

SATORI Deliverable D2.2 (public version): Views of civil society organisations, government agencies/policymakers and media actors regarding ethics assessment of research and innovation

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# February 2015

This deliverable and the work described in it is part of the project Stakeholders Acting Together on the Ethical Impact Assessment of Research and Innovation - SATORI - which received funding from the European Commission's Seventh Framework Programme (FP7/2007-2013) under grant agreement n° 612231

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#### **EXECUTIVE SUMMARY**

This deliverable is the result of work on Task 2.2 "Non-assessor stakeholder analysis and SATORI project contact list". As the deliverable is confidential, we offer here a public version of the non-assessor analysis (Section I of the original deliverable). This analysis presents the result of a stakeholder analysis of "non-assessors" relevant to the SATORI project, i. e. those stakeholders that are not usually involved in setting ethics assessment guidelines or are involved in ethical review of research projects, but nevertheless have a stake in ethics assessment of research and innovation. The introduction elaborates on the importance of ethics assessment within the notion of "Responsible Research and Innovation" and taking into account the European Union's ambition to create sustainable growth, inclusive prosperity and address societal challenges. Given the significance of research and innovation for society, it would be beneficial for the views of a wide range of stakeholders to be included in considerations of ethics assessment.

# 1. Description

As the views and experiences of those directly engaged in ethics assessment will be thoroughly elaborated in Work Package 1, the focus of this task and deliverable is on non-assessors (see definition of "non-assessors" above). As a Mobilisation and Mutual Learning Action Plan, SATORI is well positioned to gather and analyse information on those stakeholders that do not have a formal role in ethics assessment and consider their views in the construction of a common ethics assessment framework, which is one of the project's main goals.

The non-assessor stakeholder category comprises civil society organisations, governmental agencies/policymakers and media actors. The main emphasis is on CSOs who often assess research agendas and (societal and environmental) impacts of new technologies according to their set of values and principles which, in turn, usually mirror fundamental rights and are based on a concern for the public interest. This is also the motivation for numerous recent initiatives to strengthen the participation of CSOs in R&I agendas. Governmental and intergovernmental agencies and advisory organisations frequently advocate evidence-based policymaking and have a strong influence on policies and regulations. Media actors are viewed as an important link between science and society – beyond their role in dissemination of research results, they have a significant role and responsibility in shaping the public perception of R&I.

#### 2. Analysis

The non-assessor stakeholder analysis is based on interviews with 35 stakeholders carried out in work package (WP) 1 of the SATORI project: 22 CSOs of a variety of types (human rights, consumer, environmental, food and farming, patient, religious, developmental, gender equality, poverty, research agenda and social entrepreneurship organisations), 7 governmental organisations (national environmental protection and enterprise agencies, international policy advisor, national health council and science advisory body), 3 associations for science journalism and communications and 3 independent research and advisory institutes.

The findings from the interviews are summed up in a stakeholder table, structured to provide an overview of the findings regarding the nature of stakeholders' interest in R&I, ethical

values promoted by them and ethical issues addressed by them, their stake in ethics assessment and their opinions on the desirability and feasibility of formulating a common ethics assessment framework. The aim of the analysis is to explore the extent to which the SATORI ethics assessment framework could be useful for non-assessors and to provide recommendations as to how the framework should be structured in order to meet non-assessor stakeholders' needs. Given the confidential nature of the deliverable and the need to preserve the anonymity of interviewees and their organisations, the table is not included here. However, a description of the contents of the table is provided.

The table shows that many CSOs have significant interest in R&I as it can offer potential solutions or, conversely, present further risks in relation to the particular issues addressed by the CSO. Governmental organisations are interested in R&I policies and regulations, while media actors see themselves as brokers between science and society, reporting on good practices and investigating cases of malpractice.

Among the ethical values promoted by the stakeholders, the most common ones include environmental protection, equality, human rights, non-discrimination and sustainability. Other, more stakeholder-specific values include consumer and patient rights and religious values.

The issues addressed by the stakeholders depend on their area of interest/authority or the constituency they represent. Most commonly identified R&I-related ethical issues (or issues that have an ethical dimension) include environmental and societal impacts of R&I, the problem of who benefits from R&I (in terms of access, consumer rights, development, poverty reduction, gender equality etc.), participation in R&I agenda-setting by the public and all those affected by R&I, governance of emerging technologies, science based decision and policy-making, inclusiveness in terms of cultural differences and religious values and the importance of science journalism in the relation between science and society.

Many of the stakeholders included in the analysis carry out some type of R&I assessment, e. g. environmental impact assessment, risk assessment, science system assessment etc. The majority of these stakeholders feel that these assessments have an ethical dimension. Furthermore, CSOs often state that their regular campaigns include implicit ethics assessments.

