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## D1.5 – Ethics compliance report

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### Statement of originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

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## Glossary

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<b>AEPD</b>	Agencia Española de Protección de Datos
<b>DPA</b>	Data Protection Authority
<b>EAB</b>	Ethics Advisory Board
<b>EC</b>	European Commission
<b>ICO</b>	Information Commissioner's Office
<b>PA</b>	Public Administration
<b>UREC</b>	University Research Ethics Committee

## 1 Executive summary

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This document is the deliverable “**D1.5 – SIMPATICO Ethical compliance report**” of the European project “SIMPATICO - SIMplifying the interaction with Public Administration Through Information technology for Citizens and cOMpanies” (hereinafter also referred to as “**SIMPATICO**”, project reference: 692819).

SIMPATICO addresses a strategic challenge towards the **innovation and modernization of the public sector**: the need to offer a more efficient and more effective experience to companies and citizens in their daily interaction with Public Administration (PA) by (i) offering a personalized delivery of PA online services; (ii) enabling a better comprehension of the complex processes and documents (forms, regulations, etc.) behind these services; (iii) engaging them to improve the administration processes and services. SIMPATICO's goal is **to improve the experience of citizens and companies in their daily interactions with the public administration** by providing a personalized delivery of **e-services** based on advanced cognitive system technologies and by promoting an active engagement of people for the continuous improvement of the interaction with these services.

Therefore, several **ethical and data protection aspects** should be taken into account due the involvement of public/private stakeholders and citizens and due to the necessity to collect, store and process personal data. Starting from a brief illustration of the SIMPATICO project, and of the ethical concerns raised by the project activities, this report describes the procedures adopted to ensure compliance with ethical requirements. In particular, the project has appointed an Ethics Advisory Board that is responsible of providing advices and coordinating activities for what concerns the fulfilment of the ethical obligations of SIMPATICO. Moreover, the relevant ethical and legal regulations have been identified and analysed, both at the national and European level, and recommendations and guidelines have been derived.

This report does not cover the concerns related to data management, as they are the focus of a dedicated deliverable – namely report “D1.3 Data Management Plan v.1” (M6).

## 2 Introduction

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The research activities undertaken in the SIMPATICO project have important ethical and data protection aspects, in particular due to the foreseen involvement of public/private stakeholders and citizens and due to the necessity to collect, store and process personal data. This deliverable analyses the ethical implications of the activities undertaken in the project, and describes the guidelines and procedures put in place in order to ensure compliance with ethical requirements.

The rest of this section provides background information on the SIMPATICO project and identifies the ethical issues raised by the project activities, in order to pave the path for its ethical assessment according to the signed Grant Agreement. Section 3 concerns the definition of key roles and responsibilities defined to in ethics management. Section 4 presents the ethical and legal regulation relevant for the project at European and national level. Finally, Section 5 describes a set of ethical recommendations and guidelines valid for SIMPATICO. This document also includes two annexes: Annex 1 - Appointment of the Ethics Advisory Board; Annex 2 – Informed Consent Form.

### 2.1 SIMPATICO in brief

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SIMPATICO's goal is **to improve the experience of citizens and companies in their daily interactions with the public administration** by providing a personalized delivery of **e-services** based on advanced **cognitive system technologies** and by promoting an active engagement of people for the continuous improvement of the interaction with these services. The SIMPATICO approach is realized through a platform that can be deployed on top of an existing PA system and allows for **a personalized service delivery** without having to change or replace its internal systems: a process often too expensive for a public administration, especially considering the cuts in resources imposed by the current economic situation.

The goal of SIMPATICO is accomplished through a solution based on the **interplay of language processing, machine learning and the wisdom of the crowd** (represented by citizens, business organizations and civil servants) **to change for the better the way citizens interact with the PA. SIMPATICO will adapt the interaction process** to the characteristics of each user; **simplify** text and documents to make them understandable; **enable feedback for the users** on problems and difficulties in the interaction; **engage civil servants, citizens and professionals** so as to make use of their knowledge and integrate it in the system (Fig. 1).

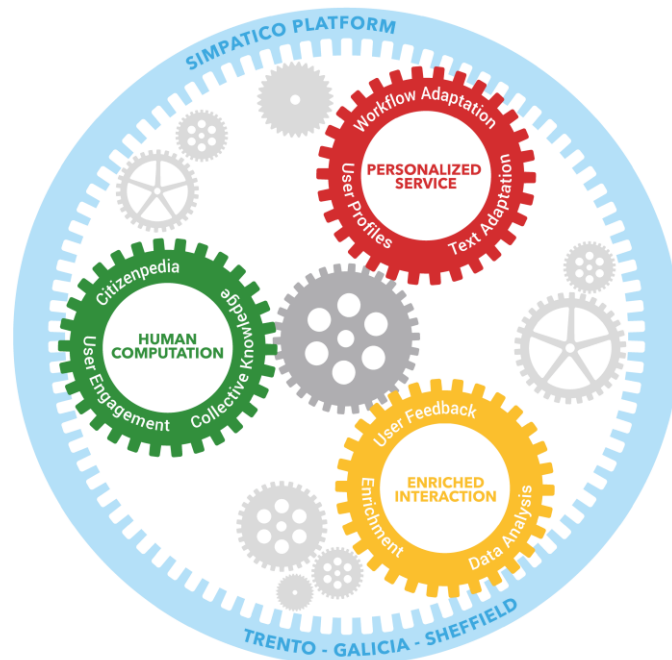


Figure 1: SIMPATICO concept as a glance

The project aims can be broken down into the following **smaller research objectives (ROs)**.

**RO1. Adapt the interaction process with respect to the profile of each citizen and company (PA service consumer), in order to make it clear, understandable and easy to follow.**

- A **text adaptation** framework, based on a **rich text information layer** and on machine learning algorithms capable of **inducing general text adaptation operations from few examples, and of customizing these adaptations to the user profiles.**
- A **workflow adaptation engine** that will take user characteristics and tailor the interaction according to the user's profile and needs.
- A feedback and annotation mechanism that **gives users the possibility to visualize, rate, comment, annotate, document the interaction process** (e.g., underlying the most difficult steps), so as to provide valuable feedback to the PA, further refine the adaptation process and enrich the interaction.

**RO2. Exploit the wisdom of the crowd to enhance the entire e-service interaction process.**

- An **advanced web-based social question answering engine (Citizenpedia)** where citizens, companies and civil servants will **discuss and suggest potential solutions and interpretation for the most problematic procedures and concepts.**
- A **collective knowledge** database on e-services that will be used to simplify these services and improve their understanding.
- An **award mechanism** that will **engage users and incentivize them to collaborate** by giving them **reputation** (a valuable asset for professionals and organizations) and **privileges** (for the government of Citizenpedia – a new public domain resource) according to their contributions.

**RO3. Deliver the SIMPATICO Platform, an open software system that can interoperate with PA legacy systems.**

- A platform that **combines consolidated e-government methodologies with innovative cognitive technologies** (language processing, machine learning) at different level of maturity, enabling their experimentation in more or less controlled operational settings.
- An interoperability platform that enables an **agile integration of SIMPATICO's solution with PA legacy systems** and that allows the exploitation of data and services from these systems with the SIMPATICO adaptation and personalization engines.

**RO4. Evaluate and assess the impact of the SIMPATICO solution**

- Customise, deploy, operate and evaluate the SIMPATICO solution on **three use-cases in two EU cities** – Trento (IT) and Sheffield (UK) – **and one EU region** – Galicia (ES).
- **Assess the impact** of the proposed solution in terms of **increase in competitiveness, efficiency of interaction and quality of experience.**

## 2.2 SIMPATICO technical framework and infrastructure

The SIMPATICO project will provide a **software platform** incorporating technical innovations to enhance **the efficiency, effectiveness and inclusiveness of public services**. To this aim, SIMPATICO collects, generates and utilizes both personal and other data in a complex way. Its key components are described below:

1. **Citizen Data Vault:** it represents the component that will take care of personal data exchange between a user and SIMPATICO components. It is a distributed repository of the citizen (or company) profile and related information. It is continuously updated through each interaction and is used to automatically pre-fill forms. In this way, the citizen will give to the PA the same information only once, as the information will be stored in the vault and used in all the following interactions;
2. **Human Computation (Citizenpedia):** SIMPATICO fosters citizens' involvement, by providing Citizenpedia, a hybrid of Wikipedia and a collaborative question answering engine, and sharing improvements on public resources in a semi-automatic basis. Citizens, companies and civil servants will discuss and suggest potential solutions and interpretation for the most problematic procedures and concepts. In addition, the user will be able to highlight portions of text that he/she considers unclear and ask for a simplified version. These interaction actions will further refine the user profile and will be stored in the citizen data vault to serve as the basis for the adaptation of future interactions. Public servants are able to moderate comments and suggestions of citizenships to prevent crowd's wisdom bias. The knowledge collected by a user on a specific e-service (e.g., a request of clarification or the explanation of a concept) can propagate and improve the understanding and interaction of potentially all users and e-services. An award mechanism that engages users and incentivize them to collaborate by giving them reputation (a valuable asset for professionals and organizations) and privileges is designed.
3. **SIMPATICO Adaptation Engine:** it is a cognitive system that will make use of innovative text processing and machine learning algorithms to adapt the text and the workflow of the interaction according to the user profile. The text adaptation engine will adapt the text of the forms and of the other documents to make it more understandable and to clarify complex elements, while the workflow adaptation engine will adapt the interaction process itself by presenting the citizen only the elements that are relevant for his/her profile (e.g., if the



citizen is not a foreigner he/she will not be presented the section of a form reserved for foreigners).

More details on the layers of the SIMPATICO solution are illustrate by Figure 2 below: i.e., 1. the **first layer** (in red) is the **adaptation layer**; 2. the **second layer** (in yellow) is the **user interaction and feedback analysis layer**; 3. the **third layer** (in green) is the **human computation layer**. The main impact of SIMPATICO will be therefore in the social domain since the underlying objective of the project is **the improvement of the quality of life in cities** in terms of socio-economic progress. One of the main issues we foresee facing during the project is the **lack of trust on e-services**. Once citizens start to use e-services, they generally find the experience highly satisfying. Despite this, many citizens never use e-services. However, this aspect is **well known and will be taken into account** when drawing requirements and designing the SIMPATICO platform. Furthermore, it will be important to highlight the **component of SIMPATICO that directly answer this issues**, like the Citizen Data Vault (addressing the concern about personal data), Citizenpedia (addressing the preference for personal contact) and Interactive front-end (addressing the lack of immediate feedback), so that citizens are aware that their concerns are being addressed.

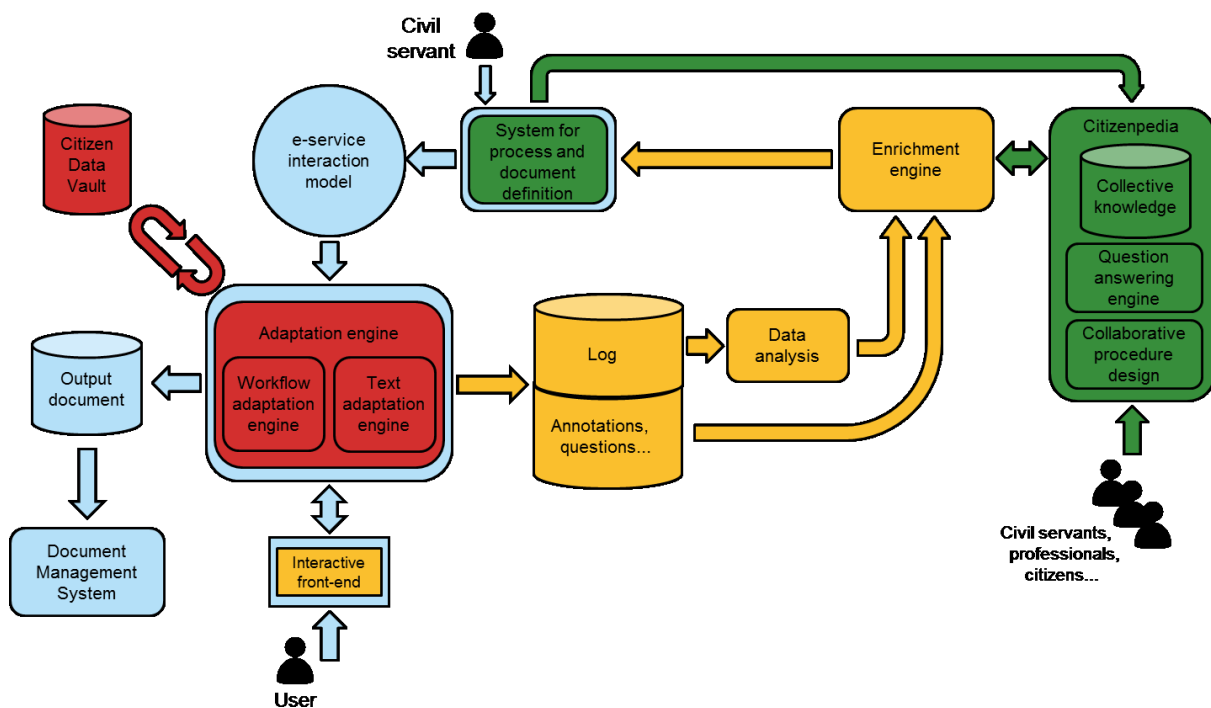


Figure 2: SIMPATICO Platform conceptual architecture and main components

### 2.3 SIMPATICO pilots

The piloting of this platform in two European cities (**Trento and Sheffield**) and one region (**Galicia**) in Italy, Spain and the United Kingdom (UK), through a **two-phase use-case validation** will enable SIMPATICO to address the important objectives in the **EU eGovernment Action Plan 2011-2015**. The stakeholders engaged in the **three use-cases** were selected for their experience and interest in e-services, as well as for the different socio-cultural backgrounds of the three regions. In this way, the Consortium have the opportunity to validate the effectiveness of the project results in **contexts which differ on the number and heterogeneity of citizens and their social and cultural background**.

