessment / guidance	The organisation does not directly engage in ethics assessment. It does, however, address several ethical questions implicitly in its activities related the societal role of ICT and its use and gender equality.
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	Ethical values and principles explicitly promoted by EO include equality, non-discrimination, and quality of life – especially in relation to ICT technology.
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [x] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards

	[ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [x] social responsibility
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**Consumers in Action** *FACUA-Consumidores en Acción – Consumers in Action*
Type of organisation	Civil Society Organisation – Consumer organisation
Country	Spain
Website address	*General:* http://www.facua.org/ *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	FACUA is an organisation that defends the rights of consumers. They demand improvements in market regulation and control and quality, labelling and advertising of products and services. They question the model of consumer society, based on the promotion of irrational and wasteful over consumption, exploitation of poor countries and the depletion of natural resources of the planet. It has a presence throughout the national territory through associations and territorial delegations, several tens of thousands of members and hundreds of volunteers. Their main mission is to empower citizens as consumers, organise, inform and educate citizens so they have a means to defend themselves against the abuses of the market.
Interest in research and innovation	
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [x] Commentary: They analyse the behaviour of companies, not only if they violate the law, but also whether their practices respond to ethical principles. Ethics is closely linked to legal practice in the market, business relationships, health services, etc. If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
Terminology for ethics	N/A

assessment / guidance	
Name and description of ethics unit(s)	FACUA does not have a specific unit dedicated to ethical assessment, but most of their activity has ethical aspects, that are assessed as needed in each department (legal department, advertising control, complaints, etc.). FACUA has established an internal ethical code, with a committee dedicated to internal ethical control.
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [ ] social responsibility
Self-assessments,	Social movements play an overly pragmatic role, aimed at specific issues, they do

strengths and weaknesses	not dedicate enough time for evaluation and discussion of ethical issues. He considers that recently, due to the economic crisis, society is devoting more attention to ethical issues. Organisations such as FACUA audit indirectly products and services offered to society.
Other	Since this is a consumer organisation, they have the perspective of the recipient of the product, the final consumer. Research ethics should avoid massively extension of the production of a new product without having clearly demonstrated that it is not dangerous. Sometimes new products are released to market due to economic interests regardless of the possible consequences they may have for the mental or physical health of the consumer. They believe that there is a lack of ethics in the markets, as it seems that the important thing is to increase sales. Advertising causes the creation of false needs, artificial dissatisfaction, injustice, generates false ideas of social success. They denounce practices in the market, business sectors or government that they consider lack ethics. They do not participate in ethical assessment in research, but they may occasionally participate in workshops and conferences. Consumer organisations represent the whole society, for that reason he believes that they should participate in ethics committees, so that in the evaluation of research projects the opinion of society (users, patients) is heard.

Name of organisation	**Federation of Patients and Consumers Organisations (NPCF)** *Nederlandse Patiënten Consumenten Federatie (NCPF)*
Type of organisation	Non Assessor / CSO
Country	Netherlands
Website address	*General:* http://www.npcf.nl/
Basic description (organisation and mission)	The Federation of Patients and Consumer Organisations in the Netherlands (NPCF) was founded to bring together hundreds of patient and consumer organisations in the Netherlands to speak as one voice on areas of common interests, such as patients' rights and access to care.
Interest in research and innovation	- Look after the quality of (innovative) health care - Defining the interest of the patients and consumers in innovations such as eHealth and health information accessibility, exchange and privacy - Making information on best practice available to patients

	Solidarity in health care, incl innovations
Ethics assessment and/or guidance	Assessment [x] Guidance [] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [x] Commentary: NCPF was involved in assessing research grant applications for medicines (of ZonMw/NWO), to bring in the experience and perspective of patients. (source in Dutch)
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	*Referentenpanel met ervaringsdeskundigen* (panel of patiënts)
Aims and motivation for ethics assessment	• Access to health care for all, • Quality of care, • Transparency and the position of patient and consumer organisations as a countervailing power to health providers and health insurers, • Solidarity in the health care system, • Strategies for strengthening the position of patients and consumers, • Defining the interest of the patients and consumers in innovations such as eHealth and health information accessibility, exchange and privacy.
Objects and scope of assessment	Bring in patients 'perspective.
Beneficiaries of assessment	Patients
Ethics assessment unit: appointment process	Only (ex) patients with high level of education are selected because grant applications are often complex and in English.
Procedure for (ethics) assessment: before	NCPF matches the project proposals with the right assessing patients (reviewers). Preferably a group of three patients review a project.
Procedure for ethics assessment: during	The group of patients fill out a form, designed by NCPF. This group comes with one common conclusion. NCPF forwards them to ZonMw (NWO/Grant giver). They pass it on to the applicant. The applicant can reply. The information is used in the grant assessment.
Procedure for (ethics) assessment: after	The participating patients receive news on the outcome of the grant application.
Principles and issues in assessment /	[] scientific integrity [] justice / fairness

guidance	[] professional integrity [x] implications for health and/or safety [x] human subjects research [] implications for quality of life [] treatment of animals in R&I [] environmental impacts [] human dignity [] social impacts [] equality / non-discrimination [] outsourcing of R&I to developing [] autonomy / freedom countries with lower ethics standards [] implications for civil rights [] dual use (possible military uses) [] implications for privacy [] other, specify: [] social responsibility
Self-assessments, strengths and weaknesses	This does not refer for self-assessment but patients' assesment as described before. Only (ex) patients with high level of education are selected because grant applications are often complex and in English. The group of patients is not diverse. Some patients are not physically well enough to participate The input from patients is not always taken seriously into account.
Other	N/A

