



Models for ethics assessment and guidance at CSOs

Authors:

Zuzanna Warso (Helsinki Foundation for Human Rights)

Dalibor Petrović (Center for the Promotion of Science)

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Annex 6

A reasoned proposal for a set of shared ethical values, principles and approaches for ethics assessment in the European context

Deliverable 4.1

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1 INTRODUCTION

This report is the result of work on Task 4.2.5. The aim of this report is to investigate how Civil Society Organisations (CSOs) can effectively become involved in ethics assessment and guidance, both formally and informally. Most of the discussion will be based on the SATORI Deliverable 1, Annex 3.g report on Civil Society Organisations and the Deliverable 4.1 reports, particularly report 4.1.3 on ethics assessment (EA) procedures. Additionally, literature on CSOs related ethics assessment as well as interviews with CSOs representatives will be consulted.

Civil society is perceived as a social sphere separated from the state and market. It is an active and communicable field (public domain), where interests steaming from the private (individual and family) and collective life (domain of education, health, housing, environmental protection, gender issues, work) are articulated from the perspective of “public use of reason for the common good”. Civil society is a field of public action of autonomous individuals, responsible citizens, who form voluntary associations, ad hoc initiative groups, civic movements, non-governmental organizations, networks of associations, in an attempt to fight against any sort of overextended state power or colonization of life by heteronymous factors of domination, or against “democratic deficit” inside modern polity.¹

Civil society is most visible and influential trough the work of Civil society organisations, i.e. non-governmental, not-for-profit, voluntary organizations formed by people in the social sphere between family and state. This term is used to describe a wide range of organizations, networks, associations, groups and movements that are independent from government and that sometimes come together to advance their common interests through collective action. Many CSOs act as control mechanism forcing authorities to be accountable and transparent. They are channels through which citizens and communities articulate their “true interests”.²

There are many typologies of CSOs. One of most recognised and used categorisation is International Classification of Non-profit Organizations, (ICNPO) that identifies twelve different categories of civil society organization activity³. These are: 1. Culture and recreation; 2. Education and research; 3. Health, 4. Social services; 5. Environment; 6. Development and housing; 7. Civic and advocacy; 8. Philanthropic intermediaries; 9. International; 10. Religious congregations; 11. Business and professional unions; 12. Not elsewhere classifies. Each of these broad categories in turn is further subdivided into subcategories.

For the purpose of the SATORI project we have accepted a broad categorization of CSOs based on their societal role and connections with R&I. Consequently, the possible types of CSOs could be: religious, environmental, civil liberties, consumer, developmental, animal

¹ Vujadinovic, D., *Civil society in contemporary context*, Faculty of Law of the University of Belgrade, 2009

² Vukovic, D., Social economy, civil society and the Serbian welfare system, in Cvejic, S. (ed). *Cooperatives and Social Enterprises in Europe and in Transitional Contexts*, ISI and Euricse 2013.

³ http://ccss.jhu.edu/wp-content/uploads/downloads/2011/09/CNP_WP19_1996.pdf

rights, disease charity, patient/disabled rights organisations and labour unions.⁴ Furthermore there are specific categories of CSOs such as trade unions and employers' organisations, the so-called social partners as well as professional associations. The size and organisational structure of CSOs is also very diverse ranging from very small to massive organisation with hundreds of employees operating from local (community, city) to regional, national or international level.⁵

This diversity in terms of their aims, cultural and value diversity, expertise, organisational structure and level/scale of activity significantly limits the possibility of creating common models for ethics assessment and guidance, which would be applicable for all CSOs.