There are indeed important **differences in the technological ecosystems**, with Trento and Sheffield having just started the process of digitalization of their services to citizens and businesses (this process will actually happen in alignment and integration with the SIMPATICO activities), and Galicia having a mature and consolidated e-service delivery infrastructure (thus allowing to test the deployment of SIMPATICO on top of an already operating system). The contexts also **differ for the point of view of the number and heterogeneity of end-users and for the variety and maturity of e-services**. Table 1.3 a shows an initial set of KPIs that we will measure in the three use-cases, along with the expected values at the end of the project.

### 2.4 SIMPATICO ethical issues

The SIMPATICO consortium is committed to perform a professional management of any ethical issue that could emerge in the scope of the activities of the project. For this reason, the consortium has identified relevant ethical concerns already during the preparation of the project proposal and, then, during the preparation of the grant agreement. During this phase, the European Commission has also carried out an ethics scrutiny of the proposal, with the objective of verifying the respect of ethical principles and legislation. With regard to SIMPATICO, the research entails specific ethical implications, involving human subjects and risks for the protection of personal data. In particular, the SIMPATICO ethical issues (requirements), as reported in the European Commission ethics scrutiny report and acknowledged by the SIMPATICO project, are the following:

#### **Humans - “D8.1 H – Requirement no. 1”**

- 1. Details on the procedures and criteria that will be used to identify/recruit research participants must be provided.*
- 2. Detailed information must be provided on the informed consent procedures that will be implemented.*

SIMPATICO involves **work with humans** (‘research or study participants’): i.e., according to the EC, collection of personal data, interviews, observations, tracking or the secondary use of information provided for other purposes. End-users (i.e., citizens and businesses) will be **engaged in the project use-cases** to test the functionalities provided by the SIMPATICO solution for the usage of e-services. Specific **engagement campaigns** will be defined and executed for each use-case. The use-cases will involve **only voluntary participants aged 18 or older and capable to give consent**, who will be informed on the nature of their involvement and on the data collection/retention procedures through an **informed consent form** before the commencement of their participations. **Terms and conditions** will be transparently communicated to the end-users by means of an **information sheet** including descriptions of: e.g., purpose of the research, adopted procedures, data protection and privacy policies. For further details, please see sections/annexes below and deliverable **“D8.1 H – Requirement no. 1”**.

**Protection of personal data – “D8.2 POPD – Requirement no. 2”**

1. *Copies of ethical approvals for the collection of personal data by the competent University Data Protection Officer/National Data Protection authority must be submitted by the coordinator to REA before commencement of data gathering.*
2. *Clarification and if relevant justification must be given in case of collection and/or processing of personal sensitive data. Requirement needs to be met before commencement of relevant work.*
3. *The applicant must explicitly confirm that the existing data are publicly available.*
4. *In case of data not publicly available, relevant authorisations must be provided, requirements to be met before grant agreement signature.*

SIMPATICO involves **collecting and processing personal data** (i.e., any information which relates to an identified or identifiable natural person, such as name, address, email) and **sensitive data** (e.g., health, sexual life, ethnicity). The **Citizen Data Vault** represents the component that will take care of personal and sensitive data exchange between a user and SIMPATICO components. Personal and sensitive data will be made **publicly available** (e.g., for the data of **Citizenpedia**) only after an **informed consent** has been collected and suitable **aggregation and/or pseudonymization techniques** have been applied. Mechanisms for encryption, authentication, and authorization (e.g., TLS protocol, Single-Sign-On implementations, Policy Enforcement Point for XACML) will be exploited in the processes, so to ensure the satisfaction of core **security and data protection requirements**, namely confidentiality, integrity, and availability. For further details, please see sections/annexes below and deliverable “D8.2 POPD – Requirement no. 2”.

**Vulnerable groups**

In addition to the above-mentioned ethical requirements, in the context of this deliverable it is also important to specify that SIMPATICO pilots may involve certain **vulnerable groups**: e.g., **elderly people and immigrants** (see also deliverable “D8.1 H – Requirement no. 1”). Please note that all the research participants will have the **capacity to provide informed consent**: i.e., individuals who lack capacity to decide whether or not to participate in research will be appropriately excluded from research. Anyway taking into account the scope and objectives of the research, researchers should be **inclusive in selecting participants**. Researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes such as culture, language, religion, race, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason for the exclusion.

Vulnerable groups could be misapplied for stigmatisation, discrimination, harassment or intimidation. Concern for **the rights and wellbeing of research participants** lies at the root of ethical review. The perception of subjects as vulnerable is likely to be influenced by diverse cultural preconceptions and so regulated differentially by localised legislation. It is likely to be one of the areas where researchers **need extra vigilance to ensure compliance with laws and customs**. Some vulnerabilities may not even be obvious until research is actually being conducted.

To reduce the risk of enhancing the vulnerability/stigmatisation of the above-mentioned individuals, the SIMPATICO **Ethics Advisory Board** (see Section 3 below) will provide **specific assessment on vulnerable groups** that may be involved, prior of the commencement of the pilots’ activities. Such an assessment will be included in the expected versions of the reports “**Project progress report**” (M12), “**D1.2 Intermediate activity report**” (M22), as well as in the reports concerning the use-case planning. In particular, it will include further details on the:

- type of vulnerability;
- recruitment/inclusion criteria and informed consent procedures;
- appropriate efforts to ensure fully informed understanding of the implications of participation.

**Example: Research involving the elderly**

*As the population ages, the proportion of elderly people is increasing, and so is their life expectancy. Research designed to improve our understanding of a wide range of aspects of aging and the lives of elderly people is important for ensuring that they stay fully integrated into society and maintain a continuing high quality of life. Research that takes into account the differential effects on the elderly and how best to accommodate their needs provides scientific evidence that can inform changes to policies and standards of care for the elderly.*

*Application. Elderly people shall not be inappropriately excluded from research solely on the basis of their age. Researchers should not exclude elderly people from research unless there is a valid reason for doing so (e.g., lack decision-making capacity). When considering the inclusion of elderly people in research, researchers and ethics advisory boards shall consider their physical and social needs to ensure adequate protections. Depending on their social circumstances, elderly people may require some reasonable support to facilitate their participation in research. Exclusion of the elderly shall not be based on easily remediable issues that are not germane to the research question.*

**Language, educational, administrative and technical barriers** affecting certain societal collectives at risk of exclusion will be captured, recognized, analysed and tackled by the dynamic adaptation of services towards **maximizing user experience**. Diversity will be tackled by matchmaking citizen and organizations profiles, securely preserved within the SIMPATICO Platform, with the services and range of adaptations readily available by SIMPATICO. The process of e-service delivery will be transformed by allowing service providers and consumers to **cooperate through the SIMPATICO Platform**, mutually enriching themselves and contributing to the co-creation of the knowledge base of **Citizenpedia**. **Political, legal and cultural obstacles** and factors affecting the acceptability and effectiveness of this transformation will be analysed and addressed throughout the project.

For the above-mentioned reasons, it remains vital on ethical grounds that all the participants (and also vulnerable groups) should be able **to freely decide for themselves**, with advocacy support if needed. If a research study like SIMPATICO enhances the provision of services to the community, then **study participants may gain both directly and indirectly**. Research which reflects the needs and perspectives of service users may even be more likely to produce **successful policy and practice recommendations**, also with regard to the vulnerable groups of populations involved.

### 3 SIMPATICO: responsibilities in ethics management

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In order to ensure that ethics, privacy and data protection-related concerns are addressed, monitored and complied with during the project lifespan, an **Ethics Advisory Board (EAB)** of the SIMPATICO project has been appointed including relevant ethical expertise. It is **competent to provide the necessary authorizations** when the collection and processing of personal (or sensitive) data is part of the planned research, with the validation of national and/or local Data Protection Authorities if needed. This board is led by an **ethics adviser** external to the project and to the host institution, totally independent and free from any conflict of interest. In addition to the external ethics adviser, the EAB is composed of **one expert representative from all members of the SIMPATICO Consortium** (1). Members of the Ethics Board are listed in **Annex 1 - Appointment of the Ethics Advisory Board** of this report with the name and contact information for persons appointed, the terms of reference for their involvement, and their declarations of no conflict of interest.

While carrying out its duties, the SIMPATICO Ethics Advisory Board refers to the **national, European and international framework of legal, deontological and ethic nature**, with a view on pluralism of ethic approaches. It is mainly inspired by the principles established on the basis of the current edition of the **Declaration of Helsinki**. The Board also aims at **stimulating awareness raising initiatives** regarding the ethical issues, which interest the Consortium as well as the entire community of stakeholders and citizens involved. The Consortium will confirm and document to the EU Commission that it does **comply with the European and national legal framework on ethics, privacy and data protection**. Relevant reporting documents of this board will be submitted to the EU Commission where applicable (see below). Hence, **standards and guidelines compatible with, and equivalent to, those of H2020 will be rigorously applied**, regardless of the Member States in which the research will be carried out.

More specifically, the **reference national and/or local Data Protection Authorities** competent to provide the above-mentioned SIMPATICO EAB with the necessary **instruction / authorizations / notifications** for each pilot are the following.

**Trento pilot (Italy): the Italian Data Protection Authority (DPA - <http://www.garanteprivacy.it/>).**

According to the “Italian Data Protection Code” (Legislative Decree no. 196/2003), an authorisation by the Italian DPA is required to enable private (and public) bodies to process specific typologies of personal and sensitive data (see Section 26 of the Italian Data Protection Code). More precisely, the DPA needs to be notified (also thorough an electronic form) whenever a public or private body undertakes a personal data collection, or personal data processing activity, as data controller. A data controller is required under the law to only notify the processing operations that concern e.g., data suitable for disclosing health and sex life, data processed with the help of electronic means aimed at profiling the data subject and/or his/her personality, analysing consumption patterns and/or choices. In such context, the DPA is also responsible for evaluating and expressing opinions on specific arguments concerning data protection (see “Simplification of Notification Requirements and Forms. Decision of the DPA dated 22 October 2008, as published in Italy's Official Journal no. 287 of 9 December 2008”).

In the case of Trento pilot, we consider this public authority appropriate for providing the SIMPATICO EAB with the necessary instructions/authorizations/notifications.

**Sheffield pilot (United Kingdom): the University Research Ethics Committee (UREC) of the University of Sheffield (<https://www.sheffield.ac.uk/ris/other/committees/ethicscommittee>).**

The University Research Ethics Committee (UREC) of the University of Sheffield is an independent, unbiased and interdisciplinary university-wide body that scrutinizes any potential issues related to research ethics for staff and students of the University of Sheffield, including collaborative research deriving from external funding. The key tasks this committee is in charge of are:

- Uphold adherence to the University's 'Ethics Policy Governing Research Involving Human Participants, Personal Data and Human Tissue' by all University staff and registered students who undertake such research, wherever that takes place, and by all individuals who undertake or contribute to such research on University premises and facilities;
- Promote awareness and understanding of research ethical issues throughout the University;
- Advise on any ethical matters in research that are referred to it from within the University; Keep abreast of the external research ethics environment and ensure that the University responds to all external requirements.

In the case of the Sheffield pilot, we consider this committee appropriate for providing the SIMPATICO EAB with the necessary instructions/authorizations/notifications. We remark that, in the case of Sheffield Council, Sheffield University and Sparta Technologies Ltd, all the involved entities comply with the UK data protection regulations and intend through the committee to ensure that act is enforced. Only if necessary, the AEB will engage the UK Information Commissioner's Office (ICO - <https://ico.org.uk/>).

