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DISCLAIMER

SoBigData (654024) is a Research and Innovation Action (RIA) funded by the European Commission under the Horizon 2020 research and innovation programme.

SoBigData proposes to create the Social Mining & Big Data Ecosystem: a research infrastructure (RI) providing an integrated ecosystem for ethic-sensitive scientific discoveries and advanced applications of social data mining on the various dimensions of social life, as recorded by “big data”. Building on several established national infrastructures, SoBigData will open up new research avenues in multiple research fields, including mathematics, ICT, and human, social and economic sciences, by enabling easy comparison, re-use and integration of state-of-the-art big social data, methods, and services, into new research.

This document contains information on SoBigData core activities, findings and outcomes and it may also contain contributions from distinguished experts who contribute as SoBigData Board members. Any reference to content in this document should clearly indicate the authors, source, organisation and publication date.

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GLOSSARY

ABBREVIATION	DEFINITION
RRI	Responsible Research and Innovation
VSD	Value Sensitive Design

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DELIVERABLE SUMMARY

This deliverable reports the definition and the installation of the ethics board for the project. The board guarantees the good governance of data and the research integrity and academic ethics, compliance with ethical and legal framework and consultation with external experts when and where required.

This deliverable includes 2 sections:

- **Section 1:** proposes an introduction of the ethical aspects related to SoBigData.
- **Section 2:** describes the role of ethical board and introduces three eminent experts prepared to serve on the Ethics Board.

EXECUTIVE SUMMARY

SoBigData has a strong ethical motivation. It aims at building an ecosystem where protection of personal information and the respect for fundamental human rights can coexist with a safe use of the same information for scientific purposes of broad and central societal interest. This deliverable describes the composition of the ethics board and its plan of activities, governance framework, by laws, responsibilities of members and principles, schedule of meetings, reporting and event calendar.

1 INTRODUCTION

SoBigData strives to formulate a view of responsible data science, associated innovations and infrastructure fit for the 21st century and to devise methodologies that enables us to arrive demonstrably at big data based solutions in accordance with shared societal and moral values. This approach exemplifies the basic idea of Responsible Research and Innovation (RRI) that was given a prominent role by the European Commission in the Horizon2020 Program. This view on Responsible Research and Innovation was embraced by the EU in the Rome declaration of 2014.

A scientific research infrastructure can only be called “responsible” if it at least does not prevent, but ideally supports users of the infrastructure in their moral thinking about the nature and consequences and assumptions of their relevant research activities.

Central to the conception of responsibility and ethics in Responsible Data Science is the idea that is referred to in recent literature as Value Sensitive Design (VSD), Design for Values, or Values by Design. This is the idea that ethical analysis and moral deliberation should not be construed as abstract and relatively isolated considerations situated at a great distance from science and technology, but that instead they should be utilized at the early stages of the research and development as non-functional or supra-functional requirements on a par with functional requirements. Another feature of this approach to ethics of computer science and information technology is that it fully embraces the growing awareness that applied science and technology are never value-neutral, but that algorithms, software, architectures, role based access matrices, interfaces, backbones, standards, models and simulations represent the choices of their makers and come with their inscribed values and world views, some of them explicit and known and others hidden or implicit and tacit.

Ethics and Law in the context of SoBigData therefore needs to (a) formulate the relevant ethical and legal considerations, but (b) also do so in a way that allows them to be implemented in the research infrastructure and all it’s components and building block in a way that is demonstrable and justifiable.

2 ETHICS BOARD

In M12 an ethical and legal framework will be provided that gives direction to work that is carried out in the project on all levels, but that will importantly guide and inform the design of the Research infrastructure as such, along the lines sketched in the Description of Work and in Section 1 above.

One of the first steps in the SoBigData project is to establish an ethics advisory board that oversees these ethical and legal aspects of the work. This board will have two functionalities: First, it mobilizes additional relevant expertise with respect to the quality control regarding the ethical and legal aspects of the project and the methodology of designing for moral and legal values. In this capacity the board will review the ethical and legal framework document that is a deliverable due in M12. Secondly, the Ethics Board can be called upon to give occasional advice, when and where required. In both capacities the board is part of the moral infrastructure required for SoBigData.

We have found three eminent experts prepared to serve on the Ethics Board:

1. Prof. **Helen Nissenbaum** of New York University. Professor Nissenbaum is an international expert in the field of ethics and IT, and has gained wide international recognition for her work on privacy, big data, ethics of algorithms, and Values and Design.
2. Prof. **Dag Elgesem** of The University of Bergen, Information Sciences and Media Studies. Prof. Elgesem has a background in logic and analytical philosophy and has published widely on Ethics and IT, and Internet research ethics. Professor Elgesem is leading large research initiative (SAMKUL) in Norway on the foundations of digital societies.
3. **Jeroen Terstegge** legal expert and independent privacy consultant. Jeroen Terstegge has decades of experience in the data protection and privacy in Europe. He was senior staff member of the Dutch Data Protection Office and Privacy Officer of Philips. Terstegge is also a member of a Privacy and Big Data Committee established (2015) by the Ministry of Economic Affairs in The Netherlands.

Members of the SoBigData consortium Profs. N Forgo, Hannover, (vice Chair) and M.J. van den Hoven, Delft (Chair) will interact with these external members when and where appropriate. Prof. Van den Hoven will collect feedback from the Board on the Ethical and legal SoBigData framework to be integrated in the draft text of the relevant deliverables.

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