Approximately one third of the stakeholders explicitly find a common ethics assessment framework desirable. Most of the others feel that it would be useful if it successfully meets certain requirements.

Reflecting on the benefits of such a framework, the stakeholders felt that it would encourage discussion among experts from different backgrounds, help implement comparable standards and inspire shared values, contribute to raising awareness and provide a reference point in countries and scientific fields in which ethics assessment is less established.

For the framework to be truly beneficial, the following requirements should be met: a) the framework should allow for broad stakeholder participation in ethics assessment processes, b) it should be integral to R&I instead of merely being a tick-box formality, c) it should be inclusive in terms of values. Some stakeholders feel that the framework should have more of a guiding or awareness - raising role as opposed to being an additional assessment protocol.

Stakeholders also expressed some concerns regarding the feasibility of the common ethics assessment framework: a) how will it overcome differences in cultures and value systems, b) how will it generate demand, and c) how will it manage to avoid being too general?

#### 3. Conclusions

This analysis can help the SATORI consortium to reflect on how to include expectations and concerns of non-assessor stakeholders with respect to R&I in its construction of a common ethics assessment framework. In this regard, the following challenges can be identified:

- providing a platform for broad stakeholder participation in ethics assessment
- being inclusive of stakeholders' values, identifying common ones but also finding ways to productively acknowledge the differences in cultural norms and world-views
- addressing the issues important to non-assessor stakeholders
- establishing a process, integrated within R&I, instead being an additional formality
- promoting ethical values, high standards and good practices, so that non-assessors can use it as a reference point in their own efforts

#### **INTRODUCTION**

Research and innovation are key elements in the European Union's ambition to create sustainable, inclusive growth and prosperity and to address the societal challenges of Europe and the world. In order to achieve this ambition, the European institutions, Member States and private business actors invest considerable financial and human resources into research, development and innovation. In parallel with these activities, there is an ever increasing emphasis on the need to gear the research and innovation processes to societal needs and to work towards outcomes with desirable societal, environmental and sustainability outcomes; the notion of "Responsible Research and Innovation" (RRI) has become a key notion in the policy and research communities.

Ethics assessment is a significant part of RRI and refers to the identification and assessment of ethical issues that may emerge in research and innovation. Ethics in research is key to anticipating potential benefits and harms of research, to identifying ethical issues specific to particular areas of research (e.g. stem cell research) and in ensuring the ethical conduct of researchers in carrying out their work. Ethics assessment of innovation facilitates the characterisation of the ethical dimensions of new technologies and applications which, in turn, allows us to make informed decisions about which technologies to promote, which to discourage and how to develop and disseminate them in just and ecologically sensitive ways.<sup>4</sup>

Ethics assessments normally involve "ethics assessors" - assessors typically include research ethics committees and councils, research funding agencies, science academies and professional organisations for scientists and innovators, to name just a few actors. Ethics assessors have a clear stake in ethics assessment and frequently carry out formal assessment, e.g. research ethics committees are tasked with carrying out ethics review of research proposals. Given the significance and place of research and innovation in all of our lives, all of us have a stake in the proper ethical assessment of research and innovation, however. In other words, society has a stake in the ethical assessment of research and innovation. In order to let society be heard on the issue of ethics in research and innovation, actors such as civil society, and media actors have an important role to play in ethics assessment. Government agencies/policymakers do not operate in the same kind of arena as civil society actors and media actors but frequently operate in the areas of the assessment and regulation of research and innovation. We call these actors "non-assessors" as they may not have a formal role in ethics assessment but do have a stake in the proper execution of ethics assessment.

Non-assessor views and experiences regarding the ethical assessment of research and innovation can contribute to shaping and influencing the way in which ethics assessment is carried out by assessors. Societal actors have a key role to play in ethics assessment as it is important that societal values, needs and interests are taken into account in ethics assessment

<sup>&</sup>lt;sup>1</sup> Jacob, K., J. van den Hoven, et al. Options for Strengthening Responsible Research and Innovation: Report of the Expert Group on the State of the Art in Europe on Responsible Research and Innovation, European Commission, Brussels, 2013.

<sup>&</sup>lt;sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> Ibid.

<sup>&</sup>lt;sup>4</sup> Sandler, R. (ed.), *Ethics and Emerging Technologies*, Palgrave Macmillan, 2014, pp. 5.