**Galicia pilot (Spain): the Research Ethics Committee of the University of Deusto (<http://research.deusto.es/cs/Satellite/deustoresearch/en/home/research-ethics-comittee>).**

This committee is an independent, unbiased and interdisciplinary body that is both consultative and advisory in nature, and reports to the Vice-Rector's Office for Research. Among other responsibilities, this committee is in charge of:

- Conducting the ethical assessment of research projects and drawing up the ethical suitability reports requested by institutions and researchers.
- Ensuring compliance with best research and experimentation practices with regard to individuals' fundamental rights and the concerns related to environmental defense and protection.
- Supervising assessment processes or ethical requirements in research carried out by institutions and public bodies.
- Preparing reports for the University's governing bodies on the ethical problems that may arise from R+D+I activities.
- Ensuring compliance with the Policy on Scientific Integrity and Best Research Practices of the University of Deusto.
- Providing guidance on laws, regulations and reports on research ethics.
- Reviewing procedures that have already been assessed, or proposing the suspension of any experimentation already started if there are objective reasons to do so.

In the case of the Galicia pilot, we consider this committee appropriate for providing the SIMPATICO EAB with the necessary instructions/authorizations/notifications. Only if necessary, the AEB will engage the Spanish Data Protection Authority, i.e., Agencia Española de Protección de Datos (AEPD - <http://www.agpd.es/>).



The **general responsibilities** of the Ethics Advisory Board include:

- Maintaining **an overview of the work** throughout the whole course of your project and help the Consortium to think ahead about possible problems that might arise and how they can be addressed (i.e., checking for compliance with ethical standards within the relevant research fields), also obtaining **instructions/authorizations/notifications** from **national and/or local Data Protection Authorities**: i.e., the competent authorities to provide the necessary validations when the collection and processing of personal (or sensitive) data is part of the planned research (see below for further specifications);
- Creating, assessing and/or validating **reports and statements** about the ethical acceptability of the planned research. In particular, the following deliverables will be evaluated:
  - a) An updated version of this deliverable ("**D1.5 Ethics compliance report**"), which, if needed, will be produced after the first meeting of the above-mentioned board and made available to the EC after the first meeting of the above-mentioned board. The EAB will assess the ethical and societal aspects that should be taken into account during the project lifespan, both when collaborating with project participants and when defining the functionalities of the final SIMPATICO platform/services. This updated version with possible amendments will be delivered before the start of the piloting activities.
  - b) An updated version of the reports "**D8.1 H – Requirement no. 1**" and "**D8.2 POPD – Requirement no. 2**", which, if needed, will be produced and made available to the EC after the first meeting of the above-mentioned board (see point a) above).
  - c) Reference on how the ethical issues are addressed in the project, which will be reported in the forthcoming reports "**Project progress report**" (M12) and "**D1.2 Intermediate activity report**" (M22).
  - d) The expected reports "**D1.3 Data Management Plan v.1**" (M6) and "**D1.4 Data Management Plan v.2**" (M36).

Further **specific responsibilities** of the Ethics Advisory Board include:

- Obtaining **instructions/authorizations/notifications** from **national and/or local Data Protection Authorities** of the involved Member States (i.e., the competent authorities to provide the necessary validations when the collection and processing of personal or sensitive data is part of the planned research), aimed at demonstrating the compliance of the ethics, privacy and data protection processes with the European and national legal frameworks. Prior to the commencement of each relevant WP that collects or processes data, and where applicable, copies of these instructions/authorizations/notifications will be forwarded to the EU Commission and reported (when necessary) through the above-mentioned reports "**Project progress report**" (M12) and "**D1.2 Intermediate activity report**" (M22).
- Providing **detailed information on the relevant project activities to the national and/or local Data Protection Authorities** of the involved Member States (i.e., the competent authorities to provide the necessary validations when the collection and processing of personal or sensitive data is part of the planned research) on the source and secondary use of the data. Their approvals will be sent to the EC and reported (when necessary) through the above-mentioned reports "**Project progress report**" (M12) and "**D1.2 Intermediate activity report**" (M22).
- Submitting **any further copies of its ethical approvals/opinions/notifications** to SIMPATICO project coordinator that will communicate them to the EC prior to the commencement of each relevant WP that collects or processes data, and where applicable.

- Coordinating and monitoring the collection of the **informed consents** of the persons concerned ('data subjects');
- Besides these documents, and where applicable, **providing to the EC – through the SIMPATICO project coordinator - further detailed information on the source of the data, privacy/confidentiality, and the procedures** that will be implemented for data collection, storage, access, sharing policies, protection, retention and destruction. Confirmation that they comply with European and national legislation will also be included, e.g., via the above-mentioned "Project progress report" (M12) and "D1.2 Intermediate activity report" (M22).



## 4 SIMPATICO: ethical and legal framework

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Ethical, privacy, and data protection-related aspects will have a **key role** over **all the operations involving human beings and performed mainly on personal and sensitive data**, i.e., any data that can disclose a person's racial origin or ethnicity, religious or other beliefs, political opinions, membership of parties, trade unions and/or associations, health, or sex life (e.g., collection, storage, analysis, transmission). This means that all the possible **precautions** for ethics and data management will be adopted in order to guarantee protection requirements (e.g. authorization/access control, message integrity and confidentiality).

**Applicable European and national ethics, privacy and data protection regulations** will be taken into account and measures to enforce these topics will be implemented in the project. While doing so, the above-mentioned **Ethics Advisory Board** and **all institutions and individual researchers** in the SIMPATICO Consortium will comply with the applicable legislation (and recommendations) at the EU and national level, and in particular (in chronological order):

- **Directive 95/46/EC** of the European Parliament and of the Council of 24 October 1995 (and subsequent modifications and supplements) on the protection of individuals with regard to the processing of personal data and on the free movement of such data.
- **Regulation 45/2001/EC** of the European Parliament and of the Council of 18 December 2001 (and subsequent modifications and supplements) on the protection of individuals with regard to the processing of personal data by the institutions and bodies of the Community and on the free movement of such data.
- **Directive 2002/58/EC** of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector (Directive on privacy and electronic communications).
- **Directive 2006/24/EC** of the European Parliament and of the Council of 15 March 2006 on the retention of data generated or processed in connection with the provision of publicly available electronic communications services or of public communications networks.
- **Charter of Fundamental Rights of the European Union** (2012/C 326/02), become legally binding on the EU institutions and on national governments on 1 December 2009, with the entry into force of the Treaty of Lisbon.
- **EU Data Protection Reform**, i.e., Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation); Directive (EU) 2016/680 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data by competent authorities for the purposes of the prevention, investigation, detection or prosecution of criminal offences or the execution of criminal penalties, and on the free movement of such data, and repealing Council Framework Decision 2008/977/JHA. Please note that on 4 May 2016, the official texts of the Regulation and the Directive have been published in the EU Official Journal in all the official languages. While the Regulation entered into force on 24 May 2016, it shall apply from 25 May 2018. The Directive enters into force on 5 May 2016 and EU Member States have to transpose it into their national law by 6 May 2018 (2) (3).
- The **Opinions of the European Group on Ethics in Science and New technologies (EGE)**, and in particular, the Opinion No. 26 of 22 February 2012 on “Ethics of information and communication technologies” (4).

- The **Opinion No. 3 of 2 April 2013 of the Article 29 Data Protection Working Party** on “Purpose limitation” (5).

The following subsections presents the ethical, privacy, and data protection framework relating to the SIMPATICO project. Subsection 4.1 illustrates the rights listed in the EU Charter of Fundamental Right pertaining to SIMPATICO. Subsection 4.2 analyses the potential influence of the EU Data Protection Reform on SIMPATICO, while Subsections 4.3 and 4.4 illustrates the country-specific legal framework of SIMPATICO use-cases, with a brief overview on big data and privacy.

#### 4.1 SIMPATICO and the EU Charter of Fundamental Rights

This subsection aims to investigate the proposed SIMPATICO solution from the viewpoint of **EU Charter of Fundamental Rights**. SIMPATICO and its various components support ideation, development and exploitation of new public services utilizing public and other data. Both the innovation process itself, as well as the new public services to be created and produced are deeply linked to the citizens’ rights named in the Charter of Fundamental Rights of the European Union.

Table 1 below provides a list of the fundamental rights defined in the European Charter of Fundamental Rights (6). The rights are organized under the corresponding basic values: dignity, freedom, equality, solidarity, citizens’ rights and justice. The rights that are the most relevant from the viewpoint of the SIMPATICO innovation process are written in bold letters and discussed in detail. The rights that may not be so relevant in the SIMPATICO context are written in grey letters.

<b>Dignity</b> <b>1 Human dignity</b> 2 Right to life <b>3 Right to the integrity of the person</b> 4 Prohibition of torture and inhuman or degrading treatment or punishment 5 Prohibition of slavery and forced labor <b>Freedom</b> 6 Right to liberty and security <b>7 Respect for private and family life</b> <b>8 Protection of personal data</b> 9 Right to marry and right to found a family 10 Freedom of thought, conscience and religion <b>11 Freedom of expression and information</b> 12 Freedom of assembly and of association 13 Freedom of the arts and sciences <b>14 Right to education</b> <b>15 Freedom to choose an occupation and right to engage in work</b> <b>16 Freedom to conduct a business</b> 17 Right to property 18 Right to asylum 19 Protection in the event of removal, expulsion or extradition <b>Equality</b>	<b>Solidarity</b> 27 Workers’ right to information and consultation within the undertaking 28 Right of collective bargaining and action 29 Right of access to placement services 30 Protection in the event of unjustified dismissal 31 Fair and just working conditions 32 Prohibition of child labor and protection of young people at work 33 Family and professional life 34 Social security and social assistance 35 Health care 36 Access to services of general economic interest 37 Environmental protection 38 Consumer protection <b>Citizens’ rights</b> 39 Right to vote and to stand as a candidate at elections to the European parliament <b>40 Right to vote and to stand as a candidate at municipal elections</b> <b>41 Right to good administration</b> <b>42 Right to access to documents</b> 43 European Ombudsman 44 Right to petition
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20 Equality before the law <b>21 Non-Discrimination</b> <b>22 Cultural, religious and linguistic diversity</b> <b>23 Equality between women and men</b> <b>24 The rights of the child</b> <b>25 The rights of the elderly</b> <b>26 Integration of persons with disabilities</b>	45 Freedom of movement and residence 46 Diplomatic and consular protection <b>Justice</b> 47 Right to an effective remedy and to a fair trial 48 Presumption of innocence and right to defense 49 Principles of legality and proportionality of criminal offences and penalties 50 Right not to be tried or punished twice in criminal proceedings for the same criminal offence
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Table 1: SIMPATICO and the EU Charter of Fundamental Rights

#### 4.1.1 Dignity and integrity

*“Human dignity is inviolable. It must be respected and protected.”*

*“Everyone has the right to respect for his or her physical and mental integrity.”*

Respect of the dignity (Article 1) and integrity (Article 3) of a person can be perceived as a fundamental general requirement for SIMPATICO. SIMPATICO collects a huge amount of data based on which various functionalities of the SIMPATICO components operate (e.g. Citizen Data Vault and adaptation and enrichment Engine). These rights may be violated, since the data can even “reveal” something which you do not know yet, or alternatively something which is not true. These negative consequences have to be taken into account when designing the functionalities of SIMPATICO components. Special attention will be given to data protection and the security of data sources, services and interfaces and the privacy of persons, which are important aspects for stakeholders and components in SIMPATICO solution.

#### 4.1.2 Respect for private and family life, and protection of personal data

*“Everyone has the right to respect for his or her private and family life, home and communications.”*

*“Everyone has the right to the protection of personal data concerning him or her... Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified... Compliance with these rules shall be subject to control by an independent authority.”*

Respect for private and family life (Article 7) and Protection of personal data (Article 8) are rights which are of special concern since they can be violated. This can be also the case of the SIMPATICO framework. In addition to the mismanagement of Citizen Data Vault and the unintended use of Adaptation Engine, the Open Data itself can increase the above-mentioned risks. These data can be implicitly or explicitly about individuals. For these reasons, special attention has to be given to Open Data, private data, social data, personal data, as they can open possibilities for wrong and unintended ways to utilize information within SIMPATICO platform (see also Article 34 of the Grant Agreement on Ethics).

#### **4.1.3 Freedom of expression and voting**

*“Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers... The freedom and pluralism of the media shall be respected.”*

*“Everyone has the right to freedom of peaceful assembly and to freedom of association at all levels, in particular in political, trade union and civic matters, which implies the right of everyone to form and to join trade unions for the protection of his or her interests...Political parties at Union level contribute to expressing the political will of the citizens of the Union.”*

The SIMPATICO platform opens an innovation area where the citizens can express their needs and where the eliciting, analyzing and improving the new service ideas in collaboration with the public administration and other actors will be done is a means to promote citizens’ freedom of assembly and association (Article 12) and their Freedom of expression (Article 11) and information. Leveraging this approach, the citizens can become active agents of change in the society. Their participation in the innovation process has therefore intrinsic value, not only instrumental value from the viewpoint of providing better services.