For the majority of CSOs their relationship with R&I is rather sporadic and indirect, although there are some CSOs with direct involvement in R&I (different associations of professionals, patient organisations, animal welfare organisations). On the other hand, as society and individuals are influenced by scientific development in everyday life as well as face (un)wanted consequences of that development, CSOs as their representative face ethical questions regularly. That is why many CSOs perform some kind of informal ethics assessment or guidance of R&I, although their activities may not always be labelled as such. In other word, although an organization does not consider its work to be “ethics assessment”, the element of assessing how the implementation of, let say, a given technology may affect the rights of an individual is an element of their advocacy work. Primarily it is a type of policy-oriented assessment or guidance regarding (new) scientific fields, methods, techniques, technologies, devices or innovation areas. CSOs also have an important role in public discussions about ethical issues. In some cases, if the legal provisions envisage this, CSO representatives participate in the work of research ethics committees.

The analysis of ethics assessment and ethical guidance done by CSOs, performed in the SATORI project, identified two basic sets of problems and challenges faced by CSOs that may affect their activities in this field:

- Lack of recourses (financial, working force, in some cases also expert technical knowledge⁶) which is closely related to the ways in which independent CSOs operate

⁴ More detailed categorization would include: private voluntary organisations, cultural groups, not-for-profit social enterprises, civic groups, community organisations, consumer organisations, environmental organisations, religious organisations, political parties, professional associations, non-governmental policy institutions, charities, activist groups, social and sports groups.

⁵See Deliverable 1.1, Anex 3g for more detailed CSOs introduction and their role in ethics assessment and guidance - http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

⁶ One of the interviewed organization provided the example of smart meters; according to the CSO representatives: „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 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 “ (interview of 14 January 2015); according to a representative of society that gathers scientist “The (animal-welfare) organizations 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.” (interview of 10 October 2014).

and are financed. Many CSOs act on the basis of project grants and receive little institutional support.⁷ This may oftentimes undermine the continuity of their work. Moreover, since many CSO employees only work on projects, there are no resources necessary to participate in additional activities, such as ethics assessment or guidance.

- Apart from environmental matters the role of CSOs in policy-making has been weakly recognized. Therefore, it is problematic for CSOs to participate in decision-making. In general, there is no legally binding obligation to consult civil society with regard to R&I plans, programs and proposals for projects.⁸ Moreover CSOs pointed out that politicians were often only superficially interested in ethics and even if they do conduct public consultation they disregard the CSOs input.⁹

In spite of, or maybe due to, these challenges the majority of CSO representatives were favourable towards the prospects of creating a common European framework of ethics assessment of research and innovation.¹⁰

In the following sections we will, first of all, review the reasons that CSOs have for engaging in ethics assessment or guidance and discuss the criteria that good guidance or assessment should meet in the context of CSOs. Secondly, we will analyse how CSOs can effectively and efficiently mobilize their resources for ethics assessment and/or guidance by analysing some typical activities they carry out and good practice examples in term of formal and informal EA. Finally recommendations for improving ethical guidance and assessment at CSOs will be offered.

⁷http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

⁸ The role of CSOs in policy-making has been recognized 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),⁸ to which the EU is party, established rights of the public, both individuals and associations, with regard to the 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, programs and proposals for projects affecting the environment; the public should be able to review procedures and challenge public decisions.

⁹http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

¹⁰ Out of 28 CSOs 18 were „positive” towards the idea of creating a framework, 8 were conditionally positive. (see SATORI deliverable 4.1.1. „Stakeholder analysis on the desirability and possibility of a shared European approach to ethics assessment of research and innovation.”)

2 ETHICS ASSESSMENT AND GUIDANCE BY CSOS: GOALS AND CRITERIA

Taking into account the work of WP1, this section reviews the reasons that CSOs have for engaging in ethics assessment or guidance. It then proposes criteria that good guidance or assessment should meet if it is to serve the interests (goals) of the CSOs.

2.1 REASONS FOR ENGAGING CSOS IN ETHICS ASSESSMENT AND GUIDANCE

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. CSOs represent interests of different groups of people: vulnerable groups, particularly patients, as well as consumers, women, children, professionals, workers. They protect the welfare of animals or the state of the environment. Finally, they represent and give voice to those, whose interests may be missing or are overlooked in reaching decisions concerning research, e.g. in setting research agendas or assessing concrete projects.