<sup>&</sup>lt;sup>5</sup> We use "ethics assessment" and "ethical assessment" interchangeably here.

of research and innovation. Indeed, as a Mobilisation and Mutual Learning Action Plan<sup>6</sup>, SATORI aims to develop an ethics assessment framework that is not only shared and supported by all of the main actors involved in the design and application of research ethics standards and principles but also in the process ensures the involvement of all relevant stakeholders in society, including civil society and other stakeholders.

To that end, this document offers an analysis of non-assessor stakeholders relevant to the SATORI project. The aim of the non-assessor stakeholder analysis is to determine ethical concerns, beliefs and attitudes for non-assessor stakeholders including civil society organisations (CSOs), governmental bodies and policy-makers, and media actors. Interview findings from work package 1 (WP1)<sup>7</sup> - Comparative analysis of ethics assessment practices will be mobilised and analysed in order to provide insights into ethics assessment and needs of these stakeholders and will also shed light on stakeholders' views regarding the need for a common EU ethics framework. Section 1 sets out the importance of non-assessor stakeholder analysis for the SATORI project. Section 2 provides a description of the different nonassessor categories, with a particular emphasis on civil society organisations (CSOs). Section 3 offers a description of the approach to the stakeholder analysis. Section 4 sets out the consolidated stakeholder analysis, addressing issues such as interest in research and innovation, ethical values, ethical issues, stake in ethics assessment and views on the desirability and feasibility of a common ethics assessment framework. Section 5 offers conclusions as the items that should be taken into account in order to facilitate the nonassessor perspective in the SATORI ethics assessment framework.

# 1. IMPORTANCE OF NON-ASSESSOR STAKEHOLDER ANALYSIS FOR THE SATORI PROJECT

Stakeholder analysis comprises a set of methods and tools for gathering and analysing knowledge about stakeholders, i.e. individuals or organisations that have an interest in or are affected by the implementation of a policy, reform, regulation, programme, project or framework. Stakeholder analysis is mostly used in policy-making, business and public management, development and aid programmes and in research and innovation projects. These methods and tools are becoming increasingly important due to the "increasingly interconnected nature of the world", where a wide range of actors have a stake in a specific problem. <sup>10</sup>

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<sup>&</sup>lt;sup>6</sup> Mutual Mobilisation and Learning Action Plans (MMLs) are designed to bring together actors from research and the wider community (e.g., civil society organisations, ministries, policy-makers, science festivals and the media) to collaborate on action plans that will connect research activities for a chosen societal challenge. See <a href="http://ec.europa.eu/research/science-society/index.cfm?fuseaction=public.topic&id=1226">http://ec.europa.eu/research/science-society/index.cfm?fuseaction=public.topic&id=1226</a>

<sup>&</sup>lt;sup>7</sup> The objective of work package 1 is the production of an up-to-date and detailed comparative analysis of EU and international practices related to ethics assessment in scientific research and related innovation activities.

<sup>&</sup>lt;sup>8</sup> Precise definitions vary according to what is being implemented; see Schmeer, Kammi, *Guidelines For Conducting a Stakeholder Analysis*, Partnerships for Health Reform, Abt Associates Inc., Bethesda, MD, 1999; The World Bank, "Stakeholder Analysis", http://www1.worldbank.org/publicsector/anticorrupt/PoliticalEconomy/stakeholderanalysis.htm; *Guidance note on how to do a stakeholder analysis of aid projects and programmes*, Overseas Development Administration, 1995

<sup>&</sup>lt;sup>9</sup> Brugha, Ruaurí and Zsuzsa Varvasovszsky, "Stakeholder analysis: a review", *Health Policy and Planning*, Vol. 15, Issue 3, Oxford University Press, 2000, pp. 239-246.

Bryson, John M., "What to do when Stakeholders Matter: Stakeholder Identification and Analysis Techniques", *Public Managment Review*, Vol. 6, Issue 1, Routledge 2004, pp. 21-53, p. 23.

In project management, stakeholder analysis can "increase the chances of project success through informing their design, preparation and implementation". 11 Research and innovation projects can use stakeholder analysis to gain insight into stakeholders' needs, interests and principles, in addition to the way in which they define issues concerning the field being investigated. The analysis is vital for the implementation of a project since it provides an understanding of stakeholders which a) helps make the project's innovations or frameworks more fit for purpose, b) facilitates participatory processes 12 and c) increases the "the likelihood of acceptance and sustainability" of what is being proposed.

SATORI aims to develop an ethics assessment framework based on thorough analysis, commonly accepted principles, participatory processes and engagement with stakeholders in Europe and beyond. Stakeholder analysis is an important exercise in this process - stakeholder analysis can provide valuable input into the comparative analysis of ethical issues and principles according to the needs and views of a variety of stakeholders and provide a broad perspective on the desirability and feasibility of a common European approach to ethics assessment.