Name of organisation	**Royal Dutch Society of Engineers (KIVI)** *Koninklijk Instituut van Ingenieurs (KIVI)*
Type of organisation	Non-assessor / professional organisation
Country	The Netherlands
Website address	*General:* https://www.kivi.nl/ *Main page(s) on ethics assessment:* A blog: 'Ethics and Engineers' (https://www.kivi.nl/CM/PAG000007238/Blog--ethiek-en-ingenieurs.html).
Basic description (organisation and mission)	KIVI is the Dutch association for engineers and engineering students. With 20,000 members KIVI is the largest engineering association in the Netherlands. All engineering disciplines are oganised within KIVI.

Interest in research and innovation	As the network body for engineers and other highly educated technical professionals in the Netherlands, KIVI's primary objective is to promote the importance of technology in our society. This ensures continuity in adequate investment in education, research and innovation. To meet this objective, KIVI conducts the following core activities: • **Technical promotion** – to promote the role of technology and engineers in general; • **Network** – to stimulate contacts and exchange of knowledge between engineers; • **Member services** – to provide services that assist members with the development of their professional careers. The key issues in KIVI are: • Education – quality of higher technical education; • Politics and technology – Solicit attention to technical aspects of topics that get/deserve public attention; • International – international recognition of Dutch professional education and certificates; • Technology-pact – structural attention to technology in primary education; • Technology promotion among the youth. **Annual topic 2015: technicians in the valleys of the future**. The Netherlands has several innovation valleys (like silicon valley) such as Chemelot (chemistry and materials), de High Tech Campus Eindhoven, Maintenance Valley, Food Valley, Watercampus, Medical Delta, Automotive Campus, Health Valley, Healthy Ageing Campus, Energy Valley, Sensor Valley, Bio Science Park, etc. All initiatives stimulate innovation, often with the objective to stimulate economic activities. KIVI will pay attention that technology will get a prominent role in each of these valleys.
Ethics assessment and/or guidance	Assessment [ ] Guidance [x] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ] Commentary: A blog 'Ethics and Engineers' (https://www.kivi.nl/CM/PAG000007238/Blog--ethiek-en-ingenieurs.html) (KIVI, 2015). Sessions on 'philosophy and technology'. Ethical issues are prominent in the list of activities. In the period February – May 2015 seven activities have 'ethics' the title (Ethics and military robots, ….robots, …healthcare, ….

	Committee Exploration innovative technologies of the council on habitat and infrastructure looks at the impact of technological innovation on the public and private domain in the area of healthy food, efficient mobility and smart buildings. Code of conduct for their members (KIVI, 2006). (https://www.kivi.nl/CM/PAG000002804/Gedragscode-2006.html)
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	KIVI is not engaged in ethics assessment. *Ethical Guidance:* A confidant can be contacted by members. This person can act as a sounding board.
Aims and motivation for ethics assessment	KIVI is not engaged in ethics assessment. It does facilitate a discussion on ethical issues among its members. KIVI also promotes ethical behaviour among its members
Objects and scope of assessment	KIVI is not engaged in ethics assessment. KIVI does facilitate a discussion on ethical issues among its members. KIVI also promotes ethical behaviour among its members. KIVI brings together engineers from a wide variety of disciplines and professional roles to support them in their work. KIVI offers guidance and a platform for exchange.
Beneficiaries of assessment	Ethical guidance to support the members of KIVI
Ethics assessment unit: appointment process	KIVI is not engaged in ethics assessment.
Procedure for (ethics) assessment: before	KIVI is not engaged in ethics assessment.
Procedure for ethics assessment: during	KIVI is not engaged in ethics assessment.
Procedure for (ethics) assessment: after	KIVI is not engaged in ethics assessment.
Principles and issues in assessment /	[x] scientific integrity [ ] justice / fairness

guidance	[x] professional integrity [x] implications for health and/or safety
	[x] human subjects research [x] implications for quality of life
	[x] treatment of animals in R&I [x] environmental impacts
	[x] human dignity [x] social impacts
	[ ] equality / non-discrimination [x] outsourcing of R&I to developing
	[x] autonomy / freedom countries with lower ethics standards
	[x] implications for civil rights [x] dual use (possible military uses)
	[x] implications for privacy [x] other, specify:
	[x] social responsibility
	Commentary: KIVI brings together engineers from very different types of disciplines. From biomedical and military, to automotive and nuclear engineering. Its members therefor touch many different kinds of ethical issues.
Self-assessments, strengths and weaknesses	It does not have strict mechanism to check whether its members act ethically but KIVI does not claim this role either. It does explore and discuss ethical issues with its members.
Other	N/A

