RESEARCH PARTICIPANTS INVOLVEMENT REPORT

D11.2: RESEARCH PARTICIPANTS INVOLVEMENT REPORT.

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Abstract

This report includes the procedures and criteria that will be used to identify and recruit research participants as well as the informed consent procedures that will be implemented for the participation of humans. Moreover, the templates of the informed consent/assent forms and information sheets (in language and terms eligible to the participants) are included. The potential involvement of vulnerable groups as research participants is analyzed and protection measures are offered.

Keywords

Ethics, procedures, data protection, informed consent, legislation, policy, methodology, guidelines, requirements.

Copyright statement

Executive summary

The objective of this document is to explain the procedure, that is used to recruit and involve research participants in the project.

D11.2 is the outcome of WP11 – task 11.2 "Ethics analysis on the involvement of research participants." The main objective of this task is to provide the templates of the information sheets for the participation of humans *(Template I)*, as well as the templates for the informed consent forms *(Template II)*.

The engagement with end-users and stakeholders is one of the key components of USER-CHI. The innovation action involves human participation through surveys, interviews, focus groups, observational studies and their participation in the pilot demonstration. End-user engagement takes place throughout the whole project but is specially addressed in WP1 and WP6, where end-user requirements, motivations and constraints are analyzed, and where the consortium will deal with the pilot activities. For those activities that will involve humans, specific procedures have been designed to explain the details on identification and recruitment criteria.

Moreover, the deliverable will outline the potential involvement of vulnerable individuals as research participants and provide measures needed for the protection of the latter.

List of abbreviations

BDSG	*German Federal Data Protection Act*
BEV	*Battery Electric Vehicle*
BfDI	*German Federal Data Protection Authority*
BlnDSG	*Data Protection Act for Berlin*
CFR	*Charter of Fundamental Rights of the European Union*
EMSP	*Emobility Service Provider*
EU	*European Union*
EV	*Electric Vehicle*
GDPR	*General Data Protection Regulation*
LEV	*Light Electronic Vehicle*
Organic Law 3/2018	*Organic Law of Protection of Personal Data and Guarantee of Digital Rights*
PHEV	*Plug-in hybrid electric vehicle*
TEU	*Treaty of the European Union*
TFEU	*Treaty on the Functioning of the European Union*
UN CRPD	*United Nations Convention on the Rights of Persons with Disabilities*

Table of Contents

1. Introduction

USER-CHI aims to foster the deployment and market acceptance of electric vehicles in Europe by conducting user-centric research. Therefore, it is foreseen to develop and demonstrate eight USER-CHI products in the context of seven specific applications in five demonstration sites (Barcelona, Berlin, Budapest, Rome and Turku) and two replication sites (Murcia, Florence). Accordingly, the engagement with end-users and stakeholders is a key component for USER-CHI.

1.1. Purpose of the document

The engagement of humans will be subject to USER-CHI throughout the whole project. In particular, humans will be involved in surveys, interviews, focus group and observational studies and will be particularly addressed in work carried out within WP1 and WP6. Both WPs focus on analyzing end-user requirements, motivations and constraints of participation, as well as planning, coordinating and organizing the pilot activities.

1.2. Scope of the document

This deliverable will cover the definition of the procedures and criteria with regard to the identification and recruitment activities of research participants. This comprises of a description of informed consent procedures that will be applied when identifying and recruiting research participants and will include respective templates of informed consent forms and information sheets. Also, involvements of vulnerable groups will be described in this deliverable by proposing and analyzing measures that protect them and minimize the risk of stigmatization.

1.3. Structure of the document

The document comprises seven chapters. Following the introduction, the second chapter gives an overview of the rationale of good research practices involving people as a basis for the

empirical research within USER-CHI. Moreover, the document outlines the relevant legislation which forms a basis for the ethical requirements.

Furthermore, the third chapter outlines the criteria and procedure which need to be followed by the project partners, who are involved in recruiting research participants for USER-CHI. In particular, the document describes the necessity of a two-step procedure before research participants can be involved. The procedure includes the information regarding USER-CHI, as well as voluntary consent in order to participate. Thereby, the three ethical requirements before participation are met: adequate information, voluntariness and competence.

In addition, the fourth chapter provides the Templates I (Information Sheets), as well as Template II (Informed Consent Form). Both templates will be translated by the demo site partners, in order to guarantee that they will be available in intelligible language for research participants.