Except in the rare cases that will be addressed in section 4, CSOs in general do not carry out or participate 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. However, it is not uncommon for CSOs or their members to carry out informal ethics assessment. This issue will also be addressed in section 4.

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

- pick up topics that are not “popular” and act as the guardians of public interest;
- provide additional perspective;
- are more creative and can react faster than international institutions that may represent Members States;
- do the translation work between more formal, academic ethics assessment and the general public.

CSO interviewees identified a multitude of aims behind the ethics assessment and guidance in the context of R&I that can be preliminary divided into three following categories:

Oriented towards society

- To ensure **dignity, informed consent, privacy, and other human rights** in the course of R&I processes;
- To research, examine, investigate and critically analyse technologies and their application and to ensure they do not pose threats to **rights and freedoms**;
- To promote **gender equality** with regard to building an innovative economy;

- To make an assessment from the viewpoint of **public interest** and **environment protection**;
- To influence the process of introducing new or amending existing laws so that they correspond with the standards of **animal protection**;
- To influence agendas and budget plans to ensure compatibility with **environmental goals, ethics, justice**;
- 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 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 promote the **responsible use** of technology in society;
- To increase **public engagement** with science and technology;
- To provide a service for civil society to encourage **informed discussion and debate**.

Oriented towards professional groups

- To promote **responsible science**, to protect the **integrity of science**;
- To improve the **quality and scientific reliability of evidence** brought into court
- To ensure **high quality of research** and **professional conduct**;
- To ensure **dialogue between research and global development practices**;
- To **improve the skills of science journalists**
- 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 promote ethical behaviour among **engineers**.

Oriented towards (vulnerable) individual

- To introduce the experience and perspectives of **patients** in the process of ethical assessment, to ensure patient organisations speak with one voice; to advocate for research that would benefit patients;
- 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 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 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 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;

2.2 BASIC CRITERIA FOR GOOD GUIDANCE OR ETHICS ASSESSMENT BY CSOS

As we stated before, even if CSOs perform ethics assessment or guidance of R&I, it is rather informal, without standardised set of ethical criteria, principles or guidelines. The great diversity of CSOs manifested through different values, aims and interests, different beneficiaries, different level of expertise and involvement in research and innovation, makes defining common criteria for good guidance or ethics assessment of R&I hard to accomplish, if not impossible. However, based on the three type of aims that we identified in section 2.1 we are able to offer some general criteria and principles which can serve as signposts for CSOs who want to be involved in ethics assessment or guidance of R&I (Table 1.).

The criteria are defined following the distinction between CSO operating in the field of issues affecting general population; different groups and associations; and those dealing with specific population groups. Accordingly, three basic criteria are: concern for the society; concern for particular interests and concern for the individual. Each criterion is associated with a specific question, corresponding ethics principles (based on SATORI deliverable 4.1.2) and assigned the relevant types of CSOs.

Table 1. Potential criteria for good guidance or ethics assessment for CSOs

Basic criteria	Who is affected	The questions behind	Ethics principles	Types of CSOs
<i>Concern for the society</i>	General population	What are the ethical issues associated with R&I that society should worry about and how should it deal with these issues?	Social responsibility Freedom Sustainability Justice Avoid dual use Precaution Preservation Environmental protection Respect for cultural heritage	<ul style="list-style-type: none"> • Environmental • Civil liberties • Religious • Developmental
<i>Concern for the particular interests</i>	Professional groups and associations	What are the ethical issues associated with R&I that different professional groups and associations should worry about and how should they deal with these issues?	Scientific integrity Scientific freedom Openness Honesty Confidentiality Carefulness Respect for colleagues, intellectual property, for the law Stewardship Social responsibility Freedom Avoid dual use Precaution Justice	<ul style="list-style-type: none"> • Professional associations • Labour unions • Employers' organisations • Trade unions
<i>Concern for the individual</i>	Nonprofessional and vulnerable groups	What are the ethical issues associated with R&I that nonprofessional and vulnerable groups should worry about and how should they deal with these issues?	Respect for human research subjects Respect for privacy Avoiding harm for human subjects Avoid biases Protect the vulnerable Respect for animal research subject Avoid harm for animals	<ul style="list-style-type: none"> • Disease charity • Patient organisation • Disabled rights organisations • Consumer • Animal rights