#### **4.1.4 Right to property**

*“Everyone has the right to own, use, dispose of and bequeath his or her lawfully acquired possessions. No one may be deprived of his or her possessions, except in the public interest and in the cases and under the conditions provided for by law, subject to fair compensation being paid in good time for their loss. The use of property may be regulated by law in so far as is necessary for the general interest...Intellectual property shall be protected.”*

Property rights in the context of SIMPATICO data are of special concern. As Volker et al. (7) in the document “Big Data Management” argue, in addition to the data protection laws (see subsection on data protection) legal framework for big data covers ownership of data as well as contractual and liability problems. Citizens actively update a huge amount of data into SIMPATICO by themselves. This calls for thorough and appropriate management mechanisms of the SIMPATICO Open Data.

#### **4.1.5 Access to public documents**

*“Any citizen of the Union, and any natural or legal person residing or having its registered office in a Member State, has a right of access to documents of the institutions, bodies, offices and agencies of the Union, whatever their medium.”*

The right of access to documents (Article 42) can be perceived as the starting point for the whole SIMPATICO solution and of its product Citizenpedia, including Open Data and user-generated data. Based on such data, more advanced and personalized e-services can be created and produced.

#### **4.1.6 Good administration**

*“Every person has the right to have his or her affairs handled impartially, fairly and within a reasonable time by the institutions, bodies, offices and agencies of the Union... This right includes: (a) the right of every person to be heard, before any individual measure which would affect him or her adversely is taken; (b) the right of every person to have access to his or her file, while respecting the legitimate interests of confidentiality and of professional and business secrecy; (c) the obligation of the administration to give reasons for its decisions...Every person has the right to have the Union make good any damage caused by its institutions or by its servants in the performance of their duties,*

*in accordance with the general principles common to the laws of the Member States... Every person may write to the institutions of the Union in one of the languages of the Treaties and must have an answer in the same language.”*

The right to good administration (Article 41) is one of the most supported right by the new public services developed and produced by the SIMPATICO solution. SIMPATICO empowers citizens and businesses by democratizing the access to, and consumption of, e-service among diverse stakeholders. Efficiency and effectiveness of the public sector are the main outcomes of SIMPATICO, as shown by the use-case KPI. In addition, SIMPATICO has the potential to create a true citizen-centric public sector: not only it will provide personalization and adaptation of e-services thanks to its Citizen data vault and Adaptation engine components, but it will also offer to citizens the possibility to contribute to public sector knowledge base through the Citizenpedia component. In this regard, Hilgers (8) talks about “Citizen sourcing”.

#### **4.1.7 Genre balance, non-discrimination and cultural diversity**

*“Equality between women and men must be ensured in all areas, including employment, work and pay.”*

*“The Union shall respect cultural, religious and linguistic diversity.”*

*“Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.”*

The equality between women and men (Article 20), non-discrimination (Article 21) and the right for cultural, religious and linguistic diversity (Article 22) represent two different coins in the SIMPATICO solution. The project should support the possibilities of people from various backgrounds to take part in the SIMPATICO service development, as well as to use those services. This calls for flexible user interfaces as well as monitoring information on various types of services available for citizens with different backgrounds. On the other hand, the same information revealing the background of the user cannot be used for discrimination.

#### **4.1.8 Rights of the child, the Elderly and Persons with Disabilities**

*“Children shall have the right to such protection and care as is necessary for their well-being. They may express their views freely. Such views shall be taken into consideration on matters which concern them in accordance with their age and maturity...In all actions relating to children, whether taken by public authorities or private institutions, the child's best interests must be a primary consideration...”*

*Every child shall have the right to maintain on a regular basis a personal relationship and direct contact with both his or her parents, unless that is contrary to his or her interests.”*

*“The Union recognizes and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life.”*

*“The Union recognizes and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”*

The rights of the child (article 24), the rights of the elderly and the integration of persons with disabilities (Article 25) can be connected to the user interfaces and functionalities of SIMPATICO, which are flexible and adjustable for people with underdeveloped or diminished mental, social, physical or cognitive or linguistic capacities. In addition, monitoring information on various types of services available for these vulnerable citizens is needed.

#### 4.1.9 Further relevant rights

*“Everyone has the right to liberty and security of person”*

*“Everyone has the right to education and to have access to vocational and continuing training.”*

*“Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited”.*

SIMPATICO offers possibilities for service development and providing in various sectors. In addition to pure information services or administrative services, especially the so-called rights of “solidarity” may be promoted with SIMPATICO, including wellbeing-related aspects and education services (e.g. Articles 14, 21). In addition, further domains where SIMPATICO service co-production might support fundamental rights is the right of liberty and security of persons (Article 6).

## 4.2 SIMPATICO and the EU Data Protection Reform

**Personal data** is any information relating to an individual, whether it relates to his/her private, professional or public life: e.g. name, photo, email address, bank details, posts on social networking websites, medical information, computer’s IP address. Current EU data protection rules apply when a person can be identified, directly or indirectly, by such data. In this regard, the above-mentioned EU Charter of Fundamental Rights says that everyone has the right to personal data protection in all aspects of life: e.g. at home, at work, whilst shopping, receiving medical treatment, at a police station or on the Internet (2). Therefore, the principles of data protection should apply to any information concerning an identified or identifiable natural person.

**Directive 95/46/EC** on data protection is the main reference regulation in effect at the present time and relevant for SIMPATICO, because it sets the frames for national legislation, including the protection of the fundamental right of individuals. This Directive has been under reconstruction for several years. The reason for the need of its amendment is linked to the differences in the way in which each EU country implemented its rules: this have led to an uneven degree of protection for personal data. The current rules also need to be modernized. Rapid technological developments and globalization have brought new challenges for data protection, including globalized nature of data flows, social networking sites, cloud computing, location-based services and smart cards (9).

The European Commission put forward its **EU Data Protection Reform** in January 2012 to make Europe fit for the digital age. On 15 December 2015, the European Parliament, the Council and the Commission reached agreement on the new data protection rules, establishing a modern and harmonised data protection framework across the EU. On 4 May 2016, the official texts of the **Regulation (EU) 2016/679** and the **Directive (EU) 2016/680** have been published in the EU Official Journal in all the official languages. While the Regulation entered into force on 24 May 2016, it shall apply from 25 May 2018. The Directive entered into force on 5 May 2016 and EU Member States will have to transpose it into their national legislation by 6 May 2018 (3) (9). It is therefore not reasonable to provide a detailed description on the impact of new data protection legislation for the SIMPATICO solution in this deliverable. However, in the current and forthcoming EU legislation especially the following issues are relevant as regards the SIMPATICO context:

- A **‘right to be forgotten’** is foreseen in the new Regulation to help people better manage data protection risks online. When they no longer want their data to be processed and there are no legitimate grounds for retaining it, the data will have to be deleted.



- Whenever **informed consent** is required for data processing, it will have to be given explicitly, rather than be assumed. In the consent forms it has to be explained clearly what data will be collected and for what purposes (i.e., information sheet).
- Data controllers must be able to **prove "consent"** (opt-in) and consent may be **withdrawn**. When consent is withdrawn, this may allow the termination or non-execution of a service which is dependent on the data.
- Provisions should be made for **the possibility for transfers** in certain circumstances where the data subject has given his/her consent, where the transfer is necessary in relation to a contract or a legal claim. Such a transfer should not involve the entirety of the data or entire categories of the data contained in the register.
- Where the processing is carried out in the public sector or where, in the private sector, processing is carried out by a large enterprise relates to more than 5000 data subjects within 12 months, or where its core activities, regardless of the size of the enterprise, involve **processing operations on sensitive data, or processing operations which require regular and systematic monitoring**, a person should assist the controller or processor to monitor internal compliance with new EU regulation.
- **Easier access to one's own data and the right of data portability**, i.e., easier transfer of personal data from one service provider to another is to be required according to the forthcoming regulation.
- Increased responsibility and accountability in relation to **processing of personal data**: e.g., introduction of data protection risk assessment procedures, data protection officers, the principles of 'Privacy-by-design' and 'Privacy-by-default'. Any processing of personal data shall foresee the appointment of a controller or a processor, according to the above-mentioned Regulation. Responsibilities of the data controller and the data processor have to be defined clearly. This is especially the challenge when data is collected from various sources and databases (i.e., the case of SIMPATICO).

### 4.3 SIMPATICO and the country-specific legal framework

The implementation of the SIMPATICO platform has to be developed according to **EU and national privacy and data protection legislation** (as already mentioned above as regard the European level), including the '**Privacy-by-design**' principles and taking also into account of the new **EU Data Protection Reform** (9). Also relevant guidelines and opinions of EU Data Protection Bodies, such as those produced by **Article 29 Data Protection Working Party**, will be considered, examined and adopted (2) (5).

One of the key issues in the field is connected to the ability of individuals to make **informed decisions**, given the complex and evolving landscape. A range of initiatives across the EU have applied different options in this regard, but there is a significant **need of harmonisation** to provide a pragmatic approach to user choices and consent. For instance, we need to identify the conditions under which it would be possible to use digital identities across different EU Member states, so that these digital identities may "circulate" and be recognized as valid and legitimate to access the services offered in the various Countries. Secondly, an **authorisation system** is needed to comply with the security requirements established in Article 17 of the Directive 95/46/EC, as laid down in the national legislation. In this sense, the system must correctly recognise the users and permit them to access their data and manage the flow of their records, while **complying with the privacy principles and legal values** embedded in the digital architecture (1) (9).

With specific regard to the above-mentioned key issues, the following subsections illustrates a **brief overview of national rules on privacy and data protection** of the Member States (MSs) involved in the SIMPATICO Consortium (i.e., Italy, Spain, and the United Kingdom). Please note that the new Regulation (EU) 2016/679 shall apply from 25 May 2018: i.e., the domestic legislation of EU MSs related to the Directive 95/46/EC is still in force (3).

#### 4.3.1 Italian legal framework

Italy's consolidated data protection code came into force on 1 January 2004 (**Legislative Decree no. 196/2003**; hereinafter also referred to as "Italian Data Protection Code", "Code" or "DP Code"). The Code brings together all the various laws, codes and regulations relating to data protection since 1996. **The main features of the Italian Data Protection Code relevant for SIMPATICO** project regards specific processing operations, e.g.:

- **Authorisations issued for the processing of personal and/or sensitive data:** An authorisation by the Italian Data Protection Authority (DPA - <http://www.garanteprivacy.it/>) is required to enable private/public bodies to process certain types of personal and sensitive data: e.g., data suitable for disclosing health and sex life, data processed with the help of electronic means aimed at profiling the data subject and/or his/her personality (see Section 26 of the DP Code; "Simplification of Notification Requirements and Forms", Decision of 22 October 2008 as published in Italy's Official Journal no. 287 of 9 December 2008). The Code provides also that "general authorisations" may be issued by the Italian DPA (see Section 40 of the DP Code). Such general authorisations may be targeted to industry sectors (e.g., banking and insurance companies) and/or specific categories of data (e.g. genetic data or medical data). Where a data controller complies in full with the provisions made in the relevant general authorisation, no ad hoc authorisation will be required. If this were not the case, a specific application will have to be lodged with the Italian DPA: the DPA will then consider all the circumstances of the case and decide whether the authorisation is to be granted.
- **Consent from data subjects is required:** The free indication of the data subjects' wish to explicitly accept a specific processing operation concerning their personal data, of which the data subject was informed beforehand by the entity empowered to decide on that processing (i.e., the data controller). If the processing concerns sensitive data, the data subject has to give written consent (e.g., by undersigning a form). Some types of processing may be performed without the data subject's consent under the terms of Section 24 of Italy's Data Protection Code.
- **Electronic Communications Data:** The Code has implemented the provisions contained in the E-Communications Privacy Directive 2002/58/EC, as well as in the Data Retention Directive 2006/24/EC (see Title 10, Part 2 of the DP Code). One of the main principles is on electronic marketing, which requires organisations to obtain prior consent before sending electronic marketing to consumers (see Section 130). This applies to all forms of e-marketing, including e-mail, fax, SMS/MMS, social posts, etc., and can be relevant for SIMPATICO.