Name of organization	Partos
Type of organization	Civil society organisation/Association for NGOs working in International Development
Country	The Netherlands
Website address	*General:* https://www.partos.nl/home/en
	Main page(s) on ethics assessment: • Partos Code of conduct https://partos.nl/webfm_send/75344 • International Framework for CSO Development Effectiveness http://cso-effectiveness.org/InternationalFramework?lang=en
Basic description (organization and mission)	Partos is the association representing Dutch NGOs working in International Development. The association creates a platform for 120 Dutch development organisations working in the field of poverty reduction, humanitarian aid, human rights and sustainable development.[46] These organisations work in development- and middle income countries cooperating with local partner organisations.[47]

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[46] Partos, https://www.partos.nl/home/en
[47] Ibid.

	However, many of the organisations also work in the Netherlands and within the EU.[48] The European activity focuses on knowledge development and policy advice.[49]
Interest in research and innovation	Partos interest in R&I is related to knowledge and effectiveness. It is important to make use of the knowledge available and that all your activities are research based. The ethical, social and environmental issues relate to the core of Partos activity. The Partos Code of Conduct includes various ethical issues that serve as a checklist when applying members' activities.
Ethics assessment and/or guidance	Assessment [x] Guidance [ ] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ] Commentary: The ethics assessment is conducted regarding members potential misconduct in their international development activities.
Terminology for ethics assessment / guidance	Innovation for Partos is perceived as social innovation because everything they do is based on a social agenda. Innovation is not about improving the things you do, but doing things differently to address new possibilities and challenges. Ethics assessment is closely related to Partos main interest - knowledge and effectiveness. Innovation is not about improving the things you do, but doing things differently to address new possibilities and challenges.
Name and description of ethics unit(s)	Partos does not have a specific unit for ethics assessment. Nevertheless, they have a unit that deals with knowledge quality and effectiveness and innovation. As part of this unit, Partos developed a code of conduct for its members, which includes ethical values according to which members should operate. In the opinion of the interviewee these ethical values can be translated into anything related to innovation. Last year, Partos published a strengthened focus on innovation. Currently, Partos is developing an innovation program including an innovation hub.
Aims and motivation for ethics assessment	The overall mission is to support Dutch development organizations in their work for global development and poverty reduction. Partos does that by lobbying and influencing policy making on behalf of their interest: including communication activities and a knowledge and effectiveness program. For this, Partos has developed joined evaluations, a code of conduct and a quality norm, the Partos 9001 that is based on the ISO 9001. Furthermore, Partos has learning platforms for the members to share knowledge and develop it. Currently, Partos is in the phase of developing an innovation program. The effectiveness of Dutch civil society organisations in international development is the main focus of the organisation.
Objects and scope of assessment	The ethics assessment is conducted regarding members potential misconduct in their international development activities. The Partos Code of Conduct is a general reference point for all member organisation of generally applicable values endorsed by Partos members as the basis for the activities of the member organisations.
Beneficiaries of assessment	In a narrow sense the beneficiaries of the assessment are the members of Partos – Dutch development organisations. In a broader sense, also local partner

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[48] Ibid.
[49] Ibid.

	organisations, local communities, the public could be considered as beneficiaries of the assessment, as the assessment of members' activity may have an influence on their day-to-day life.
Ethics assessment unit: appointment process	Regarding the assessment (appeal procedure), the interviewee said she is the secretary of the complaints commission, however the commission itself consists of external members. Nobody involved in the development sector or Partos as such is engaged in the commission. This commission deals with complaints.
Procedure for ethics assessment: before	Regarding the assessment (appeal procedure), Partos works on the basis of external complaints.
Procedure for ethics assessment: during	Partos has created a Partos Code of Conduct, which has been signed by all members and agreed upon on the highest management level – the board of directors. That is a way of implementing the ethical values. Member organisations are accountable on the basis of the Code. Nevertheless, it is up to them how they do that (some of them have a complaints procedure). If somebody from the public or a company wants to file a complaint on the basis of the code of conduct, they should address the member first. Once they were able to explain themselves, but the complainer is still not satisfied with the answer, he can still file a complaint to Partos that has its own internal appeal procedure. The complaints commission deals with complaints.
Procedure for ethics assessment: after	All complaints are being published on the website with the decision of the commission. There are a certain number of norms in the Partos Code of Conduct that are obligatory. If members do not comply with the provisions, they could be expelled from Partos.
Principles and issues in assessment / guidance	[x] scientific integrity [x] justice / fairness [x] professional integrity [x] implications for health and/or safety [ ] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [x] environmental impacts [x] human dignity [x] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [x] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [x] social responsibility Commentary: according to the Partos Code of Conduct, the member organisations should aim at three types of goals:[50] 1. Sustainable societal development, which includes sustainable positive change; local ownership; partnership relationships based on shared values such as equality, complementarity, mutual respect, trust, autonomy of the organisation and shared long-term goals, solidarity and global citizenship;

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[50] Partos, Code of Conduct, translation into English 2001, https://partos.nl/webfm_send/75344.