The particular focus in this task is on non-assessor stakeholders, i.e. those entities or organisations that do not themselves engage in ethics assessment but have a stake in its proper execution. The main emphasis in this stakeholder analysis is on civil society organisations (CSOs), with attention also given to government agencies, policymakers and media actors. CSOs (of a wide variety of types) may, for example, engage in ethics assessment of research and innovation, even though their activities may not always be labelled as such. 14 Government agencies and policymakers may also address ethical issues in research and innovation to varying degrees and for various purposes. <sup>15</sup> Journalists and the media are increasingly involved in informal ethical assessment <sup>16</sup>, e.g. the field of investigative journalism undertakes the evaluation of ethical frameworks behind new discoveries, products, industries and environmental or social phenomena.

#### 2. TAXONOMY AND DESCRIPTION OF NON-ASSESSOR STAKEHOLDERS

As mentioned previously, SATORI defines non-assessor stakeholders as "those entities/organisations that do not themselves engage in ethics assessment but have a stake in its proper execution". The non-assessor category includes civil society organisations (CSOs) from a variety of categories (including religious, consumer, environmental, human rights/civil developmental, animal rights and science journalism), agencies/policymakers and media actors.

<sup>&</sup>lt;sup>11</sup> Varvasovszsky, Zsuzsa and Ruaurí Brugha, "How to do (or not to do) ... A stakeholder analysis", Health Policy and Planning, Vol. 15, Issue 3, Oxford University Press, 2000, pp. 338-345, p. 339.

<sup>&</sup>lt;sup>12</sup> See Schmeer, Kammi. Guidelines for Conducting a Stakeholder Analysis. op. cit.

<sup>&</sup>lt;sup>13</sup> The World Bank, "Stakeholder Analysis", op. cit.

<sup>&</sup>lt;sup>14</sup> SATORI Basic concepts document

<sup>&</sup>lt;sup>16</sup> Wyatt W.N. The ethics of journalism. Individual, institutional and cultural influences. Oxford University Press, 2014.

As the majority of non-assessors analysed here are civil society organisations, most of the following section will be devoted to a description of CSOs. The description here is adapted from previous work carried out for WP1.<sup>17</sup>

# 2. 1 CIVIL SOCIETY ORGANISATIONS (CSOS)

#### 2.1.1 Increased involvement of CSOs in research and innovation (R&I)

In the European Union (EU), there seems to be general agreement that broader stakeholder engagement in technical and scientific research is desirable.<sup>18</sup> The wish to involve civil society organisations (CSOs) can be viewed as a response to concerns about the lack of legitimacy of research policies, which, apart from reinforcing the "democratic deficit" in the EU, may result in the rejection of some new developments, such as Genetically Modified Organisms. This trend is mirrored in projects financed by the European Commission. There are numerous initiatives that either aim to strengthen the participation of CSOs in research<sup>20</sup> or to investigate their involvement. The increased engagement of CSOs in R&I is also an important component in the concept of Responsible Research and Innovation.<sup>21</sup> It is believed that the increased inclusion of CSOs will improve participative research governance and legitimacy of findings, in addition to heightened public awareness and mobilising public debate. However, studies carried out thus far show that in many cases CSOs actually involved in EU-funded research projects play rather an instrumental role in the sense that they are recruited as a means of demonstrating a kind of societal legitimacy for the project while perhaps not being involved in the substantive elements of research design and implementation.<sup>22</sup> Research shows that only thirty per cent of project coordinators report that CSOs are involved from the start of the project.<sup>23</sup> Moreover, their involvement in these projects is, in many cases, limited to disseminating results of the project.

#### 2.1.2 Basic description of CSOs

There is no one agreed definition of the term "civil society organisation" and it is often used interchangeably with the notion "non-governmental organisation". According to a Communication from the European Commission to the European Parliament (September 2012), the EU "considers CSOs to include non-State, not-for-profit structures, non-partisan

<sup>&</sup>lt;sup>17</sup> "Civil society organisations as ethics assessors of research and innovation." Report for SATORI work package

<sup>&</sup>lt;sup>18</sup> According to the Special Eurobarometer, overall more than half of Europeans believe that when it comes to decisions made about science and technology public dialogue is required. European Commission, Special Barometer 401: Responsible Research and Innovation (RRI), Science and Technology, p.