Following to which, in the fifth chapter the potential involvement of vulnerable individuals as research participants in USER-CHI is outlined. A definition of vulnerable groups is provided and applied to USER-CHI scenarios. In conclusion, children and vulnerable adults, such as elderly persons and intellectually disabled persons, might be involved as research participants.

Building upon chapter five, the sixth chapter outlines protection measures, which have to be implemented in order to protect involved vulnerable research participants. Special consideration needs to be given to the absence of the ability to provide consent by vulnerable individuals. Therefore, alternative approaches to consent will be analyzed.

Finally, the last chapter provides conclusions and the most relevant synergies with other deliverables within USER-CHI. Those synergies are mainly found in WP1, WP6, WP11 and WP12.

2. Ethical guidelines and relevant legislation

Chapter 2 provides an overview of the meaning of ethics in research and outlines the most relevant ethical guidelines.

Moreover, this chapter explores the relevant legislation in which the ethical requirements are rooted to foster a deeper understanding of the overall meaning and concept.

2.1 Ethics in research

Ethics are an important aspect of research projects from the start. Ethical principles and legislation need to be applied to all fields of scientific research: for example, biomedical research, as well as social sciences and humanities.[1]

Hence, ethical requirements need to be taken into account by the USER-CHI consortium as well.

Ethical issues, which are the most common in research cover:

- "*the involvement of children, patients, vulnerable populations,*
- *the use of human embryonic stem cells,*
- *privacy and data protection issues,*
- *research on animals and non-human primates*".[2]

The first issues (*the involvement of children, patients, vulnerable populations)*, as well as the third issue *(privacy and data protection issues)* are related to USER-CHI activities and will be further addressed in *Chapter 3, 4, 5 and 6.*

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[1] *European Commission, "Horizon 2020 Programme -Ethics", <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/ethics >, accessed 15 April 2020.*

[2] *European Commission, "Horizon 2020 Programme -Ethics", <https://ec.europa.eu/programmes/horizon2020/en/h2020-section/ethics >, accessed 15 April 2020.*

The European Code of Conduct for Research Integrity offers legal, ethical and professional responsibilities for research activities.[3] Even though different fields of researcher are using different methods, they share the goal of understanding the world we live in.[4]

In accordance, the fundamental principles of research integrity are:

- ***„Reliability*** in ensuring the quality of research, reflected in the design, the methodology, the analysis and the use of resources.
- ***Honesty*** in developing, undertaking, reviewing, reporting and communicating research in a transparent, fair, full and unbiased way.
- ***Respect*** for colleagues, research participants, society, ecosystems, cultural heritage and the environment.
- ***Accountability*** for the research from idea to publication, for its management and organization, for training, supervision and mentoring, and for its wider impacts.“ [5]

Those fundamental principles need to be followed by the USER-CHI consortium in all stages of the project.

2.2 Scope of relevant legislation

For the purpose of creating a deeper understanding of relevant legislation for ethical issues in research, this chapter provides an overview of relevant international, European and national legal texts. The description of the scope and meaning of legislative sources will integrate the ethical requirements in a wider legal framework.

- Both ethical duties and legal duties build synergies and can influence each other

[3] *ALLEA- All European Academies, “The European Code of Conduct for Research Integrity”, Revised Edition, 2017, p.3.*

[4] *ALLEA- All European Academies, “The European Code of Conduct for Research Integrity”, Revised Edition, 2017, p.3.*

[5] *ALLEA- All European Academies, “The European Code of Conduct for Research Integrity”, Revised Edition, 2017, p.5.*

Those synergies can be described as follows:

"Ethics is not fully covered by legal regulation. This means that not every issue that is relevant from an ethical perspective could and should be legally regulated. On the other hand, sometimes the reason behind legal regulation is merely pragmatic. However, laws must always reflect on ethical implications and fulfil ethical demands. Therefore, ethical guidelines and principle do not render legal regulation unnecessary. "[6]

The Regulation (EU) No 1291/2013 on the establishment of the Horizon 2020 Programme clarifies the synergies between ethical principles and legislation further.

Article 19 on "Ethical Principles" states:

- All the search and innovation activities carried out under Horizon 2020 shall comply with **ethical principles** and **relevant national, Union and international legislation**, including the Charter of Fundamental Rights of the European Union and the European Convention on Human Rights and its Supplementary Protocols.

  Particular attention shall be paid to the **principle of proportionality**, the **right to privacy**, the right to the **protection of personal data**, the right to the physical and mental integrity of a person, **the right to non-discrimination** and the need to ensure high levels of human health protection.