3 ORGANIZATIONAL STRUCTURES AND RESOURCES FOR ETHICS ASSESSMENT AND GUIDANCE BY CSOS

Interviews conducted in SATORI indicated that, at the moment, in the majority of cases ethical reflection by CSOs constitutes an element of other activities they perform, such as monitoring or advocacy. Some CSOs who become involved in informal ethics assessment may have programmes or projects that focus on the assessment of (a particular type or aspect of) innovation. This is usually related to the fact that they were able to obtain financing for this particular activity. There are rarely separate structures or divisions responsible solely for ethics tasks. In the case of CSOs for which ethical guidance (even if informal and not explicitly labelled as “ethical”) is the main mission of the organisation, it is performed by the CSO as a whole.

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

- An informal group within the organization
- A specific project with dedicated financing
- A sub-group of the board
- A dedicated science unit
- Community advisory board, organized on a voluntary basis
- Specific units that deal with fields directly related to R&I, such as bioethics, environmental issues and economic and human rights

It can be expected that only the most influential and biggest international CSOs will have enough resources to establish ethics assessment units. For other CSOs it can be more realistic to plan additional qualifications (education, trainings) for staff members who would be responsible for ethics assessment related activities within the CSO.

Other possibilities for organising and performing ethics assessment are:

- engaging experts
- cooperating with other organisations, facilitating networking between different groups of stakeholders;
- establishing expert groups and forums for expert discussions;
- engaging external auditors for the purpose of ethics assessment;
- engaging in ethics capacity building and training

Due to limited capacity and resources to deal with ethical issues in R&I, CSOs who wish to become more involved in ethics assessment or guidance should be encouraged to create ethics related networks. These networks can follow one or more models listed in the Table 2. On the lowest level of mutual interdependence, CSOs can organise an informal network in order to exchange relevant information, share program approaches and identify best practices or to learn about innovative approaches to ethics assessment or guidance. In order to coordinate policies, programs or other activities related to ethics assessment of R&I, CSOs also can organise informal or formal networks. In this way they will be able to maximize the

use of resources for common purposes. Furthermore, through joint networks CSOs can try to obtain common funding for purpose of ethics assessment or guidance of R&I. They can also create more formal and strongly connected networks with the aim of promoting CSO involvement in the process of ethics assessment of R&I e.g. to carry out advocacy campaign. As a most formal type of networks some CSOs can create associations or federations in order to strengthen long-term common identities and interests e.g., to build new guidance, standards or procedures for ethics assessment or try to influence legislation change which would allow more formal engagement of CSOs in ethics assessment of R&I.

Table 2: Five Networks Model¹¹

Shared Purpose	Level of interdependence	Change in decision-making	Change in ownership of governance	Types of network structure
(1) Exchange information, learn from one another	Low	Little joint decision making	None	Informal relationships; Responsibility of member
(2) Coordinate policies, programs, or activities	Medium-low	Limited joint decision making by executives or delegates	Requires formal or informal agreement	Group or committee of authorized representatives
(3) Obtain common funding	Medium	Some joint decision making, focused on finance	Requires formal agreement & often legal organization	Project management unit, hosted by one member or jointly created.
(4) Create new joint social value, e.g. advocacy campaigns, service delivery	Medium-high	Some joint decision making, focused on program action & finance	Requires formal or informal agreement; may involve new coordinating organization	Coalition, alliance, service delivery network. Coordinating organization may be hosted by one member or jointly created.
(5) Strengthen members' long-term common identities & interests, e.g. policy, legislation, reputation, etc.	High	Permanent joint decision-making by representation of executive or senior delegate	Requires formal legal organization, bylaws, etc. as provided by legal code and social norms/practices	Member association, apex body, federation, etc. Usually involves a general membership, elected board, and a hired staff who work in a coordinating unit or secretariat.