Moreover, the crucial legal challenges of SIMPATICO project are the **security measures concerning authentication and authorization**. Pursue to the above mentioned Article 17 Directive 95/46/EC, the implementation of both computerized authentication and procedures for managing authentication credentials is required. This is foreseen also by the Art. 33 and ff. and by Annex B (p. 1-11) of the above-mentioned Legislative Decree no. 196/2003. To assure the security of and the trust in the system, it is fundamental to provide technical solutions aimed at allowing the circulation of digital identities and the access to the e- services. In this sense, the Italian Legislator is driving a process for



implementing a secure and reliable system for the **digital identity management**, known as “SPID” (see Article 64, para. 2 sexies of the Legislative Decree 82/2005 and of the Decree of the Presidency of the Council of Minister of 24 October 2014). The system involves private and public stakeholders, that after prior accreditation by the competent authority for the Italian Digital Agenda, manage the service of registration and make available both the credentials and the means of access to citizens and companies.

Another fundamental legal challenge for SIMPATICO is represented by the above-mentioned **authorizations** (Articles 33 and ff. and Annex B, p. 12-14, of the Italian Data Protection Code) and their interoperability with the specific European and national provisions. In this regard, it is necessary to remind that the Consortium aims at verifying solutions able to allow the users to directly manage their data. Therefore, the IT architecture will be designed in strict accordance to privacy and security principles. Lastly, we have to consider that such a legal scenario will need to be verified and updated taking into account the incoming provisions of the **EU Data Protection Reform** that will be effective for the first semester of 2018 (10).

#### 4.3.2 Spanish legal framework

The Spanish legal framework on privacy and data protection includes the **Spanish Data Protection Act 15/1999 (Law 15/1999 of 13 December 1999** on Protection of Personal Data, last updated on 5 March 2011) and the **Royal Decree 1720/2007** of 21 December 2007, approving the regulations implementing Law 15/1999 (“Data Protection Regulations”; Last updated: 8 March 2012). These acts protect individuals with regard to the processing of personal data and the free movement of data. There are no sector-specific laws regulating the processing of personal data, but there are regulations that contain specific provisions on personal data processing. The most relevant regulations are: the Spanish Information Society Services Act (**Law 34/2002** on information society services and e-commerce); and the Spanish General Telecommunications Act (**Law 9/2014**). **The main features of the Spanish Data Protection Act relevant for SIMPATICO** project regards specific processing operations, e.g.:

- **Authorisations issued for the processing of personal and/or sensitive data:** Prior to the processing of personal data, data controllers must register the data file containing such personal data with the Spanish Data Protection Authority, i.e., Agencia Española de Protección de Datos (AEPD - <http://www.agpd.es/>). Such registration needs to be carried out by completing a standard notification form called “NOTA”. In general terms, the NOTA must include details as the data controller’s corporate identity, the security measures implemented on the processing (indicating whether these are basic, medium or high level measures), the type(s) of data processed, the purpose(s) of the processing, details of foreseeable disclosure(s) and/or international transfer(s), and information about existing data processor(s). Data controllers are required to keep data file registrations up to date. Thus, they are required to notify the AEPD (again, via a NOTA form) about any changes related to the personal data files registered. Also data transfer agreements must be previously authorised by the AEPD.
- **Consent from data subjects is required:** Consent must be informed. Depending on the circumstances, it can be implied, express (for example, for sensitive data) or written (for example, for data revealing ideology). Unless the law requires express consent, the Data Protection Regulations establish that data controllers can inform data subjects of the processing they intend to carry out and give them 30 days to oppose it. This way of obtaining consent is subject to limitations (for example, a data controller cannot request the same

consent again until a year has passed). Data subjects from whom personal data is requested must be previously provided with specific information.

- **Security measures:** Data controllers and data processors must implement security measures to protect personal data against accidental or unlawful destruction, accidental loss, alteration or unauthorised disclosure or access. The Data Protection Regulations set out specific minimum security measures to be implemented by controllers and processors, establishing three cumulative security levels: basic, medium and high. The applicable measures depend on the nature of the data.
- **Electronic communications:** Recipients must consent to receiving electronic communications. An opt-out is valid for communications relating to first party products or services similar to those initially requested by the customer (or citizen). An opt-in is required when communications relate to third party products or services, or products or services other than those initially requested by the customer (or citizen).

Further issues that are involved in the data processing are: (i) to determine the **legal ground** to process data; (ii) the **data transfer** from one service provider to another; (iii) the **scope and kind of information** given to the user; and (iv) **obligations/responsibilities of the different stakeholders** involved. It must be underlined the fact that, the Spanish legal system on data protection establishes different rules regarding the processing of data in private and public cases. Lastly, we have to consider that such a legal scenario will need to be verified and updated taking into account the incoming provisions of the **EU Data Protection Reform** that will be effective for the first semester of 2018 (11).

#### 4.3.3 UK legal framework

The **UK Data Protection Act 1998** (DPA) is an Act of Parliament of the United Kingdom of Great Britain and Northern Ireland that defines UK law on the processing of data on identifiable living people. It is the main piece of legislation that governs the protection of personal data in the UK. Although the Act itself does not mention the concept of privacy, it was enacted to bring British law into line with the 1995 EU Data Protection Directive. In the UK the highest government body to define and regulate the data protection and privacy issues is the **Information Commissioner's Office** (ICO - <https://ico.org.uk/>), i.e., an independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals. It has less powers than some of its other EU countries counterparts: for instance, also the government has currently no obligation to ask for ICO authorization or even opinion before setting up a new database. The ICO covers four main areas, in relation with the following legislation and regulations: Data Protection Act, Privacy and Electronic Communications Regulations, Freedom of Information Act, Environmental Information Regulations. The Data Protection Act 1998 requires only every data controller (e.g., organisation, sole trader) who is processing personal information to register with the ICO, unless they are exempt. **The main features of the DPA relevant for SIMPATICO** project regards specific processing operations, e.g.:

- **Authorisations issued for the processing of personal and/or sensitive data:** If a private/public body process personal data, it is considered a 'data controller' for the purposes of the Data Protection Act 1998. The Act requires data controllers to give details about the way they process personal information to the ICO for inclusion in a data protection public register. This notification is required so that people can find out what personal information an organisation is processing and why. The notification is a statutory

requirement and all businesses which handle personal data must comply, unless they are exempt.

- **Consent from data subjects is required:** Except under specific exceptions (e.g., crime and taxation), the individual needs to consent to the collection of their personal information and its use in the purpose(s) in question. One of the conditions for processing is that the individual has consented to their personal data being collected and used in the manner and for the purposes in question. The Data Protection Act also specifies that sensitive personal data must be processed according to a stricter set of conditions, in particular any consent must be explicit.
- **Privacy and Electronic Communications Regulations (PECR):** PECR are not just concerned with marketing by electronic means. They also contain provisions that concern the security of public electronic communications services and the privacy of customers using communications networks or services. Special data protection rules apply to the protection of personal data by data controllers in the electronic communications sector. Data controllers must give effect to a specific security policy which protects personal data against accidental or unlawful destruction, accidental loss or alteration, and unauthorised or unlawful storage, processing, access or disclosure of personal data; ensure that personal data can only be accessed by authorised personnel for legally authorised purposes; and provide information to subscribers on any particular risk of a breach of the security of a public communications network.

In addition, also the **UK Freedom of Information Act 2000** (FoIA) is pertinent to SIMPATICO framework its aim being to provide public access to information held by public authorities. It does this in two ways: (i) **public authorities are obliged to publish certain information** about their activities; (ii) **members of the public are entitled to request information from public authorities**. Public authorities include government departments, local authorities, the NHS, state schools and police forces. However, the Act does not necessarily cover every organisation that receives public money. For example, it does not cover some charities that receive grants and certain private sector organisations that perform public functions. Recorded information includes printed documents, computer files, letters, emails, photographs, and sound or video recordings. The Act does not give people access to their own **personal data** (information about themselves), such as their health records or credit reference file. If a member of the public wants to see information that a public authority holds about them, they should make a subject access request under the Data Protection Act 1998.

The Consortium via the support of the EAB will start by developing a Privacy Impact Assessment (PIA) to explore the various scenarios and risks involved in the proposed pilot to determine what mechanisms are appropriate and robust according to the DPA and FoIA. Lastly, we have to consider that such a legal scenario will need to be verified and updated taking into account the incoming provisions of the **EU Data Protection Reform** that will be effective for the first semester of 2018 (12) (13).

#### **4.4 SIMPATICO: big data and privacy challenges**

The term big data refers to large amounts of different types of data produced with high velocity from a high number of sources. The **goals of big data and privacy** are fundamentally opposed to each other. Big data and knowledge discovery are aimed reducing information **asymmetries between organizations and the data sources**, whereas privacy is aimed at maintaining information

asymmetries of data sources. A number of different definitions of privacy are used to investigate some of the tensions between different characteristics of big data and potential privacy concerns. The fundamental right to personal data protection applies to big data **where that data is personal**: data processing has to comply with all applicable data protection rules (14).

The interaction among service providers and users generates **a great amount of information**. Personal information collection is viewed as “the new oil of the internet and the new currency of the digital world” (15). It presents many new opportunities for service providers. Analysing, mining, monitoring, leveraging and managing the collected personal data, enables service providers to produce more efficient, effective and convenient services for users. **Personal data management** can boost user experience and contribute to value creation (16). However, its management by service providers yields a range of risks such as undermining end-user confidence and trust, which are mainly caused by lack of transparency and accountability of users’ privacy. A main research challenge is to protect individuals’ privacy and simultaneously allow other service providers to take advantage of the socio-economic opportunities driven by that personal data. The **Personal Data Ecosystem (PDE) consortium** is coordinating a set of initiatives and tools aimed at facilitating individuals to control their personal data (17), e.g., **Personal data vaults (PDV)** allow individuals to manage their own information.

A **Citizen data vault (CDV)** is as a PDV that interoperates **with government services**. As stated in (18) “Citizen data vaults are services that provide data subjects with the ability to access their data outside the context of a particular government transaction, allowing them much finer-grained control over when and how data can be accessed, and by whom, within the relevant legal framework to which they are subject. They need to interoperate with government, as well as with third-party systems that directly provide services to constituents”. CDVs are in an embryonic state, and the target is moving from personal health data management to others fields like citizens’ e-ID and social services, e.g. Australia’s government PCEHR, a platform that allows storing and share personal health data with trusted health professionals.

**SIMPATICO will tackle interoperability, network latency, data availability and security issues** impeding a more widespread adoption of CDVs. It will address the perceived liability for public entities which fail to deliver services because of the absence of data vault services. Its CDV will enable citizens to use it as a single point of access to their data when interacting with the public administration. It will be composed of personal information items fed by authorized data sources (e.g., civil registry) and supplied automatically by the CDV to the open services consumed by citizens.

**Data management** is therefore a key issue for SIMPATICO. Special attention will be given to the **security** of data sources, services and interfaces and the **privacy** of persons, which are important aspects for stakeholders and components in SIMPATICO solution. In particular, **privacy** will be managed by the **Citizen data vault**: this component allows citizens to manage and share their own personal data and to control how the data should be accessed and by whom, within the legal framework in which they are involved. The Citizen data vault is used to keep a safety vault where the user personal data, preferences and profile details are preserved and exploited only by authorized components (e.g. the Adaptation engine). More detailed information on this topic will be illustrated in the following deliverables “**D1.3 Data Management Plan v.1**” (M6) and “**D1.4 Data Management Plan v.2**” (M36).

## 5 SIMPATICO: ethical recommendations and guidelines

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Ethical, privacy and data protection-related issues expected during the project are mainly limited to the **involvement of human participants** in the above-described use-cases and to the **collection of personal and sensitive information** (e.g. also concerning users' profiles). The use-cases will involve only **voluntary participants aged 18 or older**, who will be informed on the nature of their involvement and on the data collection/retention procedures through an **informed consent form** (Annex 2 – Informed Consent Form), before the commencement of their participations. Informed consent will follow procedures and mechanisms compliant with European and national regulations in the field on ethics, data protection and privacy. Only participants that, according to the relevant law, are **capable of providing informed consent** will be selected. SIMPATICO pilots may involve certain **vulnerable groups**, e.g., **elderly people and immigrants** (see also Section 2 above).

In this framework, this section aims at providing some useful recommendations and guidelines on the identification, selection and recruitment of end-users, as well as on data protection, informed consent procedures, and security issues. Finally, a first draft of the SIMPATICO model-based privacy compliance checker is included. For further information, please see the deliverables “**D8.1 H – Requirement no. 1**” and “**D8.2 POPD – Requirement no. 2**”.

### 5.1 Identification, selection and recruitment of end-users

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End-users will be engaged in the project use-cases to **test the functionalities provided by the SIMPATICO solution** for the usage of e-services; each use-case will identify specific e-services, depending on the specific need of the public administration running the use-case. End-users are **citizens and businesses that are the beneficiaries of the e-services** that will be tested. Specific requirements for these end-users will be identified as part of the use-case definition (see **Task T6.2 "Use-case requirements, planning and KPI definition"**). These requirements will express **objective conditions** in terms of:

- end-user profiles (e.g., the capacity of the end-user to provide informed consent, or the fulfilment of the specific conditions for the end-users to be a beneficiary of an e-service selected for the use-case); and
- the technological constraints for accessing the e-services (e.g., possibility of the end-user to exploit given technologies such as specific versions of web browsers or mobile devices).