For the purpose of creating a deeper understanding of the legal framework for ethical research, this chapter provides an overview of the Charter of Fundamental Rights of the European Union (CFR), the European Convention on Human Rights (ECHR), as well as the General Data Protection Regulation (GDPR). In addition, it will offer information on national data protection laws.

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[6] *Datenethikkommission der Bundesregierung Bundesministerium des Innern, für Bau und Heimat/Bundesministerium der Justiz und für Verbraucherschutz (Editors), „Kurfassung des Gutachten der Datenethikkommission der Bundesregierung", ("Short version of the Report of the commission of data ethics"), 2010.*

Furthermore, the USER-CHI consortium takes into account any legal guidelines regarding ethical conducts within the countries involved with the project, which are not further outlined in this document.

2.1.2 The Charter of Fundamental Rights of the European Union (CFR)

This sub-section explores the nature of the Charter of Fundamental Rights of the European Union (CFR) and provides an overview of the relevant fundamental rights arising out of it in regard to the participation of humans in research projects.

The CFR builds an important basis for the ethical requirements of research. It is a legally binding instrument, which codifies the fundamental rights in the European Union's legal order.[7]

Art. 6 (1) of the Treaty of the European Union (TEU) states that, the Union recognizes the rights, freedoms and principles set out in the Charter of Fundamental Rights of the European Union (...) which shall have the same legal value as the Treaties.

Accordingly, the CFR constitutes primary EU law. Therefore, it serves as a framework for the validity of secondary EU legislation as well as national measures.[8]

The substantive part of the Charter is divided into six titles, which enumerate specific types of rights: Title I ('Dignity'), Title II ('Freedoms'), Title III ('Equality'), Title IV ('Solidarity'), Title V ('Citizens' Rights'), Title VI ('Justice')."[9]

The relevant rights of the CFR for research participants, which need to be taken into account while involving them in research activities, are:

- **Article 3 – Right of the integrity of the person**

  (1) Everyone has the right to respect for his or her physical and mental integrity.

  (...)

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[7] *European Parliament, Fact Sheets on the European Union, "The Charter of Fundamental Rights", 2017, p.1.*

[8] *European Parliament, Fact Sheets on the European Union, "The Charter of Fundamental Rights", 2017, p.1.*

[9] *European Parliament, Fact Sheets on the European Union, "The Charter of Fundamental Rights", 2017, p.1.*

- **Article 7 – Respect for private and family life**

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

- **Article 8 – Protection of Personal Data**

  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

- **Article 21 – Nondiscrimination**

  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.

2.2.2 The European Convention on Human Rights (ECHR)

This sub-section explores the nature of the European Convention on Human Rights (ECHR) and provides an overview of relevant human rights arising out of the Convention for research participants.

The ECHR was established as the first convention of the Council of Europe, which is an international organization. The implementation of the Convention is overseen by the European Court of Human Rights. Moreover, the ratification of the ECHR is a pre-requirement in order to join the Council.[10]

Providing an overview of the rights guaranteed within the Convention, it secures:

- Life, freedom and security
- Respect of private and family life
- Freedom of expression
- Freedom of thought, conscience and religion
- Vote in and stand for election
- A fair trial in civil and criminal matters

[10] *Council of Europe, "A convention to protect your rights and liberties", <https://www.coe.int/en/web/human-rights-convention/home>, accessed 15 April 2020.*

- Property and peaceful enjoyment of possessions."[11]

The relevant rights of the ECHR for research participants, which need to be taken into account while involving them in research activities, are:

- **Art. 8 Right to Privacy**

  Everyone has the right to respect for his private and family life, his home and his correspondence.

  There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

- **Art. 14 Prohibition of discrimination**

  The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinions, national or social origin, association with a national minority, property, birth or another status.

2.2.3 The General Data Protection Regulation (GDPR)

Regulation (EU) 2016/679, the General Data Protection Regulation (GDPR), was established in order to protect individuals regarding the free movement of their personal data as well as the processing of it.[12] The directive entered into force in 2016 and is applicable since 2018.[13]

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[11] *Council of Europe, "A convention to protect your rights and liberties", <https://www.coe.int/en/web/human-rights-convention/home>, accessed 15 April 2020.*

[12] *European Commission, "Data Protection in the EU", <https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en>, accessed 15 April 2020.*

[13] *European Commission, "Data Protection in the EU", <https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en>, accessed 15 April 2020.*

The regulation in important improvement in the field of personal data protection in comparison to the former fragmentation in different national law systems. [14] It strengthens individual's fundamental rights in the age of digitalization. [15]

- *The research activities planned in WP1 and WP6 fall within the material scope of the GDPR, as personal data will be proceeded.*

The **material scope of the Directive** is defined in Art. 2 GDPR. Art. 2 (1) of the GDPR states that, the

- this Regulation applies to the processing of personal data wholly or partly by automated means and to the processing other than by automated means of personal data which form part of a filing system or are intended to form part of a filing system.