4 PROCEDURES OF ETHICS ASSESSMENT AND GUIDANCE BY CSOS

The aim of this section is to discuss formal and informal CSOs involvement in ethics assessment of R&I in order to detect some typical activities performed by CSOs and examples of good practice. In the following section we provide some recommendations for

¹¹ Darcy Ashman et al., *Supporting Civil Society Networks, in international development programs*, AED Center for Civil Society and Governance, 2005.
<http://www.ngoconnect.net/documents/592341/749044/Supporting+Civil+Society+Networks+in+International+Development>

increasing the involvement of CSOs and their efficiency in the process of ethical guidance and assessment of R&I, given their resources and goals.

As understood in the SATORI project, ethics assessment is aimed at institutionalized assessment of R&I goals, new directions, projects, practices, products, protocols, new fields, etc. and it is based primarily on ethical principles or criteria. Ethical guidance diverges from ethics assessment because it is not aimed at judging particular R&I to be right or wrong, but sets general standards (ideals, norms) for rightness or wrongness according to which activities or outcomes of R&I may be guided or evaluated. Ethics assessment and ethical guidance can be directed at: project and practice, policy or professional conduct. Ethics assessment can be formal (or institutionalized) or informal, the distinction being, however, a matter of degree. An institutionalized (or formal) assessment is one that is incorporated into a well - established system of practice for ethics assessment that takes place in an institutional setting. An informal assessment is one in which no such institutionalized practice exists, and it is merely the case that a set of moral judgments are made concerning research and/or innovation. It is worth reminding that the distinction between ethical guidance for projects and practices and policy-oriented guidance is sometimes blurred, because policy-oriented assessments sometimes focus strongly on particular research and innovation practices, and may for that reason have a secondary use for project and practice assessment.¹²

In the case of CSOs ethics assessment or guidance is rarely termed by them as such. There are cases when CSOs deliberately avoid the term “ethics”.¹³ In general, ethics assessment or guidance is closely related to the overall mission of the CSO, which is value-based.

4.1 FORMAL INVOLVEMENT

While CSOs carry out their activities regarding ethical questions and issues predominantly informally regardless of its focus, and typically are not a part of a system of practice for ethics assessment that takes place in an institutional setting, research in SATORI revealed that some CSOs perform activities that can serve as examples of CSOs formal involvement. These are: involvement in assessing research applications and proposals, acting as an ethics assessment agent, assessment of professional conduct (which has an internal character), and participation in research ethics committees.

I. Involvement in the process of assessing research applications and proposals. It implies bringing in the experience and perspective of interested parties (patients, consumers, animal right protectors, environmentalists) and using their opinion in the process of assessing a grant proposal. A good practice example is provided by the NCPF (Federation of Patients and

¹² http://satoriproject.eu/media/D1.1_Ethical-assessment-of-RI_a-comparative-analysis.pdf

¹³ As one interviewee pointed out “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 “moralizing”. The respondent said that in order to avoid such a label CA chooses to use the term “good practices” when referring to ethical issues.” (interview of 1 October 2014).

Consumers Organisations in Netherlands) that was involved in assessing research grant applications for medicines.¹⁴ Their procedure for ethics assessment is as follows:

Before ethics assessment: NCPF matches the project proposal with a group of patients who act as reviewers. Preferably a group of three patients review a project.

During ethics assessment: The group of patients fill out a form, designed by NCPF. This group comes with one common conclusion. NCPF forwards it to the grant giver. They pass it on to the applicant. The applicant can reply. The information is used in the further grant assessment.

After ethics assessment: The participating patients receive news on the outcome of the grant application.