	2. Professional organisation, that should be based on professionalism and effectiveness; the creation and sharing of expertise; financial standards; transparency and accountability; good employment standards; good governance; 3. Communication and fundraising, focusing on responsible fundraising methods and external publications. The Partos Code of Conduct makes an explicit reference to human rights, respect for the human dignity, the equality of all mankind, solidarity and justice, gender equality, vulnerable people, adherence to the generally applicable standards for Socially Responsible Enterprise, the health and safety and welfare of all employees and volunteers.[51]
Self-assessments, strengths and weaknesses	One of the strengths and the added value of civil society organisations is that they work in the interest of local people, not of governments. They have a good local network, so they are well-informed of any issues in the field and they have the capacities to develop lobby- and campaign strategies to address the issues. Regarding weaknesses, there is a great diversity amongst the member organisations. The interviewee said that there is room for improvement, but Partos can only act on the basis of complaints. In some cases more could be done to involve local citizens in research and innovation projects. Innovation and scaling of innovation should be done on the basis of good research and feedback from the field, but the interviewee is not sure if it is always done properly.
Other	According to the interviewee, any political decision maker should take into account the ethical issues of any project, also in the area of research and innovation. Ethics assessment should be better integrated in political decision-making through providing information and training about ethical issues for decision makers and including these in the decision-making procedures.

Name of organisation	**Genetic Alliance UK**
Type of organisation	National civil society organisation
Country	United Kingdom
Website address	*General:* http://www.geneticalliance.org.uk/ *Main page(s) on ethics assessment:* N/A
Basic description (organisation and mission)	Genetic Alliance UK is a UK umbrella organisation for those affected by genetic conditions. It is primarily a membership organisation in that it includes more than 180 patient organisation members each of which deliver care and support and in

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[51] Ibid.

	some cases fund research into individual genetic conditions, ranging from very rare diseases to relatively common single gene disorders or chromosomal abnormalities and common complex diseases that have a genetic component (e.g. heart disease). Genetic Alliance supports, campaigns and unites members and those affected by genetic conditions. Its focus is predominately on **policy work** in the following areas: 1) living with a genetic condition (e.g. genetics and insurance); 2) access to diagnostics and treatment in the health service for people affected by genetic conditions (e.g. the commissioning of genetic testing) and 3) focus on innovation pathway from basic research to clinical findings (addressing unmet needs of the genetic community) and making sure that there is a legal process to access that treatment, that it passes its cost-effectiveness trials and then into commissioning. This includes working with NICE (National Institute for Health and Care Excellence), the European Medicines Agency and also doing work around the regulation of medical research and non-clinical medical research, animal research, etc.
Interest in research and innovation	Please see text above.
Ethics assessment and/or guidance	Assessment [ ] Guidance [ ] Other [ ] None [x] Commentary: While Genetics Alliance UK has no ethics department, ethical considerations touch on most of the work they do. They also do project work, e.g. educating members about specific issues or a particularly targeted campaign or a network between members. Two of those projects include a permanent role in projects including Rare Disease UK (a campaign on rare disease strategy in the UK) and SWAN UK (a patient network for people with undiagnosed children). In some cases, consideration of ethics extends to relationships with those members of those projects, in addition to higher, more abstract consideration of ethical issues around policy work. Moreover, there is a culture of discussion of ethical issues within the organisation but no specific framework.
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	N/A
Objects and scope of assessment	N/A
Beneficiaries of assessment	N/A
Ethics assessment unit: appointment	N/A

process	
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [ ] justice / fairness [ ] professional integrity [ ] implications for health and/or safety [ ] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [ ] social responsibility Commentary: ethical issues of concern to the organisation: Research involving animals is a particular issue. There are many unmet health needs within the communities that they represent – there is a need to balance that need to address the lack of treatments with the impact of the research process required to address those needs. One of those impacts is that it is currently necessary to use animals to research the causes of genetic diseases and potential treatments. When thinking about policy in this area, the organisation will have discussion around the balance between the harm to animals in carrying out that research and the potential benefit to patients. Genetic Alliance UK has taken the position that while no one wants to see research done on animals *per se,* because they regard research to develop cures and treatments for rare diseases as paramount to improving the lives of those affected, they therefore support animal research under certain circumstances where there is no alternative, where the experiment has been refined to the maximum possible degree and made efficient as possible and as minimally invasive to the animal as possible, and where all alternatives have been properly exhausted. Research involving human embryos is another ethically controversial issue. The organisation follows the same stream of logic regarding this issue, i.e. the need for research to meet and address an unmet need outweighs the issues surrounding the use of human embryos in research. Once the