Moreover, personal data is defined in Art. 4 (1) GDPR as:

- (...) any information relating to an identified or identifiable natural person ('data subject'); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

In addition, the term processing is defined in Art. 4 (2) GDPR as:

- „any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organization, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction."

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[14] *European Commission, "Data Protection in the EU", <https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en>, accessed 15 April 2020.*

[15] *European Commission, "Data Protection in the EU", <https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en>, accessed 15 April 2020.*

In order to act in compliance with the GDPR regulation, the project partners which are involved in processing date need to meet the requirements arising out it:

- *The most essential duty, which derives under GDPR for involving humans as research participants is the* requirement of consent.

The requirement of the individual's consent in order to process personal data is established in Art. 7 GDPR.

Art. 7 (1) GDPR states that,

- where processing is based on consent, the controller shall be able to demonstrate that the data subject has consented to processing of his or her personal data.

Furthermore, Art. 7 (2) GDPR requires that,

- if the data subject's consent is given in the context of a written declaration which also concerns other matters, the request for consent shall be presented in a manner which is clearly distinguishable from the other matters, in an intelligible and easily accessible form, using clear and plain language.

Recital 32 of the GDPR outlines that,

- consent should be given by a clear affirmative act establishing a freely given, specific, informed and unambiguous indication of the data subject's agreement to the processing of personal data relating to him or her, such as by a written statement, including by electronic means, or an oral statement.

The implementation of the requirement of free consent in order to participate in research activities will be further addressed in Chapter 3, 4, 5 and 6.

Additional requirements for the protection of personal data:

- No data collected will be sold or used for any purposes other than the current project.
- A data minimization policy will be adopted at all levels of the project and will be supervised by each responsible pilot demonstration. The confirmation of the

application of the data minimization principle will be provided by the project partners and will be part of D12.2.

- Any shadow (ancillary) personal data obtained during the course of the research will be immediately deleted. However, the plan is to minimize this kind of ancillary data as much as possible.

2.2.4 Overview of national data protection laws

Beside EU's aforementioned General Data Protection Regulation, which has harmonized the subject of personal data protection, there are also national legal frameworks on data protection that apply to the project's demo sites, which will be briefly presented in this chapter.

A more detailed overview of these national laws can be found in the framework of D12.1.

The process of harmonization through EU regulations implies that the regulation turns into effective laws within the EU member states, when they enter into force.[16] In case of an EU regulation an act of transposition into national law is not necessary.[17]

According to Art. 288 (II) Treaty on the Functioning of the European Union (TFEU) the GDPR has primacy of application to the subject of personal data protection in the EU member states in regard to national data protection laws.

However, the GDPR also outlines a set of "opening clauses", where the regulation can be supplemented by national data protection laws on specific topics.[18]

One example for an opening clause is Art. 89 (II) GDPR, which states that

- Where personal data are processed for scientific or historical research purposes or statistical purposes, Union or Member State law may provide for derogations from the rights referred to in Articles 15, 16, 18 and 21 subject to the conditions and safeguards referred to in paragraph 1 of this Article in so far as such rights are likely to render impossible or seriously impair the achievement of the specific purposes, and such derogations are necessary for the fulfilment of those purposes.

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[16] *European Union, EU law, "Regulations, Directives or other acts", <https://europa.eu/european-union/eu-law/legal-acts_en>, accessed 15 April 2020.*

[17] *European Commission, "Types of EU Law", <https://ec.europa.eu/info/law/law-making-process/types-eu-law_en>, accessed 15 April 2020.*

[18] *Paal/Pauly, in: Paal/Pauly, DS-GVO BDSG, 2. Edition 2018, Introduction, Rn. 20 f.*

Yet, this report does not analyze the detailed national regulation in the scope of opening clauses under the GDPR. It merely gives an overview of relevant national legal texts on data protection in order for the demo site partners to take them into account.