II. Acting as ethics assessment agents. This model of formal involvement implies monitoring compliance by using internal resources or hiring independent auditors to do the ethics assessment. Activities and procedures of Green Choice Alliance (GCA, a coalition of Chinese NGOs) can serve as an example of a good practice.¹⁵ GCA uses a procedure of audit carried out by a third party, called the GC Audit. The third party is always an accredited auditing entity and is monitored by the GCA members. The CSO organises, arranges and supervises the assessment and is responsible for it. The procedure for ethics assessment includes the following activities:

Before assessment: In order to remove the environmental violation record from the IPE database,¹⁶ the enterprise submits relevant documents explaining the violation record and relevant documents for the assessment.

During assessment: The GCA participates in all auditing activities by informing the auditing company of anything that could affect the auditing procedures. GCA checks the audit reports.

After assessment: The auditing body sends the final report to the GCA who forwards it to the audited enterprise. GCA prepares an audit conclusions report within 7 days based on the audit conclusions and the on-site circumstances. This report is known to CSOs who are GCA members. If the environmental violation record of the corporation is removed from the IPE database, this fact is made public.

III. Performing assessment of professional conduct i.e. alleged violations of scientific integrity or codes of conduct (fraud, unethical conduct, etc.) by individual professionals in R&I. It has an internal character and as such this kind of ethics assessment is relevant for CSOs who: 1) gather scientists, engineers or other R&I actors and 2) have established a Code of Conduct along with some kind of a procedure set to react to violations. An example of good practice is provided by Partos (the Association for NGOs working in International Development; its interest in R&I is related to knowledge and effectiveness)¹⁷. Partos does not have a specific unit for ethics assessment, nevertheless, they have a unit that deals with

¹⁴ http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

¹⁵ http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

¹⁶ 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.

¹⁷ http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

knowledge quality and effectiveness of 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. Procedure for ethics assessment includes following activities:

Before assessment: Assessment is triggered by a complaint.

During assessment: If somebody from the public or a company wants to file a complaint on the basis of the Code, they should address the member organisation first. If the complainer is not satisfied with the answer, they can still file a complaint to Partos that has its own internal appeal procedure. The complaints commission deals with complaints.

After assessment: All complaints are being published on the website with the decision of the commission. If members do not comply with the provisions, they could be expelled from Partos

IV. Participation in research ethics committees. Several country reports within SATORI revealed that it is not uncommon that representatives of patient organisations or religious organisations are members of research ethics committees, or, in the case of committees that oversee animal experimentation, people from animal welfare organisations.

4.2 INFORMAL INVOLVEMENT

The interviews with CSO representatives carried out in the course of the SATORI project revealed that most CSO do not perform formal ethics assessment. Informal engagement implies that CSOs who become involved in these processes do not have an established ethics committee or unit, nor their role as ethics assessors has been formally recognized. In these cases, the goals of ethics assessment or guidance are closely related to the overall mission of the CSO, which is value-based, and include: influencing agendas, performing a watchdog function, promoting ethical behaviour, defending citizen and consumer rights, facilitating dialogue between research and global development practices. Their activities range from producing guidelines for conducting R&I (sets of general standards for rightness or wrongness according to which any specific activity or outcome of research and/or innovation may be guided or evaluated) to providing opinions (position papers) and recommendations about existing R&I. Following SATORI results, two basic groups of activities associated with CSOs informal involvement in ethics assessment can be distinguished, along with examples of organisations who perform them.

I. Influencing R&I agendas by means of various advocacy activities. An example of good practice is provided by the organisation Forschungswende (English “Transition of Research”, FW)¹⁸ from Germany. Forschungswende’s main focus is the research and innovation agenda setting process. The goal of Forschungswende is to enable CSOs of all kinds to engage in research and innovation system and to be advocates for their special themes, such as biodiversity, climate change, consumer protection, etc. Forschungswende 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 renewable energy research. Forschungswende is giving feedback to the Parliament and to the Ministry of Education and Research and asks them to reshape the

¹⁸ http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

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. Moreover, 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.

II. Monitoring the field of R&I policy and developments, which includes producing position papers, reports, or lobbying letters, as well all disseminating knowledge, raising awareness and triggering public debate about the ethical aspects of R&I. This kind of assessment considers ethical issues associated with science and technology and particularly its application from a general, societal point of view.