<sup>5, &</sup>lt;a href="http://ec.europa.eu/public\_opinion/archives/ebs/ebs\_401\_en.pdf">http://ec.europa.eu/public\_opinion/archives/ebs/ebs\_401\_en.pdf</a>
Tor a discussion on the "democratic deficit" in the European Union see for example Follesdal, Andreas and Hix, Simon, "Why There is a Democratic Deficit in the EU: A Response to Majone and Moravcsik", JCMS 2006 Volume 44. Number 3. pp. 533-62.

<sup>&</sup>lt;sup>20</sup> See for example, Living Knowledge, The International Science Shop Network, www.livingknowledge.org, particularly PERARES Public engagement with research and research engagement with society, http://www.livingknowledge.org/livingknowledge/perares. According to the website the project "aims to strengthen the interaction between researchers and Civil Society Organizations (CSOs) and citizens in Europe." <sup>21</sup> For example example the project CONSIDER Civil society OrganizationS in Designing rEsearch goveRnance, http://www.consider-project.eu/

<sup>&</sup>lt;sup>2</sup> CONSIDER Civil Society Organizations in Designing Research and Governance, Policy Brief: Optimising

http://ec.europa.eu/research/science-ociety/document library/pdf 06/optimising civil society participation.pdf 23 Ibid.

and non-violent, through which people organize to pursue shared objectives and ideals, whether political, cultural, social or economic". The World Bank views "civil society" as including a wide array of non-governmental and not-for-profit organizations 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. <sup>25</sup>

In general, 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, CSOs' activities can be viewed as an expression of a set of values and a specific understanding of what constitutes public interest.

Despite the fact that, as indicated above, CSOs often merely play an instrumental role in R&I, there are also counter examples, which demonstrate that CSOs do become involved in ethics assessment (even though this may not be explicit and CSOs rarely term their activities "ethics assessment"). Examples include organisations such as Greenpeace, Friends of the Earth International, Statewatch and the initiative Oneofus.<sup>26</sup>

#### 2.1.3 Aims of ethics assessment

CSOs' involvement in the ethical assessment of research and innovation usually begins with the monitoring and analysis of policy and practices, as well as the contextualisation of the former. The ultimate goal behind these activities is often to influence the decision-making process.

The role of CSOs in policy-making has been recognised, especially in environmental matters.<sup>27</sup> In monitoring and participating in policy-development, CSOs offer "democratic" input into decision making on strategic and transformative developments. CSOs also inform the public and engage them in the process. Furthermore, the involvement of CSOs in the value-related assessment of research and innovation opens and promotes discussion in the scientific and policy communities, in addition to facilitating political dialogue between scientific institutions and social actors on science and society issues at a global level.<sup>28</sup>

Depending on the type of CSO, more effort can be devoted to documenting developments and providing access to reliable information (quasi media-like function), or lobbying decision-makers in order to affect a change in the policy or practice.

<sup>26</sup> See http://www.oneofus.eu/

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<sup>&</sup>lt;sup>24</sup> 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, <a href="http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2012:0492:FIN:EN:PDF">http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2012:0492:FIN:EN:PDF</a>

<sup>&</sup>lt;sup>25</sup> 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

<sup>&</sup>lt;sup>27</sup> Under the Aarhus Convention, the public (both individuals and associations) should be able to comment on plans, programmes and proposals for projects affecting the environment and should be also able to review procedures and challenge public decisions.

<sup>&</sup>lt;sup>28</sup> GEST global ethics in science and technology, Ethics State of the Art: EU Debate, http://www.uclan.ac.uk/research/explore/projects/assets/cpe\_gest\_D1\_1.pdf

#### 2.1.4 Objectives and levels of ethics assessment

Ethics assessment by CSOs is carried out at different levels. CSOs may assess research agendas in order to influence policy making on a larger scale. Initiatives or organisations with a religious background may also focus on research practices, which are contrary to their set of beliefs. The assessment and criticism of research agendas is often closely linked with the assessment of research systems and infrastructures, that is, the way in which decisions which concern research agendas are reached. CSOs often assess the potential impact of new technologies on the individual and society, e.g. the impact of new Information and Communication Technologies (ICTs) on the right to privacy.

# 2.1.5 Ethical values and principles

CSOs usually pursue a defined set of objectives based on a concrete set of values. These guiding principles are often enshrined in the document establishing an organisation.

CSOs' values and principles often mirror EU fundamental rights (with the emphasis dependent on the type of CSO), or complemented by religious beliefs in the case of religious CSOs. 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, equality – and two principles – democracy and the rule of law. In addition, CSOs often emphasize the value of sustainability, identified by the Treaty.

One of the key principles repeatedly referred to by CSOs with regard to research policies is the principle of transparency, which is closely linked to the right to access information. Support for more transparency is coupled with the call for more democratic decision-making.