2.2.4.1 National data protection laws in Germany[19]

German pilot demonstrations which will take place in Berlin have to comply with German legislation "Bundesdatenschutzgesetz BDSG" (German Federal Data Protection Act-BDSG) and the responsible state data protection acts (for Berlin: "Berliner Datenschutzgesetz" (Gesetz zum Schutz personenbezogener Daten in der Berliner Verwaltung (Data Protection Act for Berlin – BlnDSG)) of June 13th, 2018), relating to the collection, processing and use of personal data. [2] The BDSG (in the version promulgated on January 14th, 2003 (Federal Law Gazette I p. 66) [3], as most recently amended by Article 1 of the Act of June 30th, 2017 (Federal Law Gazette I p.2097)) serves to adapt to the GDPR (Regulation (EU) 2016/679 of the European Parliament and the Council) and Directive (EU) 2016/680 of the European Parliament and the Council, both of April 27th, 2016.

Due to the broad scope and primacy of the GDPR, both the national data protection act on the federal level and also on the state level have a very restricted scope of application regarding private organisations. Nevertheless, the following issues relevant to the USER-CHI project are defined:

The federal regulatory authority of Germany is the German Federal Data Protection Authority (BfDI) [4].

The purpose of the BDSG is to protect the individual against his/her right to privacy being impaired through the handling of his/her personal data (any information concerning the personal or material circumstances of an identified or identifiable individual).

2.2.4.2 National data protection laws in Finland

The Finnish pilot trial which will be conducted in the city of Turku has to comply with The Data Protection Act (1050/2018) specifies and supplements the EU's General Data Protection Regulation and its national application. Among other things, the Act provides for the appointment, organization and powers of the supervisory authority on data protection matters.

The Data Protection Act also provides for:

- the age limit for offering information society services to a child;
- the processing of special categories of personal data;
- the processing of personal data for journalistic purposes or the purposes of academic, artistic or literary expression;
- the processing of personal identity codes;

[19] *Provided by ETRA (D12.1).*

- the certain situation in which the public interest constitutes a legal basis for processing personal data; and
- restrictions of the right of the data subject.

In addition to general data protection legislation, Finland has specific legislation on the processing of personal data. The majority of such legislation deals with the processing of personal data by the authorities. Specific enactments either impose more precise provisions on the processing of personal data in a certain field or specify how the personal data may be processed by derogation from the general legislation.

Specific legislation is divided into enactments dealing with personal data files with a major role in the functioning of society (e.g. the Population Register and registers related to studies and the right to study) and enactments providing for the processing of personal data in a specific field (e.g. the Act on the Protection of Privacy in Working Life and the Credit Information Act). Individual provisions on data protection can also be found in legislation on other matters.

2.2.4.2 National data protection laws in Hungary

Act CXII of 2011 on the Right of Informational Self-Determination and on Freedom of Information regulates the general data protection and management issues. Its purpose to determine the primal rules on data management in the matters covered in order to oblige the data controllers to respect the privacy of individuals, as well as to make the public affairs transparent by the right of access to and spread of data of public interest and data public on grounds of public interest. The act is applicable to every kind of data management which is related to personal information as well as data of public interest.

Other relevant regulations on the national level:

- Act L of 2013 on the Electronic Information Security of Governmental and Municipal Bodies
- Act LXII of 2012 on the Recycling of Data of Public Interest
- Government Decree 305/2005 (XII. 25.) on the detailed rules of electronic disclosure of data of public interest, unified research system on data of public interest, as well as the data content of the central registry and data integration
- Government Decree 301/2016 (IX. 30.) on the reimbursement of expenses after the request of data of public interest
- Ministry Decree of Informatics and Telecommunication 18/2005 (XII. 27.) on the disclosure samples which are necessary to the disclosure of data on disclosure lists

Regulations on the municipal level:

- Joint Instruction 1/2019 (I. 3.) on the data privacy of the Municipality of Budapest the Mayor's Office, the data security and the procedures of disclosure of data of public

interest (Privacy Policy) Its purpose is to guarantee that the work of the Municipality of Budapest and the Mayor's Office during the administering of its prescribed tasks – in compliance with the pertinent regulations, especially with 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) and with the Act CXII of 2011 on the Right of Informational Self-Determination and on Freedom of Information –, as the data controller, respect the privacy of individuals and make the data of public interest freely accessible and spreadable for everyone. It is applicable to all of the internal organizational units, as well as to all of its employees and the City Council of Budapest and its Committees, Representative and Non-representative Members who perform any activity related to administering, storing or providing either personal data or data of public interest or preparing documents (proposals, handouts, reports, etc.) containing such data.