	organisation is sure that research has been ethically reviewed in an appropriate manner, they will support it because they need every avenue that could lead to a cure or treatment to be investigated thoroughly.
Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**SciDev.Net**
Type of organisation	Civil society organisation
Country	International organisation (UK)
Website address	*General:* http://www.scidev.net/ *Main page(s) on ethics assessment:* n/a
Basic description (organisation and mission)	SciDev.Net is committed to bringing scientific evidence and technological innovation to development policy and practice. This is done through original journalism and support to improving the practice of science journalism, particularly in the global south. Development is defined as sustainable equitable development with a focus on poverty alleviation. The organisation's aims include providing access to understandable scientific information, providing socio-economic analysis of research findings, capacity building to support and sustain uptake of science, etc. On www.scidev.net, news, analysis and a variety of multimedia content are provided.
Interest in research and innovation	Research and innovation is being considered from the viewpoint of uptake, usage and impact. There are ethical concerns about the practice of research (principles of sustainability and equity), the implications for research (for development) and communication of research (by researchers themselves and by science journalists).
Ethics assessment and/or guidance	Assessment [ ] Guidance [x] Other [x] None [ ] Commentary: Developmental impact assessment when reporting on scientific practices; guidance for science communication and journalism If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	SciDev does not do ethical assessment as such but it could be said many of their stories are ethics assessments of R&I implicitly. The organisation is not likely to use the word "ethics". From SciDev's perspective, ethical R&I is R&I that can be

	instrumentalised for developmental outcomes.
Name and description of ethics unit(s)	N/A
Aims and motivation for ethics assessment	SciDev believes an important aspect of research practice should be an instrumental application for global development practices. Sometimes development implications of R&I are not clear at first, but when reflecting on research, it is important to engage in an interdisciplinary conversation.
Objects and scope of assessment	News stories and reports on developmental impacts of R&I and ethical issues in science communication and journalism.
Beneficiaries of assessment	Public interest.
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[x] scientific integrity [x] justice / fairness [ ] professional integrity [x] implications for health and/or safety [ ] human subjects research [x] implications for quality of life [ ] treatment of animals in R&I [x] environmental impacts [ ] human dignity [x] social impacts [x] equality / non-discrimination [x] outsourcing of R&I to developing [x] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [ ] dual use (possible military uses) [ ] implications for privacy [ ] other, specify: [x] social responsibility

Self-assessments, strengths and weaknesses	N/A
Other	N/A

Name of organisation	**European civil society organisation** Interviewee asked for the name of the organisation to remain anonymous.
Type of organisation	Civil society organisation
Country	UK/Europe
Website address	N/A
Basic description (organisation and mission)	The organisation is a non-profit-making voluntary group comprised of lawyers, academics, journalists, researchers and community activists. Its European network of volunteer contributors is drawn from 18 countries. It encourages the publication of investigative journalism and critical research in Europe the fields of the state, justice and home affairs, civil liberties, accountability and openness. One of the organisation's primary purposes is to provide a service for civil society to encourage informed discussion and debate - through the provision of news, features and analyses backed up by full-text documentation so that people can access for themselves primary sources and come to their own conclusions. The organisation is funded by grant-making trusts and donations from individuals. Volunteer contributors include anyone the organisation comes across in its work and sends information to it with interests in the work it carries out or has interests in. The organisation's constituency is those interested in the information it provides and also those who don't have a strong interest but might read something it publishes, get interested and take action on it.
Interest in research and innovation	The organisation has an interest/stake in research and innovation (in particular, with regard to ethical, social implications).
Ethics assessment and/or guidance	Assessment [x] Guidance [ ] Other [ ] None [ ] Commentary: It does not have a unit specifically devoted to ethical issues. Ethical issues are examined as part of its investigative and critical research work. If assessment/guidance is undertaken: In-house [ ] Outsourced [ ] Other [ ]

Terminology for ethics assessment / guidance	Ethical issues. The organisation is not an ethics assessor and does not use the term 'ethics' in its work, but indirectly engages in ethics assessment by investigating and publishing about issues of ethical concern.
Name and description of ethics unit(s)	It does not have a unit specifically devoted to ethical issues. Ethical issues are examined as part of its investigative and critical research work.
Aims and motivation for ethics assessment	The organisation's work involves the examination, for instance, new technologies, and effects of the development of new technologies. It looks at issues such as surveillance, privacy, data protection, border security, right to claim asylum. Investigation and critical analysis depends on the case at hand.
Objects and scope of assessment	The organisation uses global and regional human rights and civil liberties standards and principles and case law as a basis of the evaluations.
Beneficiaries of assessment	The organisation, European society.
Ethics assessment unit: appointment process	N/A
Procedure for ethics assessment: before	N/A
Procedure for ethics assessment: during	N/A
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [x] justice / fairness [ ] professional integrity [x] implications for health and/or safety [x] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [x] human dignity [x] social impacts [x] equality / non-discrimination [ ] outsourcing of R&I to developing [x] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [x] dual use (possible military uses) [x] implications for privacy [ ] other, specify:

	[x] social responsibility Commentary: Marked according to data gleaned from interview, but more categories might be applicable as the scope of the organisation's evaluations may vary. Note, the organisation uses global and regional human rights and civil liberties standards and principles and case law as a basis of the evaluations. Also relevant here are its Charitable Objects. Ethical values and principles explicitly promoted include: privacy, data protection, freedom of speech and expression, non-discrimination, rule of law.
Self-assessments, strengths and weaknesses	The organisation might advocate a certain viewpoint but unlike other civil society organisations or NGOs does not run campaigns. By transmitting information, it acts as a sort of a conduit between people who observe what is going on and those that take action. Other CSO organisations may play a different role. In terms of contribution, a CSO brings a different perspective as compared to other actors such as those responsible for drafting research agendas. When there are different types of stakeholder's one party always has more power (influence, money) and that is the outcome of political economy. One point of note is whether and to what extent such types of organisations can influence the research agendas – for instance by ensuring they are privacy and ethics friendly.
Other	Conceptions of ethical issues (e.g. as shown in the case of privacy and data protection) differ. This enhances the complexity of dealing with ethical issues. The organisation does not, for this reason, have a single tick-box exercise to assess ethical issues but examines and analyses these as they arise in its work on a case by case basis. There are some common problems but you have to look at the detail in each project.

Name of organisation	**American Association for the Advancement of Science (AAAS)**
Type of organisation	Civil Society Organisation
Country	USA
Website address	*General:* http://www.aaas.org/ *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	The work of the AAAS includes the promotion of responsible science, to increase the public engagement with science and to protect the integrity of science[52]. AAAS further publishes the renowned scientific journal *Science[53]*.

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[52] http://www.aaas.org/about-aaas
[53] http://www.aaas.org/science-journals

	The mission of AAAS is "[…] to "advance science, engineering, and innovation throughout the world for the benefit of all people."[54]"
Interest in research and innovation	As a scientific CSO the AAAS interest is obvious.
Ethics assessment and/or guidance	Assessment [ ] Guidance [x] Other [ ] None [ ] Commentary: If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ] Commentary:
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	The *Scientific Responsibility, Human Rights and Law Program* (SRHRLP) is part of the Center Science, Policy and Society Programs under AAAS. The program "addresses ethical, legal and human rights issues related to the conduct and application of science and technology.[55]"
Aims and motivation for ethics assessment	Two specific examples that led to the SRHRLP is an investigation into the treatment of two scientists and student activist protesting the "[…] irresponsible complicity by scientists with the military in perpetuating the Vietnam war.[56]" These and other examples led to AAAS "[…] develop[ed] policies and procedures to protect scientists, engineers and health care professionals against infringements of scientific freedom and responsibility, to monitor policies and actions taken by governments that might affect their professional rights and duties, and to promote attention to scientific freedom and responsibility within AAAS, its affiliated societies, and the general public.[57]"
Objects and scope of assessment	SRHRLP does specific projects related to contested of science and engineering. According to their homepage the projects falls into two broad categories: *Human Rights* and *Ethics and Law[58]*. Examples of specific projects are the *Human Rights Action Network* (calls to attention human rights abuses involving scientists[59]) and Forensic Science Assessments (an evaluation of studies into forensic tools currently used in the justice system and recommendation of a research agenda for the field)[60].
Beneficiaries of assessment	Some of the reports by SRHRLP are aimed as policy or legal recommendation, while some reports, are an attempt to educate and explain issues to. SRHRLP has

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[54] http://www.aaas.org/about-aaas

[55] http://www.aaas.org/page/srhrl-about

[56] http://www.aaas.org/page/srhrl-history

[57] http://www.aaas.org/page/srhrl-history

[58] http://www.aaas.org/program/scientific-responsibility-human-rights-law

[59] http://www.aaas.org/page/aaas-action-alerts

[60] http://www.aaas.org/page/forensic-science-assessments-quality-and-gap-analysis

	further assisted the Government in developing new regulations.
	The results of projects are used by a very varied group and depend on the specific projects, examples are the media, universities, CSOs, industry or other scientific societies.
Ethics assessment unit: appointment process	In many ethic assessment projects is the work done by a committee and in some cases by researchers. If the AAAS does not have the expertise within the organisation, they often use external experts. AAAS they can rely on a broad range of expertise from their members.
	Two to three persons are involved in ethical assessments at the SRHRL, with the same amount of people covering legal assessments. The expertise of the ethical assessment group is a recent interviewee (Mark Frankel) and one scientist who focuses on the legal issues of Science and Technology, while the one junior staff-member changes from time to time.
Procedure for ethics assessment: before	SRHRLP projects are mainly funded by external sources. SRHRL therefore competes for grants in order to receive the necessary funding.
Procedure for ethics assessment: during	The most important organisations of interaction for the SRHRL are dependent on the project, but providers of funding are considered to be important. Another important collaboration partner might be other scientific societies. In some cases SRHRL have collaborated with organisations, which are not scientific societies, e.g. organisations who does work within science policy or science ethics, but it is different from project to project.
	The SRHRLP is advised by two standing Committees appointed by AAAS. **"The Committee on Scientific Freedom and Responsibility […] advises on issues related to human rights, freedom of scientific inquiry, and the professional responsibilities of scientists and engineers. The National Conference of Lawyers and Scientists […] is a joint committee of AAAS and the American Bar Association's Section of Science and Technology Law.[61]"**
	It depends on the project whether or not the public is consulted. Some of the projects of the SRHRLP have a public component, where the public is asked to comment or give feedback on the findings of a project. This is done through a number of methods, e.g. as a public meeting or via the internet. Some projects may consult with public advocacy groups, e.g. work done within stem cell research. The SRHRL have also held a series of public events not tied to a specific project, but as an outreach program. This should be seen as a way of getting the public interested and educated.
Procedure for ethics assessment: after	The projects mostly end with a deliverable, typically a report, with most of them available on SRHRLP website[62].
	The recommendations of SRHRLP are non-binding and the program has no