These conditions will be transparently communicated to the potential end-users. All end-users fulfilling the requirements will be allowed to participate. **Specific engagement campaigns** will be defined and executed for each use-case, in order to ensure sufficient participation (see project **Task T6.3 "Use-case community building"**). The objective conditions and engagement campaigns depend on the specific e-services selected for the use-cases. Their detailed definition will hence be carried out in parallel with the specification of the use-cases, and will hence be included in deliverables “**D6.1 Use-case planning & evaluation v1**” (M6) and “**D6.2 Use-case planning & evaluation v2**” (M24).

### 5.2 Data protection, informed consent procedures, and security issues

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The interaction with the e-services will occur through the interactive (web) front-end; an **informed consent form** (with related information sheet) will be presented to the users, who will be asked to agree to contribute to the research in the SIMPATICO project (Annex 2 – Informed Consent Form).

The Informed Consent Form will be translated in English, Italian and Spanish, because the information that is given to the subject or the legal representative shall be in language understandable to the subject or the representative. Information on the project, the importance to participate, and incentives to participation will be highlighted. **Terms and conditions**, compliant with the European and national regulations on privacy and data protection, will be presented and will need to be agreed on for a user to be able to access the SIMPATICO solutions. **The access is subject to registration** and sign-in by the user, so that the capability of the user to provide informed consent will be checked against the registered user profile; and only capable users will be allowed to participate. End-users have the right to withdraw at any time from the research in the SIMPATICO project: the use of any private data of the withdrawn users will be disallowed in the project. The **procedure to withdraw** from the project will be made explicit to the end-users as part of the terms and conditions presented at registration time. We will take into account all privacy issues arising from the processing of personal data with the software components and tools produced in the project.

**Ethical/legal approvals and reporting documents.** Ethical/legal approvals and reporting documents are listed in the Section 3 above “SIMPATICO: responsibilities in ethics management”. For further information, please refer to the above-mentioned declarations and to Annex 1 - Appointment of the Ethics Advisory Board.

**Personal and sensitive data.** Project SIMPATICO involves collecting and processing personal data, according to the definition of Art. 2(a) of the Directive 95/46/EC: “Personal data means any information, private or professional, which relates to an identified or identifiable natural person”. Some of the personal data collected and handled during the SIMPATICO use-cases may be “sensitive”, according to Art. 8(a) of the Directive of the Directive 95/46/EC: data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and data concerning health or sex life. This is due to the nature of the e-services that will be tested within the use-cases, which require handling also sensitive data of the users participating to the research: more precisely, end-users may be requested to provide sensitive data (e.g., information on health or ethnic origin) since these data are required by the procedures underlying the e-services. According to Art. 8(b) of the Directive 95/46/EC, sensitive data may be processed under specific conditions, such as “the data subject has given his/her explicit consent to the processing of those data”. Within SIMPATICO, sensitive data will be processed in accordance with principles and conditions that aim to limit the impact on the persons concerned and ensure data quality and confidentiality (a summary of the related procedures is provided below), only after an informed consent has been collected.

A thorough assessment of the personal and sensitive data that need to be collected and handled in the different SIMPATICO use-cases will be exploited as part of the definition of user-case requirements (see project task T6.2 “Use-case requirements, planning and KPI definition”; deliverables “D6.1 Use-case planning & evaluation v1” at Month 6 and “D6.2 Use-case planning & evaluation v2” at Month 24).

Within the SIMPATICO Platform, the Citizen Data Vault (CDV) represents the component that will take care of the storage of personal and sensitive data of the user, and of the exchange of these data with the user, the legacy systems of the PA, and components of the SIMPATICO Platform. The CDV is a repository of the citizen (or company) profile and related information; this profile is continuously updated through each interaction and is used to automatically pre-fill forms; in this way the citizen (or company) will give to the PA the same information only once, as the information will be stored in the vault and used in all the following interactions. Mechanisms for encryption, authentication, and



authorization will be exploited in the processes, so to ensure the satisfaction of core security and data protection requirements, namely confidentiality, integrity, and availability. For further details, please see sections below. Sensitive data will be published (e.g., for reporting demographic data on the engaged users) only after suitable aggregation and/or pseudonymization techniques have been applied, in order to ensure the privacy of the users of the e-services.

**Procedures for handling personal and sensitive data.** State-of-the-art mechanisms for encryption, authentication, and authorization will be exploited in the implemented processes (concerning data collection, storage, protection, retention and destruction), so to ensure the satisfaction of core security and data protection requirements, namely confidentiality, integrity, and availability. We will: (a) refer, for instance, to the TLS protocol for encryption, which exploits the AES Standard; (b) exploit the state-of-the-art Single-Sign-On implementations as authentication mechanisms; (c) and consider suitable authorization mechanisms such as Policy Enforcement Point for XACML. The project coordinator (FBK) has internationally recognised expertise in the field of privacy, which will ensure the usage of state-of-the-art security techniques within the project. A detailed analysis of privacy issues is part of the deliverable “D1.5 Ethics compliance report” and will be part of the deliverables named “D1.3 Data Management Plan v.1” (M6) and “D1.4 Data Management Plan v.2” (M36). These issues will be taken into account in the definition of the SIMPATICO technical architecture.

**Public availability of data.** In order to discuss the public availability of data, it is convenient to distinguish three different types of datasets within the SIMPATICO project.

First, not publicly available personal data will be collected and processed as part of the execution of the SIMPATICO use-cases, more specifically for the execution of the e-services. Specifically, the use-cases will involve only voluntary participants aged 18 or older and capable to give consent, who will be informed on the nature of their involvement and on the data collection/retention procedures through an informed consent form before the commencement of their participations. Informed consent will follow procedures and mechanisms compliant with European and national regulations in the field on ethics, data protection and privacy (see also deliverables “D1.5 Ethics compliance report” and “D8.1 H – Requirement no. 1”).

Second, SIMPATICO adheres to the open access policy of all project results. Specifically, we are committed to make available, whenever possible, the data collected during the execution of SIMPATICO, in particular data collected during the use-cases, also to researchers and other relevant stakeholders outside the project Consortium. Whenever possible, these additional data sources will also be made available as open data or through open services. In this context, any personal data will only be published after suitable aggregation and/or pseudonymization techniques have been applied, and after an informed consent that explicitly authorize this usage has been collected.

Third, through Citizenpedia, SIMPATICO intends to build an open knowledge base on public services and processes, released as a new public domain resource co-created and co-operated by the community (i.e., citizens, professionals and civil servants). The initial content of Citizenpedia will be based on datasets and other digital goods that are publicly available. In the case of datasets and other digital goods owned by the PAs and not already publicly available, the Consortium will pursue to obtain an authorization for public release, as open content, before inclusion in the Citizenpedia. For what concerns the data contributed to Citizenpedia by the community, SIMPATICO will require that they are made available as open content (e.g., with licenses such as Creative Commons).

The Data Management Plan – deliverables “D1.3 Data Management Plan v.1” (M6) and “D1.4 Data Management Plan v.2” (M36) – will better describe datasets characteristics and define principles and rules for the distribution of data within SIMPATICO. In such deliverables, specific data aggregation

and pseudonymization techniques will be identified and applied to data before their public release, when necessary (19).

**Aggregation and/or pseudonymization techniques.** Personal and sensitive data will be made publicly available only after an informed consent has been collected and suitable aggregation and/or pseudonymization techniques have been applied. Before starting the project activities that require user involvement, a careful investigation on privacy and security issues will be undertaken, covering in particular Italian, Spanish and UK privacy laws; a Data Management Plan [“D1.3 Data Management Plan v.1” (M6) and “D1.4 Data Management Plan v.2” (M36)] will be composed, defining principles and rules for the distribution of personal/sensitive data. In the Data Management Plan, suitable data pseudonymization and aggregation techniques will be identified and applied to personal/sensitive data before their public release (see “Security issues” below).

**Security issues.** In the SIMPATICO project we do not perform activities, neither produce results, raising any large scale security issues. The project does not have the potential for military applications, and also does not involve the use of elements that may cause any harm to humans, animals, plants or environment. However, the process of collecting, processing, storing data might hide some pitfalls. To reduce the risk of potential malevolent/criminal/terrorist abuse, which might be perpetrated also by malicious people authorized to access the information, the SIMPATICO Consortium is examining the deployment of a twofold security protection strategy:

1. by ensuring that the employed security layers and privacy-preserving measures will work properly, keeping access logs and following best practices for system administration;
2. by employing techniques to prevent information leakage “on-the-fly”, i.e., through the adoption of the pseudonymization approach (see above) of personal/sensitive information at collection/communication/storage time (e.g. via an encryption scheme, hash functions, and/or tokenization). Such an approach will neutralise eavesdropping and/or similarly dangerous hack attempts in the unlikely event of successful retrieval, since it will secure data, making them completely meaningless to the attacker.

The pseudonymization of data is a method of ensuring confidentiality, according to the Article 29 Working Party Opinion on Anonymization Techniques and in relation to the upcoming EU General Data Protection Regulation (20). Where data are particularly sensitive (e.g. data using detailed personal narratives) then risks to confidentiality increase. In this case, participants will be carefully informed of the nature of the possible risks. This does not preclude the responsibility of the applicant to ensure that maximal pseudonymization procedures are implemented. A detailed description of the measures that will be implemented to prevent improper use, improper data disclosure scenarios and ‘mission creep’ (i.e., unforeseen usage of data by any third party), within the above-mentioned security protection strategy, will be provided before the commencement of research activity, and in particular in the deliverables named “D1.3 Data Management Plan v.1” (M6) and “D1.4 Data Management Plan v.2” (M36).

The optimal solution will be decided by using a combination of different techniques, while taking into account the practical recommendations developed in the above-mentioned Opinion. Pseudonymization approaches reduces the linkability of a dataset with the original identity of a data subject, and is accordingly a useful security measure. These techniques have to adhere certain requirements to comply with data protection and privacy-related legislation in the EU. The following set of requirements (among others) has been extracted from the Directive 95/46/EC and the Article 29 Working Party Opinion on Anonymization Techniques and will be the guidelines for security protection strategy drafting (20) (21):



- **User authentication:** the system has to provide adequate mechanisms for user authentication.
- **Limited access:** the system must ensure that data is only provided to authenticated and authorized persons.
- **Protection against unauthorized and authorized access:** the records of an individual have to be protected against unauthorized access.
- **Notice about use of data:** the users should be informed about any access to their records.
- **Access and copy users' own data:** the system has to provide mechanisms to access and copy the users' own data.
- **Fall-back mechanism:** the system should provide mechanisms to back up and restore the security token used for pseudonymization.
- **Unobservability:** pseudonymized data should not be observable and linkable to a specific individual in the system.
- **Secondary use:** the system should provide a mechanism to export pseudonymized data for secondary use and a possibility to notify the owner of the exported data.
- **Modification of the database:** if an attacker breaks into the system, the system must detect modifications and inform the system administrator about this attack.

In sum, the potential “unforeseen usage” implications of this project will be examined by the Ethics Advisory Board. These issues will be reported to the EU Commission through the two expected versions of the “D1.3 Data Management Plan v.1” (M6) and “D1.4 Data Management Plan v.2” (M36).

### 5.3 SIMPATICO model-based privacy compliance checker (Draft)

This subsection provides a draft of a “Policy Compliance Checking System” in the field of ethics, privacy and data protection, which will be subsequently validated and followed by the **Ethics Advisory Board** of the SIMPATICO project (Section 3): i.e., **the SIMPATICO model-based privacy compliance checker** that may be a useful instrument to assess the compliance of relevant project activities with policies and procedures in the context of personal/sensitive data processing.

With reference to the key concepts deducible from the **applicable European and national ethics, privacy and data protection regulations** (Section 4), the data processing shall be carried out in compliance with the so-called **principles of quality, legality, purpose and fairness**, namely data shall: (1) be obtained and processed fairly and lawfully; (2) be recorded for the specific and legitimate purposes; (3) not be used in a different way than the purpose specified in the project; (4) be adequate, relevant and not excessive in relation to those purposes; (5) be accurate and, where necessary, updated; (6) be stored in such a way that you can identify the persons of interest for the period strictly necessary to the treatment. The **principle of lawfulness of processing and further processing of data** is included in the above-mentioned EU Directive on the protection of personal data 95/46/EC, Article 6, paragraph 1, letters a) and b). The **principle of the purpose of the treatment** is framed in Article 6, letter b) of the same Directive. The **principle of fairness** is explained not only in the EU Directive, but also in Article 5, letter a) and Article 6, paragraph 1, letter a) of the Council of Europe Convention no. 108 for the Protection of Individuals with regard to Automatic Processing of Personal Data of 29 January 1981. Finally, Article 5, letter c), d) and e) of the Convention and Article 6, letter c), d) and e) of Directive materialize the **principle of data quality**.