- Joint Instruction 55/2016 (IX. 22.) on the rules of electronic disclosure of data of public interest.
- Normative Instruction 91/2015 (XII. 11.) on the Information Technology Regulation of the Mayor's Office.
- Normative Instruction 19/2018 (V. 14.) on the Information Technology Security Regulation of the Mayor's Office. The goal is the Protection of personal data, as well as the protection of documents and personal data administered paper-based and in electronic systems.

2.2.4.3 National data protection laws in Italy

In Italy, the regulatory framework for the protection of personal data is governed the Code for the protection of personal data (Privacy Code Dlgs 196/2003) and the Legislative Decree n.101/2018, which was issued on 10 August 2018 and entered into force on 19 September 2018 on a national level.

The Decree 101/2018 has a dual purpose:

- the first "repealing", for some provisions of the old code: principles, rights of data subjects, general obligations of owners and managers, security measures, fulfilments and notifications to the Authority;
- the second "innovative", with the insertion and modification of new provisions to complete the framework of the "new privacy" by adapting the old provisions of the Privacy Code remaining in force in a new all "European" re-reading regulated by the GDPR.

In adapting to the New European Regulation, the implementing Decree 101/2018 introduces significant changes regarding sanctions, the rights of the data subject, the usability of data acquired in violation of the provisions, the attribution to the Guarantor of stronger powers and additional tasks, the methods of implementation of the GDPR for micro, small and medium enterprises, information services and minors, codes of conduct, rules of conduct, the processing of "special categories of data" for purposes of scientific research, statistical purposes, historical research and of significant public interest.

One of the main changes in regard of the processing of data is for purposes of overriding public interest: a list of processing operations is identified for "special" categories of data whose processing is legitimate on the assumption that they are carried out for the performance of a task carried out in the public interest or in the exercise of official authority (access to administrative documents and civic access, keeping of records and civil status registers, the registries of the population residing in Italy and of Italian citizens residing abroad, electoral rolls, issue of identification or travel documents or change of personal details, keeping of public registers relating to immovable or movable property, keeping of the national registry of drivers and the national archive of vehicles, citizenship, immigration, etc..).

Italian pilot demonstrations, which will take place in Rome have to comply with Italian legislation as described above. Moreover, no data will be used outside the scope of the USER-CHI project.

2.2.4.4 National data protection laws in Spain[20]

Spanish pilot trial which will be conducted in Area Metropolitana de Barcelona has to comply with the Spanish legislation “Organic Law 3/2018”, (“Organic Law of Protection of Personal Data and Guarantee of Digital Rights” LOPDGDD as its Spanish acronym). This law is part of the Spanish legislation regarding personal privacy and data protection.

In accordance with Chapter VI-Article 51 GDPR, each Member State shall provide for one or more independent public authorities to be responsible for monitoring the application of GDPR, in order to protect the fundamental rights and freedoms of natural persons in relation to the processing and to facilitate the free flow of personal data within the Union (‘supervisory authority’).

The main supervisory authority in Spain is an authority called “Data Protection Agency” or “Agencia Española de Protección de Datos” (AEPD).

Nevertheless, as stated in GDPR, Spain has created a second supervisory authority with a specific scope of application, called “Catalan Data Protection Authority” or “Autoridad Catalana de Protección de Datos” (APDCAT) [5]. This public authority, with its own legal personality and full capacity act, its scope of action are Catalan public institutions and also Catalan private entities which its capital comes from public institutions, which applies to AMB. The Catalan Data Protection Agency creation and regulation are established in Decree 48/2003, of 20th February,

[20] *Provided by ETRA (D12.1).*

passing the statute of the Catalan Data Protection Authority and Law 32/2010 of the Catalan Data Protection Agency.

Another legal basis regarding data protection is the Royal Decree 1074/2015 of 27 November [5]. This Royal Decree amends some aspects related to the data to be stored in the Supply Points Information System or "Sistema de Información de Puntos de Suministro" (SIPS) which is regulated by Article 7 of the Royal Decree 1435/2002 [6] setting the basic conditions for the acquisition of energy contracts and access to low voltage grids. The SIPS is a database managed by the Distribution System Operators (DSOs). Only the National Regulatory Authorities (NRA), the National Commission on Markets and Competition (CNMC), and energy suppliers are able to access this database.