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[61] http://www.aaas.org/page/srhrl-about
[62] www.aaas.org/program/scientific-responsibility-human-rights-law

	formal authority other than moral suasion and the reputation of the AAAS.
Principles and issues in assessment / guidance	[x] scientific integrity [x] justice / fairness [x] professional integrity [ ] implications for health and/or safety [x] human subjects research [ ] implications for quality of life [ ] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [ ] implications for civil rights [ ] dual use (possible military uses) [x] implications for privacy [x] other, specify: Human Rights as a general subject seems important to SRHRLP, while also the Law in relation to number of subjects is important. [ ] social responsibility Commentary: The SRHRLP uses ethical values, principles and directives created both in- and externally. For the content of statements and resolutions with an ethical component, SRHRLP look at what the AAAS has previously stated to ensure consistency, if not the SRHRL would offer an alternative or update. Another example would be AAAS' work on human rights, where they use the universal declaration of human rights as basis. In general must any statement or research done by the AAAS be consistent with their mission, which has embedded values. The above are some principles and issued that can be inferred from recent reports.
Self-assessments, strengths and weaknesses	The impact of the work of SRHRLP is unknown to the interviewee, Mark Frankel, a recent interviewee, other than the experience of having a good reputation and being asked often for advice, e.g. by members of congress or civil servants. SRHRL has no procedures for assessing the impact of their assessments (see above). There might be Ad Hoc efforts in the AAAS to estimate the impact. From academic referencing, the SRHRLP can see that their results have been used quite a lot in scientific literature. There are very few empirical studies on what scientists believe their social responsibility to be. In contrast there are many studies attitudes to their professional responsibility. SRHRL has recently distributed a questionnaire on social responsibility to investigate the expectations and the actual behaviour of scientist and researchers. The knowledge from this study should form the background for a globally distributed, statistical generalisable survey.
Other	In general, RRI is seen as more popular in the EU than in the USA. In the USA attention has primarily been given to the professionally responsibility of the researcher, i.e. not to falsify and only take authorship where it is appropriate. Within the last decade, however, there has been a larger emphasis on the need for

professional responsibility to integrate a notion of social responsibility of science. European research communities seem to be ahead when it comes to the issue of responsible innovation and social responsibility. SRHRL makes an effort to change the current status by for example giving talks where the relationship between scientists professional and social responsibility is the topic.

Name of organisation	Public Responsibility in Medicine and Research (PRIM&R)
Type of organisation	National Civil Society Organisation
Country	USA
Website address	*General:* http://www.primr.org/ *Main page(s) on ethics assessment:*
Basic description (organisation and mission)	PRIM&R is a 40 years old, non-profit organisation. Their mission is to advance "[…] the highest ethical standards in the conduct of biomedical, behavioral, and social science research. We accomplish this mission through education, membership services, professional certification, public policy initiatives, and community building.[63]" The eight core values of PRIM&R are excellence, community, diversity, integrity, knowledge, respect, social responsibility and creativity[64]. PRIM&R has approximately 4.000 individual professional members. "Membership is open to anyone whose responsibilities and interests include advancing the highest ethical standards in the conduct of research[65]". "PRIM&R is governed by a Board of Directors responsible for the oversight of all activities and programs in addition to the implementation of new projects that benefit members and the community.[66]"
Interest in research and innovation	As a membership organisation for medical research professionals and with a mission focusing on research PRIM&R has a clear interest in research and innovation. According to a recent interviewee they are mainly focused on the protection of animals and humans subjects that are used in research.
Ethics assessment and/or guidance	Assessment [ ] Guidance [x] Other [x] None [ ] Commentary: PRIM&R engages in ethics guidance by providing and organising courses related to ethical conduct of biomedical, social science and behavioral research and through their public policy piece.