#### 2.2 GOVERNMENTAL AGENCIES AND POLICYMAKERS

Various government agencies provide advice and analysis on science and technology issues to national governments and decision-making bodies. Part of this advice may include the assessment of ethical issues. This advice is frequently employed in evidence-based policymaking. International or intergovernmental organisations established to promote cooperation in a particular area or sector may also address ethical issues that arise in the course of their mission and work. Policy-makers - including high-level staff in government ministries and agencies and parliamentarians - have different positions with regard to research and innovation, i.e. some policy-makers work to promote research and innovation, while others will work in the area of control, i.e. assessment and regulation. Ethical assessment may feature in the work of both kinds of policy-maker.

#### 2.3 MEDIA ACTORS

project and not only as passive recipients of the project results in the dissemination phase. Journalism itself is a strong determinant of the public perception of the ethical background of

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The SATORI consortium views media representatives as independent stakeholders in the

Charter of Fundamental Rights of the European Union (<a href="http://www.europarl.europa.eu/charter/pdf/text\_en.pdf">http://www.europarl.europa.eu/charter/pdf/text\_en.pdf</a>) and the Treaty of Lisbon (<a href="http://europa.eu/legislation\_summaries/institutional\_affairs/treaties/lisbon\_treaty/ai0033\_en.htm">http://europa.eu/legislation\_summaries/institutional\_affairs/treaties/lisbon\_treaty/ai0033\_en.htm</a>)

science and innovation and often contributes to the shaping of public opinion on controversial issues. 30

The presence of media representatives in the debate between different stakeholders can create opportunities to foster the debate between scientists, social scientists and the general public about ethical issues and controversies. It is important to raise awareness of the media's social role and the positive impact free and independent journalism can have in acting as gatekeeper against malpractices within the scientific community. In recent years, there have been many examples in which journalism had a role in investigating the ethical frameworks of research, e.g. scientific fraud such as the falsification of data regarding the relationship between autism and vaccines that was discovered by science journalists investigating sensitive topics. Selfevaluation of the quality of scientific or medical information is often based on self-elaborated check lists with a strong ethical background (see www.healthnewsreview.org). Finally, journalists set up the first systematic database on scientific retractions http://retractionwatch.com/).

The media representatives selected by the SATORI consortium are associations of science journalists at EU level. Science journalists have a key role in the informal ethical assessment of science and new technologies. Their impact on the public sphere can be more important than the impact of journalists at large because they are focused specifically on controversial topics in science. Science journalism has also a more developed tradition of ethical debate within the profession.

#### 3. APPROACH TO STAKEHOLDER ANALYSIS

Preliminary steps leading to the analysis – stakeholder identification and data collection – were achieved in work packages 10<sup>31</sup> and 1 of the SATORI project, respectively. Data was collected by means of semi-structured interviews with stakeholders who were identified by the SATORI consortium.

The scope of data on stakeholders' characteristics to be considered and the selection of tools to be used for data analysis are dictated by the purpose of the analysis, which must be welldefined in advance.<sup>32</sup> The purpose of stakeholder analysis in SATORI is determined by the aim to develop a common ethics assessment framework on the basis of stakeholder participation.

Due to the focus on the non-assessor category, information collected on stakeholders' views, interests and practices relates to ethics assessment of research and innovation in a mostly indirect way. The interview tool was designed to elicit information regarding:

- the nature and level of stakeholders' interest in research and innovation;
- ethical issues related to research and innovation as addressed in stakeholders' practices (CSOs' missions, policy implementation, science journalism);
- the ways in which ethics assessment comprises part of stakeholders' regular activities (either explicitly or implicitly);

<sup>&</sup>lt;sup>30</sup> Ho SS et al. Effects of Value Predispositions, Mass Media Use, and Knowledge on Public Attitudes Toward Embryonic Stem Cell Research. Int J Public Opin Res (2008) 20 (2): 171-192; Dulworth S. From Schiavo to Death Panels: How Media Coverage of End-of-Life Issues Affects Public Opinion. 58 N.Y.L. Sch. L. Rev. 391

<sup>(2013–2014)
&</sup>lt;sup>31</sup> Work package 10 is the communication work package. Task 10.1 involved the identification of stakeholder categories, their motivations and individual stakeholders relevant to the SATORI project.

<sup>32</sup> Bryson, John M., "What to do when Stakeholders Matter: Stakeholder Identification and Analysis Techniques", op. cit. and Schmeer, Kammi, Guidelines for Conducting a Stakeholder Analysis, op. cit.