Finally, no data will be used outside the scope of the USER-CHI project. Further information can be found at the webpages of Agencia Española de Protección de Datos (www.agpd.es), Autoridad Catalana de Protección de Datos (www.apdcat.gencat.cat) and Fundación Española para la Ciencia y la Tecnología [6] (www.fecyt.es).

3. Recruitment of Research Participants – Criteria and Procedures

The specific cases in USER-CHI that will be demonstrated, will involve various groups of humans, e.g. inhabitants, drivers and/or users of EVs. The identification and recruitment, therefore, require ethical compliance with the guidelines and legislation described in the previous chapter.

Ethical compliance ensures the protection and guarantees non-discriminatory participation of research participants in USER-CHI. Accordingly, each person that is volunteering or willing to participate in one or more research activities, e.g. surveys, interviews, focus group and observational studies, and participation in demonstration activities, will be part of a procedure that fulfils ethical standards complying with fundamental ethical principles according to the EU Charter of fundamental rights, the European Convention of Human Rights and other relevant European and national legislation, alike.

Within the identification and recruitment process of USER-CHI research participants, special attention will be given to gender equality. In fact, research in the field of transportation (e.g. motor

vehicles usage) has shown, that the share of users divided by gender is often unequal, whereas the share of female users is significantly lower than the share of male users.[21]

This chapter outlines the procedures and criteria which need to be considered when recruiting research participants for USER-CHI.

3.1 Criteria for the involvement of research participants

The city and demonstration site partners of USER-CHI have the task to acquire suitable research participants. Therefore, various criteria need to be considered that build the foundation of informed consent which guarantees voluntary participation in research.[22] The criteria described will be subject to different dimensions combining both ethical criteria with criteria that enable high-quality research. The later implies the golden rules for ethical research conduct.[23]

- „Respects the integrity and dignity of persons (that this intrinsic worth protects them from being used for greater perceived benefits)
- Follows the "Do no harm" principle. Any risks must be clearly communicated to subjects involved
- Recognises the rights of individuals to privacy, personal data protection and freedom of movement
- Honours the requirement of informed consent and continuous dialogue with research subjects

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[21] *Results of a project in the research field of electromobility has shown that a more than 90 % of EV users (BEV and PHEV) out of 168 registered EMSP customers surveyed are male (cf. ANS Project - Analyse der Nachfragereaktionen und der Stellplatzbelegung bei Variation des Preismodells für die Nutzung von Ladeinfrastruktur im Berliner Modell; Frenzel/Jarass/Trommer/Lenz, „Erstnutzer von Elektrofahrzeugen in Deutschland -Nutzerprofile, Anschaffung, Fahrzeugnutzung", DLR, 2015, p.10.*

[22] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.14.*

[23] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.24.*

- Respects the principle of proportionality: not imposing more than is necessary on your subjects or going beyond stated objectives (mission creep)

3.1.1 Adequate information, voluntariness and competence

Informed consent is the most important principle in research ethics and is not only relevant in clinical research, but in social science, as well. The foundation for informed consent are the three dimensions adequate information, voluntariness and competence. [24]

3.1.1.1 Adequate information

The first step in order to acquire valid consent is to provide adequate information to prospect research participants. This comprises of both general information and in-depth information of the project based on two main questions: what should the prospective research participant be told, and how should the researcher tell them?[25]

General information will highlight the purpose and the research goals of the project. It also includes information that will clarify what will happen with the results of the project. More detailed information to be provided includes all information that is subject to the research procedures and its duration.[26] Therefore, the amount of relevant information needs to meet the standard based on what a reasonable person might need to know before making a decision on whether to participate in the research project or not.

3.1.1.2 Voluntariness

The second criterion is voluntariness and depicts an important dimension. Accordingly, consent to participate in the research must not result from coercion, manipulation or undue inducements.[27] Each of the mentioned aspects should not be existent.

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[24] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.14.*

[25] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.37.*

[26] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.14*

[27] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.38.*

The aspect of coercion might take a more subtle form within EU research activities, e.g. a person believes if he or she would not participate in research carried out by their doctor, nurse, lecturer, or any other related person, will have a disadvantageous effect on their future dealings with this specific individual. The following activities may be undertaken in order to eliminate this subtle form of coercion: [28]

- Conduct research with eligible candidates that might not be directly related to the researchers that carry out the research
- The process of consent may be carried out by an impartial intermediary
- Clarify that the decision to not participate will not affect the eligible candidate in any way

The aspect of manipulation involves deception and non-deceptive approaches that influence the decision-making process of each individual by deliberate statements that are often branded as information (e.g. use of smells to encourage purchasing).[29] Inducements are regarded as rewards for the participation in research, e.g. providing monetary rewards. The use of inducement does not render the consent invalid automatically. However, problems may arise if the rewards are excessively high.[30]

3.1.1.3 Competence

The criterion of competence implies sufficient mental competence or capacity of the eligible research candidate in order to understand and retain the information about respective research activities and to be able to communicate their views regarding the research.[31] The person does not have competence to fully understand the research activities, the consent may be invalid.