As regards **sensitive data**, the processing can only be done if there is: (1) the express permission of data subjects (separated from the general consent for treatment); (2) a law providing for a

derogation from the prohibition on processing sensitive data, to fulfil the obligations and rights of the controller in the field of Labour Law; (3) a law providing for an exception to the prohibition of treatment for a medicinal purpose, namely to protect the vital interests of the data subject or a third party. The discipline on the lawfulness of the processing of sensitive data is contained in Article 8 of the EU Directive on the protection of personal data. Data subjects have a series of rights that they may oppose against the data owner, the first of which is (1) the **right to obtain general information on processing operations performed**, which shall indicate: (a) the data owner (or responsible for the treatment); (b) the nature of the treatment; (c) the purpose for which the data are collected; (d) the recipients or categories of recipients; (e) the opportunity to obtain erasure or blocking of any data that is processed. Then data subjects have: (2) the **right to access their own personal data** directly at the entity holding such data, and (3) the **right to have inaccurate and/or incomplete data updated, rectified or supplemented**. These rights are specified in Articles 12 and 14 of the EU Data Protection Directive.

The founding principle of the automated data processing is the **informed consent**, i.e., the free indication of the data subjects' wishes to explicitly accept a specific processing operation concerning their personal data, of which the data subject was informed beforehand by the entity empowered to decide on that processing (i.e., the data controller or data owner). It is enough for written "proof" of consent to be available, i.e., for the consent to be noted, transcribed, entered by the data controller and/or the data processor and/or a person tasked with processing in a register, instrument or minutes - unless the processing operation concerns sensitive data: in this case, the data subject has to give mandatorily a written consent (e.g., by undersigning a form).

The treatment can be carried out **without the informed consent** when processing is necessary: (1) for the performance of a contract to which the data subject is party or in order to take steps at the request of the data subject prior to entering into a contract; (2) for compliance with a legal obligation to which the controller is subject; (3) in order to protect the vital interests of the data subject; (4) for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. The definition and requirements for valid consent are identified by the EU Directive on data protection, Article 2, letter h) (22).

Following this legal background, we elaborated some '**compliance indicators**' relevant for the future development of the **SIMPATICO model-based privacy compliance checker** by the Ethics Advisory Board of the SIMPATICO project. These indicators have been extracted from the above-described international, European, and national legal frameworks currently in force:

- **Indicator (1) - Data quality.** Data processing shall meet the principle of data quality, that refers to the level of quality of data, which includes in particular:
  - a. Principle of data adequacy: data can be processed if they are adequate, relevant and not excessive for the purposes for which they are collected and/or processed;
  - b. Principle of the data accuracy: data shall be accurate and, where necessary, kept up to date;
  - c. Principle of necessity: data must be kept in a form that permits the identification of data subjects for no longer than is necessary for the purposes for which they are collected and/or processed.
- **Indicator (2) - Processing personal data for specified purposes.** The purpose of the data processing shall be specified before the treatment begins.
- **Indicator (3) – Processing personal data fairly and lawfully.** It means that you must: (a) have legitimate grounds for collecting and using the personal data; (b) not use the data in ways that have unjustified adverse effects on the individuals concerned; (c) handle people's

personal data only in ways they would reasonably expect; (d) and make sure you do not do anything unlawful with the data.

- **Indicator (4) - Transparency.** The data controller has the obligation to be transparent about how he/she intends to use the data, and give individuals appropriate privacy notices when collecting their personal data.
- **Indicator (5) - Prohibition against processing 'sensitive data'.** Sensitive data can only be processed without the informed consent when processing is necessary for contractual reasons, in the field of Labour Law or for sanitary purposes, namely to protect the vital interests of the data subject or a third.
- **Indicator (6) – Data Subjects Rights.** Among the other data subject rights, there are: (a) a right of access to a copy of the information comprised in their personal data; (b) a right to object to processing that is likely to cause or is causing damage or distress; (c) a right to prevent processing for direct marketing; (d) a right to object to decisions being taken by automated means; (e) a right in certain circumstances to have inaccurate personal data rectified, blocked, erased or destroyed; (f) a right to claim compensation for damages caused by a breach of the law.
- **Indicator (7) – Informed consent.** Data subject consent is defined as any freely given, specific, informed and explicit indication of his or her wishes by which the data subject, either by a statement or clear affirmative action, signifies agreement to personal data relating to them being processed. In addition, the following requirements apply to consent: (a) the controller bears the burden of proof for the data subject's consent; (b) where written consent relates to more than one matter, consent must be separate and distinguishable in appearance from the other matter; (c) consent may be withdrawn at any time; (d) consent will not be valid as a legal basis where is a significant imbalance between the position of the data subject and the controller (2) (4).

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## **Annex 1 - Appointment of the Ethics Advisory Board**

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(Scanned copy of the document will be provided as soon as the Ethics Advisory Board will be definitively appointed)

**Ref.: Project SIMPATICO - SIMplifying the interaction with Public Administration Through Information technology for Citizens and cOmpanies. Appointment of the Ethics Advisory Board**

The purpose of this document is to appoint the Ethics Advisory Board (EAB) members of the European project “SIMPATICO - SIMplifying the interaction with Public Administration Through Information technology for Citizens and cOmpanies” (hereinafter also referred to as “SIMPATICO”, project reference: 692819). Project activities will last 3 years from 1 March 2016 to 28 February 2019.

Ethics Advisory Board of SIMPATICO is led by an ethics adviser external to the project and to the host institution, totally independent and free from any conflict of interest. In addition to the external ethics adviser, the EAB is composed of one representative from each member of the SIMPATICO Consortium. While carrying out its duties, the EAB refers to the national, European and international framework of legal, deontological and ethic nature, with a view on pluralism of ethic approaches. Its work is mainly inspired by the principles established on the basis of the current edition of the Declaration of Helsinki. The board also aims at stimulating awareness raising initiatives regarding the ethical issues, which interest the Consortium as well as the entire community of stakeholders and citizens involved.

### **Terms of reference and responsibilities of the EAB**

The general responsibilities of the Ethics Advisory Board include:

- Maintaining an overview of the work throughout the whole course of your project and help the Consortium to think ahead about possible problems that might arise and how they can be addressed (i.e., checking for compliance with ethical standards within the relevant research fields), also obtaining instructions/authorizations/notifications from national and/or local Data Protection Authorities: i.e., the competent authorities to provide the necessary validations when the collection and processing of personal (or sensitive) data is part of the planned research (see below for further specifications);
- Creating, assessing and/or validating reports and statements about the ethical acceptability of the planned research. In particular, the following deliverables will be evaluated:
  - a) An updated version of this deliverable (“D1.5 Ethics compliance report”), which, if needed, will be produced after the first meeting of the above-mentioned board and made available to the EC after the first meeting of the above-mentioned board. The EAB will assess the ethical and societal aspects that should be taken into account during the project lifespan, both when collaborating with project participants and when defining the functionalities of the final SIMPATICO platform/services. This updated version with possible amendments will be delivered before the start of the piloting activities.

- b) An updated version of the reports “D8.1 H – Requirement no. 1” and “D8.2 POPD – Requirement no. 2”, which, if needed, will be produced and made available to the EC after the first meeting of the above-mentioned board (see point a) above).
- c) Reference on how the ethical issues are addressed in the project, which will be reported in the forthcoming reports “Project progress report” (M12) and “D1.2 Intermediate activity report” (M22).
- d) The expected reports “D1.3 Data Management Plan v.1” (M6) and “D1.4 Data Management Plan v.2” (M36).

Further specific responsibilities of the Ethics Advisory Board include:

- Obtaining instructions/authorizations/notifications from national and/or local Data Protection Authorities of the involved Member States (i.e., the competent authorities to provide the necessary validations when the collection and processing of personal or sensitive data is part of the planned research), aimed at demonstrating the compliance of the ethics, privacy and data protection processes with the European and national legal frameworks. Prior to the commencement of each relevant WP that collects or processes data, and where applicable, copies of these instructions/authorizations/notifications will be forwarded to the EU Commission and reported (when necessary) through the above-mentioned reports “Project progress report” (M12) and “D1.2 Intermediate activity report” (M22).
- Providing detailed information on the relevant project activities to the national and/or local Data Protection Authorities of the involved Member States i.e., the competent authorities to provide the necessary validations when the collection and processing of personal (or sensitive) data is part of the planned research) on the source and secondary use of the data. Their approvals will be sent to the EC and reported (when necessary) through the above-mentioned reports “Project progress report” (M12) and “D1.2 Intermediate activity report” (M22).
- Submitting any further copies of its ethical approvals/opinions/notifications to SIMPATICO project coordinator that will communicate them to the EC prior to the commencement of each relevant WP that collects or processes data, and where applicable.
- Coordinating and monitoring the collection of the informed consents of the persons concerned (‘data subjects’);
- Besides these documents, and where applicable, providing to the EC – through the SIMPATICO project coordinator - further detailed information on the source of the data, privacy/confidentiality, and the procedures that will be implemented for data collection, storage, access, sharing policies, protection, retention and destruction. Confirmation that they comply with European and national legislation will also be included, e.g., via the above-mentioned “Project progress report” (M12) and “D1.2 Intermediate activity report” (M22).

More specifically, the **reference national and/or local Data Protection Authorities** competent to provide the above-mentioned SIMPATICO EAB with the necessary **instructions, authorizations and notifications** for each pilot are the following.



*Trento pilot (Italy): the Italian Data Protection Authority (DPA - <http://www.garanteprivacy.it/>).*

According to the “Italian Data Protection Code” (Legislative Decree no. 196/2003), an authorisation by the Italian DPA is required to enable private (and public) bodies to process specific typologies of personal and sensitive data (see Section 26 of the Italian Data Protection Code). More precisely, the DPA needs to be notified (also thorough an electronic form) whenever a public or private body undertakes a personal data collection, or personal data processing activity, as data controller. A data controller is required under the law to only notify the processing operations that concern e.g., data suitable for disclosing health and sex life, data processed with the help of electronic means aimed at profiling the data subject and/or his/her personality, analysing consumption patterns and/or choices. In such context, the DPA is also responsible for evaluating and expressing opinions on specific arguments concerning data protection (see “Simplification of Notification Requirements and Forms. Decision of the DPA dated 22 October 2008, as published in Italy's Official Journal no. 287 of 9 December 2008”).

In the case of Trento pilot, we consider this public authority appropriate for providing the SIMPATICO EAB with the necessary instructions/authorizations/notifications.

*Sheffield pilot (United Kingdom): the University Research Ethics Committee (UREC) of the University of Sheffield (<https://www.sheffield.ac.uk/ris/other/committees/ethicscommittee>).*

The University Research Ethics Committee (UREC) of the University of Sheffield is an independent, unbiased and interdisciplinary university-wide body that scrutinizes any potential issues related to research ethics for staff and students of the University of Sheffield, including collaborative research deriving from external funding. The key tasks this committee is in charge of are:

- Uphold adherence to the University's 'Ethics Policy Governing Research Involving Human Participants, Personal Data and Human Tissue' by all University staff and registered students who undertake such research, wherever that takes place, and by all individuals who undertake or contribute to such research on University premises and facilities;
- Promote awareness and understanding of research ethical issues throughout the University;
- Advise on any ethical matters in research that are referred to it from within the University;
- Keep abreast of the external research ethics environment and ensure that the University responds to all external requirements.

In the case of the Sheffield pilot, we consider this committee appropriate for providing the SIMPATICO EAB with the necessary instructions/authorizations/notifications. We remark that, in the case of Sheffield Council, Sheffield University and Sparta Technologies Ltd, all the involved entities comply with the UK data protection regulations and intend through the committee to ensure that act is enforced. Only if necessary, the AEB will engage the UK Information Commissioner's Office (ICO - <https://ico.org.uk/>).

*Galicia pilot (Spain): the Research Ethics Committee of the University of Deusto (<http://research.deusto.es/cs/Satellite/deustoresearch/en/home/research-ethics-comittee>).*

This committee is an independent, unbiased and interdisciplinary body that is both consultative and advisory in nature, and reports to the Vice-Rector's Office for Research. Among other responsibilities, this committee is in charge of:

- Conducting the ethical assessment of research projects and drawing up the ethical suitability reports requested by institutions and researchers.
- Ensuring compliance with best research and experimentation practices with regard to individuals' fundamental rights and the concerns related to environmental defense and protection.