- the ways in which a common ethics assessment framework could be useful for, or integrate with stakeholders' basic activities;
- opinions as to the possibility, benefits and challenges of formulating such a framework, as expressed by the stakeholders.

Tools for stakeholder analysis include a variety of tables, charts, grids, matrixes, diagrams and maps. The key to a specific analysis, however, is in defining "the exact stakeholder information or characteristics to be considered", according to which tools are selected and adapted. Some of the stakeholder analysis tools, commonly used in policy-making and management – e. g. the ones measuring the level of stakeholders' support or opposition to a policy or programme proposal in relation to their influence or power – are not suited to the purposes of SATORI, since the aim of the stakeholder analysis is not to propose a strategy for a successful policy or programme implementation. Rather, the aim of the analysis is to uncover the kinds of research and innovation-related ethical issues that are important to stakeholders who are not directly involved in established ethics assessment practices. This will facilitate a wider perspective in developing a common ethics assessment framework and enhance the usefulness of the framework for a broader range of stakeholders.

In order to achieve these goals, a stakeholder table was created, filled with information mentioned in the bullets above, allowing for a comparative analysis. Due to the need for confidentiality of the interview data, the table will not be included here.

On the basis of the analysis, the following conclusions were possible:

- the extent to which the SATORI ethics assessment framework could be useful for non-assessors:
- recommendations as to how the framework should be structured in order to meet non-assessor stakeholder's needs.

#### 4. THE STAKEHOLDER ANALYSIS

- The analysis was carried out on 35 stakeholders, namely: 22 CSOs (63 %)
  - 3 human rights and/or civil liberties organisations
  - 2 consumer organisations
  - 2 environmental organisations
  - 2 food and farming organisations
  - 2 patient organisations
  - 2 religious organisations
  - 2 research ethics organisations
  - 1 consumer and patient organisation
  - 1 developmental & gender equality organisation
  - 1 developmental & media organisation
  - 1 gender equality organisation
  - 1 poverty organisation
  - 1 research agenda organisation
  - 1 social entrepreneurship organisation
- 7 governmental organisations (20 %):
  - 2 national environmental agencies
  - 1 intergovernmental policy advisor

<sup>&</sup>lt;sup>33</sup> Schmeer, Kammi, Guidelines for Conducting a Stakeholder Analysis, op. cit., p. 10.

- 1 national research integrity agency
- 1 national enterprise agency
- 1 national health council
- 1 national science advisory body
- 3 international associations of science journalists and science communication (8.5 %)
- 3 other types of organisations (8.5 %):
  - 1 independent bioethics research institute
  - 1 independent science advisory body
  - 1 independent think tank

# 4. 1 Interest in R&I

Most of the stakeholders included in the analysis have a direct or at least an indirect interest in R&I. Many types of CSOs address issues in relation to which R&I can offer potential solutions or presents further risks. Some CSOs are directly engaged in research-ethics related activities or are involved in some other type of R&I assessment. Furthermore, CSOs are often users or even funders of research.

Interest in R&I related to issues, often addressed by CSOs is summarised below:

- human rights, civil liberties, social justice:
  - societal impact of innovation: opportunities (e. g. poverty reduction) and risks (e. g. surveillance technology)
- consumers:
  - assessing innovation with regard to consumer rights and consumer needs;
- environment protection:
  - assessment of environmental impact of innovation
  - research in alternative solutions, green technologies
  - research used to asses environmental impacts
- development:
  - R&I has a major role in development
  - R&I can have a negative effect on development if the following questions are neglected: who benefits from R&I and who is negatively affected by R&I
- food and farming:
  - societal, environmental and health impact of R&I in the sector
- patients' rights and needs:
  - protection of research participants
  - advocating research that would benefit patients
- religion:
  - advocating religion-based values in research ethics
- gender:
  - equality in academia
  - access to technology
- research ethics and agenda:
  - advancing high standards, education and promoting ethical research,
  - campaigning for the participation of a wide range of stakeholders in setting the R&I agenda

Media actors see science journalists as brokers between science and society, providing access to R&I information to the general public and reporting on good practices and misconduct.

Other stakeholders included in the table are national and international governmental organisations and independent advisory institutions. All of them have an influence on policies and regulations directly (science policies, assessment frameworks) or indirectly (environmental and health regulations) related to R&I.

#### 4. 2 ETHICAL VALUES

Among the most common values, explicitly promoted by the stakeholders are:

- environmental protection
- equality
- fairness
- human rights
- justice
- non-discrimination
- public participation in decision-making processes
- quality of life
- respect for people and cultures
- sustainability
- transparency

Other stakeholder-specific values include:

- consumer rights
- patients' rights
- protection of research participants
- religious values
- research integrity

# 4. 3 ETHICAL ISSUES

Ethical issues identified by stakeholders vary according to their area of interest, the field they are working in and the constituency they represent.