An example of how it is done is provided by Greenpeace (GP).¹⁹ The procedure implemented by GP entails the following steps:

- detection of an innovation with a potential environmental impact (this is done by the most experienced GP experts);
- establishment of an internal forum of GP experts and researchers;
- discussion in the course of which an assessment and thus an official GP standpoint is formulated;
- publishing reports and position statements and making them public.

All this is performed by Greenpeace Science Unit and is not labelled ethics assessment or guidance.

In the case of the American Association for the Advancement of Science (AAAS) there is a separate programme (*Scientific Responsibility, Human Rights and Law Program*) that “addresses ethical, legal and human rights issues related to the conduct and application of science and technology.”²⁰ SRHRLP produces reports that are aimed as policy or legal recommendations. Other reports are an attempt to educate and explain issues related to science.

5 RECOMMENDATIONS

In the course of the SATORI project, several instances of CSOs’ formal involvement in ethics assessment were identified (i.e. involvement in the process of assessing research applications, acting as ethics assessment agents, assessment of professional conduct, participation of CSOs representatives in research ethics committees). It would not be, however, justified to recommend these examples as general models for all CSOs, bearing in mind the great diversity of CSOs in terms of their aims, the type of expertise, their organisational structure and level or scale of their activity. Since the vast majority of CSOs were not established as ethics assessors, most of them would lack resources, both in terms of financing, staff as well as in terms of ethics assessment related knowledge, that would be required in order to perform full-fledged ethics assessment. Additionally, there may be a lack

¹⁹ http://satoriproject.eu/media/3.g-Civil-society-organisations__.pdf

²⁰ <http://www.aaas.org/page/srhrl-about>

of trust in CSOs opinions as ethics assessors, since they may be seen as leaning towards a specific set of values that defines and shapes their agendas.

In the case of some CSOs it seems, however, justified to recommend their further involvement in research ethics committees as representatives of a specific vulnerable group (e.g. consumers or patients) or spokespeople for a specific interest (e.g. the animal welfare). This would be legitimate if acting on behalf of these groups was defined in the CSOs statutes as one of their key objective. Such a model ensures that the perspective of those affected by the research is taken into consideration, and contributes to a greater diversity of views within RECs. Moreover, CSO who are involved in R&I more directly should consider establishing structures (codes of conduct and procedures) for internal ethics assessment.

CSOs who perform informal ethics assessment as an element of their other activities (such as advocacy, monitoring activities, preparing policy briefs, campaigning), which is the majority, should be offered trainings, in order to increase the awareness of ethical issues, as well as tools such as checklists and general guidelines that can be easily used on an on-going basis in different types of projects. Trainings could be organized as an element of EU funded projects that concern Ethics in R&I and Responsible Research and Innovation.

Moreover it would be advisable to support the development of independent CSO that would focus on assessing public research and innovation agendas and cooperate with other CSOs in developing strategies of their own.

Already now CSOs who become involved in the informal ethical assessment, perform the translation work between formal assessment, and the general public. Providing funding for different types of participatory activities, such as for example citizen meetings, could strengthen this important function of an intermediary between science and society.

Another way of strengthening CSOs capacity to deal with ethical issues in R&I could be building ethics assessment related CSO networks. These networks could vary in terms of structure, level of interdependence, aims etc. The purpose of networking would be to exchange information (knowledge and experience) and learn from each other (through sharing best practices, coordinating activities, obtaining common funding, organising advocacy campaigns, influencing the adoption of new regulative acts, etc.). Since there is a disparity between different states as regards the level of civil society involvement in ethics assessment of research and innovation (as regards for example the existence of dedicated organisations, or the level of involvement of the public in debates about the societal aspects of research and innovation), there is a need to exchange best practices between organizations and groups from different states. This could be done at the EU level, for example by means of establishing dedicated working groups in the existing CSO networks (e.g. the Euclid network).