- Supervising assessment processes or ethical requirements in research carried out by institutions and public bodies.
- Preparing reports for the University's governing bodies on the ethical problems that may arise from R+D+I activities.
- Ensuring compliance with the Policy on Scientific Integrity and Best Research Practices of the University of Deusto.
- Providing guidance on laws, regulations and reports on research ethics.
- Reviewing procedures that have already been assessed, or proposing the suspension of any experimentation already started if there are objective reasons to do so.

In the case of the Galicia pilot, we consider this committee appropriate for providing the SIMPATICO EAB with the necessary instructions/authorizations/notifications. Only if necessary, the AEB will engage the Spanish Data Protection Authority, i.e., Agencia Española de Protección de Datos (AEPD - <http://www.agpd.es/>).

Membership of the SIMPATICO Ethics Advisory Board (EAB) is better specified in the document “D1.5 – Ethics compliance report”.

#### **Terms of reference and working procedures**

Upon appointment to the EAB, external members have been also required to sign a Confidentiality Agreement and must declare any real or potential conflict of interest. During the first session of the EAB, the board will appoint one of the members as Chairman.

The Board will meet via conference call at least 2 times a year. In determining meeting frequency, it will take into account the need of the SIMPATICO Consortium. Following the closing date for the commencement of each project activity and for project deliverables, the Chairman will prepare an agenda for the meeting. After the meeting, the Chairman will record the board decisions and draft the evaluation and comments on each activity/deliverable. The Chairman will also prepare minutes of the meeting.

All members will be fully informed by receipt of all relevant documents and will have an opportunity to contribute their views in the decision-making process on each activity/deliverable. Members who are unable to attend a meeting may submit written comments before the meeting. The Chairman will ensure that comments from absent members are available to be discussed at the meeting if required.

### Appointment of the Ethics Advisory Board

All members of the board have been appointed by the Project Management Board and are listed in the table below. Any changes in the membership that may occur shall be approved by the Project Management Board.

No.	Name	Gender	Affiliation	Internal/External Member	Contact information
1	TBA	/	/	External	/
2	Marco Pistore	M	FBK	Internal	<a href="mailto:pistore@fbk.eu">pistore@fbk.eu</a>
3	Diego Lòpez de Ipiña	M	DEUSTO	Internal	<a href="mailto:dipina@deusto.es">dipina@deusto.es</a>
4	Lucia Specia	F	USFD	Internal	<a href="mailto:l.specia@sheffield.ac.uk">l.specia@sheffield.ac.uk</a>
5	Antonio Filograna	M	ENG	Internal	<a href="mailto:antonio.filograna@eng.it">antonio.filograna@eng.it</a>
6	Raúl Santos de la Cámara	M	HIB	Internal	<a href="mailto:rsantos@hi-iberia.es">rsantos@hi-iberia.es</a>
7	Zulf Choudhary	M	SPA	Internal	<a href="mailto:zulf@spartatec.co.uk">zulf@spartatec.co.uk</a>
8	Orazio Tomarchio	M	BENG	Internal	<a href="mailto:orazio.tomarchio@gmail.com">orazio.tomarchio@gmail.com</a>
9	Giacomo Fioroni	M	TRENTO	Internal	<a href="mailto:giacomo_fioroni@comune.trento.it">giacomo_fioroni@comune.trento.it</a>
10	Carmen Orgeira Naya	F	GALICIA	Internal	<a href="mailto:carmen.orgeira.naya@xunta.es">carmen.orgeira.naya@xunta.es</a>
11	Eddie Coates-Madden	M	SCC	Internal	<a href="mailto:eddie.coates-madden@sheffield.gov.uk">eddie.coates-madden@sheffield.gov.uk</a>

Members have received a formal notice of appointment, which includes:

- specification of the category of membership to which the person is appointed;
- notification that the term of membership is until the end of the project (28 February 2019);
- a statement that the SIMPATICO Consortium accepts legal responsibility for decisions and advice received from the EAB, and indemnifies members for any action taken against them in respect of EAB business;
- reference to the requirement that all members be fully informed and have an opportunity to contribute their views on each project activity/deliverable considered by the EAB;
- and information on the EAB and its operations, including the EAB terms of reference and working procedures;
- a specific confidentiality agreement and a declaration of conflict of interest to be signed.

Any changes in the membership that may occur shall be approved by the Project Management Board.

This document is in continuation of all the earlier agreements entered into on the subject unless modified later.

SIMPATICO Project Coordinator  
Marco Pistore

.....

## Annex 2 – Informed Consent Form

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### Informed Consent Information Sheet

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#### **Informed consent procedures**

Key ethical issues concerning research activities of the European project “SIMPATICO - SIMplifying the interaction with Public Administration Through Information technology for Citizens and cOMpanies” (hereinafter also referred to as “SIMPATICO”), coordinated by Fondazione Bruno Kessler – FBK (Italy), are identified and defined here according to European and national regulations. These issues are examined from SIMPATICO point of view and include recruitment of participants, information to participants, informed consent and data handling during the planned research activities.

Before requesting consent, researchers shall make sure that the potential participant has received written and, if requested, additional oral information. This information shall be provided in such a way that it is probable that the potential participant understands the contents. Furthermore, the potential participant should be given sufficient time to make a proper decision on the requested consent. Participants shall be informed that they are free to withdraw from participation at any point, that their personal data will remain confidential and anonymous, and that collected data will be analysed for the entire group of participants, rather than individually, thus securing their privacy and anonymity.

Detailed information is provided to the potential participants by means of this information sheet including descriptions/specifications of:

- purpose of the research;
- duration of the research activities;
- adopted procedures;
- voluntary participation;
- possible risks, discomfort or disadvantages;
- benefits to the subject or others;
- data protection and confidentiality and privacy policies;
- where to get more information;
- what happens to data and results at the end of the research.

A sample informed consent document is provided (please see below). In order to make it more efficiently usable in research activities, the document will be translated in Italian and Spanish for activities involving non-English speaking participants.

#### **Ethics and privacy/data protection requirements**

The project activities will be carried out with regard to ethical implications and respecting the regulations expressed in international, European and national texts and codes of practices in force, in particular the Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 (and subsequent modifications and supplements) on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

The activities will not entail any risk and burden for the individuals concerned. All the data will be collected and used in respect of the European and national legislation in force. Involved persons will be properly informed of the project aims, expected results and limits of the research in the information supplied before getting the informed consent. Due to the nature of the research

activities to be performed, ethically relevant incidental findings are not expected. In case of actual incidental findings, details will be collected and provided to the SIMPATICO Ethics Advisory Board. In case of other ethics issues, copies of ethical approvals by the competent national authorities will be submitted to the European Commission.

## **Informed Consent Document**

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### **Introduction**

You have been invited to take part in the European project “SIMPATICO - SIMplifying the interaction with Public Administration Through Information technology for Citizens and cOmpanies” (hereinafter also referred to as “SIMPATICO”), coordinated by Fondazione Bruno Kessler - FBK (Italy). Before making a decision on whether you want to participate or not, please read this document carefully. Please ask all the questions you may have so you can be completely sure that you understand all the proceedings of the research, including risks and benefits. This informed consent document may include words that you do not understand. If this is the case, please ask the contact researcher or any other member of the study to fully explain the meaning of the word or clarify pieces of information. At all times, we assure the compliance with the current European and national legislation.

### **Summary of the project**

A seamless interaction with public administrations (PA) is crucial to make the daily activities of companies and citizens more effective and efficient, saving time and money in the management of administrative processes. In particular, online public services have an enormous potential for reducing the administrative burden of companies and citizens, as well as for creating saving opportunities for the PA. This potential is however far from being fully exploited. Online services made available by the PA typically rely on standardized processes, copied from their offline counterparts and designed only from the public sector organizations’ own perspective. This results in online services that fail to adapt to the specific needs of citizens and companies.

With SIMPATICO, we address the issues above by proposing a novel approach for the delivery of personalized online services that, combining emerging technologies for language processing and machine learning with the wisdom of the crowd, makes interactions with the PA easier, more efficient and more effective. SIMPATICO combines top-down knowledge of the PA with bottom-up contributions coming from the community. These contributions can be of different types, ranging from the qualified expertise of civil servants and professionals to problems and doubts raised by citizens and companies that find online services difficult to use. Our approach is able to take into account both explicit information sources coming from citizens, professionals and civil servants, and implicit ones, extracted from user logs and past user interactions. SIMPATICO’s ‘learning by doing’ approach will use this information and match it with user profiles to continuously adapt and improve interactions with the public services. All the collected information on public services and procedures will be made available within Citizenpedia, a collective knowledge database released as a new public domain resource.

The piloting of the SIMPATICO solution in two European cities (Trento and Sheffield) and one region (Galicia) through a two-phase use-case validation will enable SIMPATICO to address the important objectives in the European Union eGovernment Action Plan 2011-2015. The stakeholders engaged in the three use-cases were selected for their experience and interest in e-services, as well as for the different socio-cultural backgrounds of the three regions. In this way, the Consortium have the opportunity to validate the effectiveness of the project results in contexts which differ on the

number and heterogeneity of citizens and their social and cultural background. Project activities will last 3 years, from 1 March 2016 to 28 February 2019.

#### **Risks or inconveniences**

No risk is foreseen. You are only requested to be available to participate. All information provided will be treated in the strictest of confidence.

#### **Benefits**

With your participation you will make a substantial contribution to achieve SIMPATICO project main goal, i.e., to improve the experience of citizens and companies in their daily interactions with the public administration by providing a personalized delivery of e-services based on advanced cognitive system technologies and by promoting an active engagement of people for the continuous improvement of the interaction with these services.

#### **Privacy and confidentiality**

Responses you give may be recorded. Your recorded data will not include any personal identification. Information will be processed during the phase of data analysis and will be shown in project reports. It will not be possible to identify the source of the information. The results of this investigation may be published in scientific journals or conferences and may be used in further studies. Nothing of the provided personal data will be handled out to third parties. The authorization for the use and access to this information is valid until the end of the project unless you decide to cancel it before. If you should decide to deny your consent, please contact the contact person and let her/him know of your intention of leaving the research. Your decision to whether or not give your authorization for the use and diffusion of the information provided by you is completely voluntary.

Researchers will also make clear that participants have the right to refuse permission or withdraw from involvement in research whenever and for whatever reason they wish. Research participants have the right to withdraw from the research at any time and for any reason without adverse consequences.

#### **Contact persons**

In case of any issue involving you in your role of participant of this project, you are invited to inform the SIMPATICO project coordinator and contact person Dr. Marco Pistore of Fondazione Bruno Kessler – FBK (Italy) via email: [pistore@fbk.eu](mailto:pistore@fbk.eu).

#### **Confirmation**

Your participation in this project is only possible if you freely and independently sign this consent to authorize us to use the personal and sensitive data you provide.

I hereby declare:

- I am 18 years or older and am competent to provide consent;
- I have been fully informed about the aims and purposes of the Project SIMPATICO. I understand that there is no compulsion to participate in the project and, if I choose to participate, I may at any stage withdraw my participation;
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me;

- I agree that my data is used for scientific purposes and I have no objection that my data is published in a way that does not reveal my identity, without my explicit consent;
- I understand that, subject to the constraints above, no recordings will be replayed in any public forum or made available to any audience other than the current researchers/research team;
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights;
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty;
- I understand that my participation is fully anonymous and that no personal details about me will be recorded, without my explicit consent;
- Information may be shared between any of the other researcher(s) and partners participating in this project in an anonymous form. All information I give will be treated as confidential. The researcher(s) will ensure to preserve my anonymity;
- I have received a copy of this agreement.

This consent form is made pursuant to the relevant national, European and international data protection laws and regulations and personal data treatment obligations. Specifically this consent document complies with the following laws and regulations: EC Data Protection Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 (and subsequent modifications and supplements) on the protection of individuals with regard to the processing of personal data and on the free movement of such data; Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation)<sup>1</sup>.

Fondazione Bruno Kessler – FBK (Italy) is the data controller of SIMPATICO project and requires this information for scientific purposes and will only process your personal and sensitive data in accordance with the current data protection legislation. By signing below, you accept that the data controller can pass details contained in this document to other project partners and relevant stakeholders as necessary.

.....  
*Name and surname of the participant*

.....  
*Place, date and signature of the participant*

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<sup>1</sup> Please note that on 4 May 2016, the official texts of the new Regulation and the Directive on EU data protection have been published in the EU Official Journal in all the official languages. While the Regulation entered into force on 24 May 2016, it shall apply from 25 May 2018. The Directive entered into force on 5 May 2016 and EU Member States will have to transpose it into their national law by 6 May 2018.

I have explained the nature and purpose of this procedure, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

.....  
*Name and surname of the researcher*

.....  
*Place, date and signature of the researcher*