Below is a list of the major issues that touch on ethics in R&I, as identified by the stakeholders:

- balancing patient needs with ethical restrictions on research
- corporate responsibility in relation to environmental protection, sustainability, development and consumer rights
- data protection and surveillance
- dealing with research misconduct
- environmental impact of R&I and integrity of research on environmental impact
- governance of emerging technologies and risk management
- inclusiveness in terms of cultural differences and religious values
- participation in R&I agenda setting by the public and all those affected by R&I
- protection of research participants
- ethical issues uncovered in the process of science based decision making
- societal impact and benefits of R&I in terms of the common good, access to knowledge and innovation, development, gender equality, poverty reduction, consumer needs etc.
- the role of science journalism in public access to science

#### 4. 4 STAKE IN ETHICS ASSESSMENT

Three of the stakeholders included in the stakeholder analysis table are directly involved in ethics assessment of R&I by way of doing research in the field, advancing high standards or developing their own assessment tools.

Other stakeholders' stake in ethics assessment is indirect but still significant in relation to their interest in R&I. Many stakeholders carry out other types of R&I assessment, e. g.:

- environmental impact assessment
- risk assessment
- societal impact assessment
- science-systems assessment
- research agenda assessment

The majority of these stakeholders (notwithstanding some exceptions) view these assessments as having an ethical dimension.

As shown by the stakeholder table, CSOs that address specific issues or represent a particular constituency often state that their regular activities include implicit ethics assessments. They often participate in, or organise public debates to raise awareness of research ethics-related issues and values.

#### 4. 5 DESIRABILITY AND FEASIBILITY OF A COMMON ETHICS ASSESSMENT FRAMEWORK

Eleven stakeholders explicitly stated that a common ethics assessment framework would be desirable. Some stakeholders felt that it could be useful if it meets certain requirements. Only one stakeholder claimed the framework is not desirable.

Stakeholders felt that such a framework could have the following benefits:

- comparing different practices in different fields, encouraging discussion among experts from different backgrounds
- implementing comparable standards
- identifying and inspiring shared values
- raising awareness of ethical issues in R&I
- introducing a common narrative
- helping fields and countries in which ethics assessment is less developed to impose higher standards

However, for the framework to be beneficial, the following requirements should be met:

- stakeholder participation the framework should establish a platform of wide stakeholder engagement in ethics assessment of R&I (seven stakeholders explicitly stated this as being crucial)
- ethics assessment should be embedded from the outset in R&I projects, instead of being a tick-box exercise
- the framework should be broad and inclusive in terms of values

Some stakeholders feel that the framework should have more of a guiding role, providing key ethical questions that should be considered in R&I. The framework would thus be more of a movement than a protocol, promoting good practices and raising awareness of research ethics.

Stakeholders also expressed some concerns regarding the feasibility of the framework. The most important ones can be summarised in the following questions (the number of stakeholders who have expressed this concern is quoted in brackets):

- How would a common framework overcome differences in cultures, research cultures, value systems and political levels (national vs. international)? (10)
- How will the demand for the framework be generated? In areas in which ethical assessment is well established, there will be reluctance to delegate power; in those areas where it is not established, the need for a framework may not be apparent to actors (6)
- What kinds of steps can be taken to overcome having a framework that is too general and vague? (4)

#### 5. CONCLUSION

This non-assessor stakeholder analysis offers an opportunity to broaden the horizons of ethics assessment by taking into account the needs and views of those who have a stake in ethics assessment without being directly involved in its procedures and practices. The analysis here has shown that the expectations and concerns of non-assessor stakeholders with respect to R&I can, at least in part, be considered within an ethical framework.

In order for the SATORI common ethics assessment framework to be useful for non-assessor stakeholders, it should strive to be inclusive of stakeholders' values, identifying common ones but also finding ways to productively acknowledge the differences in cultural norms and world-views. Another challenge for SATORI will be addressing the issues important to non-assessor stakeholders, recognising their ethical dimension and integrating it in the assessment framework.

If the framework is to meet these stakeholders' needs, it should be based on a comparative analysis of various related practices and the input of a wide range of experts. It should also provide a platform for broad stakeholder participation in ethics assessment. According to most non-assessor stakeholders, assessment should be perceived as a process that is integrated within R&I, instead of a mere formality. The SATORI framework should also have a strong emphasis on promoting ethical values, high standards and good practices, so that non-assessors can use it as a reference point in their own efforts.