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[63] http://www.primr.org/about.aspx?id=1487
[64] http://www.primr.org/about.aspx?id=1487
[65] http://www.primr.org/Subpage.aspx?id=1869
[66] http://www.primr.org/about/

	If assessment/guidance is undertaken: In-house [x] Outsourced [ ] Other [ ]
Terminology for ethics assessment / guidance	N/A
Name and description of ethics unit(s)	The entire organisation has a focus on advancing ethical standards of biomedical, behavioural and social science research.
Aims and motivation for ethics assessment	According to the homepage of PRIM&R the two core goals of the organisation are: "Creating a strong and vibrant community of ethics-minded research administration and oversight personnel, and providing educational and professional development opportunities that give that community the ongoing knowledge, support, and interaction it needs to raise the bar of research administration and oversight above regulatory compliance.[67]"
Objects and scope of assessment	PRIM&R provides education to people in the biomedical, behavioral, and social science research fields, primarily related to human subjects and animals.
Beneficiaries of assessment	The beneficiaries of the assessments are primarily the members of the PRIM&R, i.e. primarily IRB and IACUC administrators and staff, as well as administrators, researchers, research staff, institutional officials, government representatives, subject advocates, ethicists, policy makers, pharmaceutical and biotechnology personnel, academics, and attorneys working in research ethics, human subject protections, animal care and use and biosafety.
Ethics assessment unit: appointment process	PRIM&R has 18 staff members and most of them are not subject matter experts in ethics. The staff members do the administration of the conferences and short courses. PRIM&R depend on people who are working in the field, senior IRB administrators, other kinds of compliance administrators and policy makers to design and teach the substance of their programs. PRIM&R depend on volunteers and have a core group they rely on. This group has been a part of the organisation for a long time and the volunteers are very senior. They are for example senior IRB administrators, which help PRIM&R to identify emerging issues and recommend new courses. PRIM&R invite people from outside the organisation to do the teaching of their courses.
Procedure for ethics assessment: before	PRIM&R do short educational courses. To set up a course PRIM&R identify people in their voluntary committee who are experts in a particular area and work closely with them to develop the content of the course. On top of that PRIM&R has a director of education and professional development who knows about adult learning principals, structures and designs who makes the structure and turns it into a PRIM&R course. Different faculties are able to teach it. The experts get paid for the development of the course.

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[67] http://www.primr.org/about/

Procedure for ethics assessment: during	PRIM&R ethical guidance takes form are educational projects. For instance PRIM&R has recently held their annual conference on advances in ethics and research on human subject research. There were 2400 attendees and 350 subject matter experts who were teaching across that program. PRIM&R do short educational courses. To set up a course PRIM&R identify people in their voluntary committee who are experts in a particular area and work closely with them to develop the content of the course. On top of that PRIM&R has a director of education and professional development who knows about adult learning principals, structures and designs who makes the structure and turns it into a PRIM&R course. Different faculties are able to teach it. The experts get paid for the development of the course.
	PRIM&R collaborate with many organisations like the Kennedy institute that have similar goals but with different audience and experts to combine strengths. PRIM&R is about to launch an educational program with 'Citi programme'. They recently co-hosted a webinar with the Presidential Commission for the Study of Bioethical Issues. PRIM&R co-sponsor the Asia Pacific Research Ethics Conference (APREC), which is the only Asia Pacific platform focusing on Human Subject Protection.
	Tools and methods used to do different educational programs are: 'At Your Doorstep program' where PRIM&R comes and educate at the institution, PRIM&R conferences, PRIM&R develops educational materials, PRIM&R offers an online course for students to navigate the human subject protection landscape called E-ROC. PRIM&R host Regional meetings that make experts, ideas, information, and networking readily available. PRIM&R uses webinars as an educational and information tool.
Procedure for ethics assessment: after	N/A
Principles and issues in assessment / guidance	[ ] scientific integrity [x] justice / fairness [x] professional integrity [x] implications for health and/or safety [x] human subjects research [x] implications for quality of life [x] treatment of animals in R&I [ ] environmental impacts [ ] human dignity [ ] social impacts [ ] equality / non-discrimination [ ] outsourcing of R&I to developing [ ] autonomy / freedom countries with lower ethics standards [x] implications for civil rights [ ] dual use (possible military uses) [x] implications for privacy [ ] other, specify: [x] social responsibility Commentary: PRIM&R is primarily focused on human and animal subjects

	research, though a recent interviewee stated at great number of other areas of concern.
Self-assessments, strengths and weaknesses	N/A
Other	A recent interviewee stated that a general challenge for ethical assessment is, at the moment, the lack of dialogue and translation between academic research, payments, exploitations and the people doing the on the ground practices, i.e. a gap between research and practice.
	There is a role for CSOs who can do translation work between more formal, academic ethics assessment and act as a bridge between researchers and practitioners. PRIM&R wants to help in this area and has added some sessions to their annual meeting with focus on how to engage and read the empirical literature on research ethics. PRIM&R is also trying to educate their members on how to engage with the literature and they are in contact with journals who publish research ethics and they discuss how the research can be made more useful for the community.
	Another challenge stated is whether ethics gets lost in institutional recourses and budgets and the bureaucracy around research. Where the interviewee found that people in general are not good at extracting what really needs ethical consideration. The problem with bureaucracy is that ethics becomes check boxes. The interviewee recommends that there should be more focus on worrisome ethical issues and that regulatory flexibility should be emphasised where possible. Another suggestion for the future is that ethics and informed consent should be taught at high school level, because people are in a vulnerable position when they sign up for medical research.