An alternative approach in order to deal with eligible candidates that may not fully comply with this criterion will be addressed in chapter 6.

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[28] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.38.*
[29] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.39.*
[30] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.39.*
[31] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.40.*

3.2 Procedure for the involvement of research participants

The following sub-section describes the procedures that will be considered and applied throughout USER-CHI research activities in order to meet the criteria described in the previous sub-section. Therefore, USER-CHI project partners need to apply a two-step approach before research activities involving people can begin.

3.2.1 The two-step approach

As part of USER-CHI, the demo site partners may acquire suitable research participants. Therefore, they make use of various channels to reach out to eligible candidates. Examples of dedicated channels are requests via newsletter, (online) forums or both personnel and topic-related networks.

The project partner needs to follow a two-step procedure before the research actions, such as focus groups, surveys, interviews, demonstration at demonstration sites etc., could be performed: this includes the information of eligible research candidates, which is supplemented by the usage of the Informed Consent Forms. Both steps are further described in sub-section 3.2.1.1 and 3.2.1.2.

3.2.1.1 Inform eligible research candidates

As described in the previous sub-section, it is crucial, that participants understand the full scope of the USER-CHI project and the impact of the research carried-out on themselves, as well as on society.[32] Therefore, it is mandatory to hand out information sheets to eligible candidates. The information sheet will include the following information regarding USER-CHI:

- General information (project name, project acronym, project duration, project-ID and the financial source of the project)
- Project goals information
- Research-related data collection information
- Procedure, duration and implication information
- Information regarding the use of data and guarantee of confidentiality
- Information regarding voluntary participation and the right to withdraw the consent

[32] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.15.*

- Information on questions and doubts
- Confirmation

In order to make sure each research participant has the possibility to fully understand the research scope of USER-CHI and feel fully informed, it is also possible to contact an appointed researcher of the project that will provide further information, accordingly. The template for USER-CHI's information sheet is indicated in section 4.1.

3.2.1.2 Informed Consent

After providing sufficient information regarding USER-CHI, project partners are obliged to hand out informed consent documents to each research participant for two reasons. First, each research participant approves that he or she received sufficient information through the information sheet and further measures taken by the project partner as stated on the information sheet. Second, based on the information procedure, each participant confirms to participate in USER-CHI under the condition of informed consent and free will. The template for USER-CHI's informed consent form is indicated in section 4.2.

Once the informed consent forms are signed, project partners in each demo site should keep a copy of each document on file.

4. USER-CHI templates for involvement of research participants

This chapter provides the Template I (Information Sheets), as well as Template II (Informed Consent form), which need to be used by project partners involved in research activities with humans. The use of the templates is essential in order to guarantee, that the relevant legal and ethical requirement for the protection of personal data are met.

Disclaimer regarding the Review Process:

The templates for the **Information sheets** as well as the **Informed Consent Forms** regarding the USER-CHI project are currently being reviewed by the law firm BBH. Their review will ensure the conformity with EU data protection laws. The templates will be updated as soon as possible within the review process.

Applicable languages for different project partners:

The template of the Information Letter as well as the Informed Consent Forms are inserted in English below. However, the USER-CHI project partners, which use the forms before performing research activities with participants are required to translate the forms into the intelligible language. Research participants should be asked, which language suits them the most. This could be either English or the local language of the demo site partners. Therefore, the project partners are asked to translate both the Information Letter and the Informed Consent Forms into either a Spanish, Italian, Finnish, Hungarian, or German version.

4.1 Template I – Information Letter for Research Participants

The following *Template I* needs to be handed out to the potential research participants in order to guarantee, that they receive sufficient information about USER-CHI. On the basis of the information provided by *Template I* the potential research participants can then decide, whether they want to participate in USER-CHI or not.

Therefore, the *Template I* includes information about the project goals, the procedure of research activities, as well as the duration of the project. In addition, it emphasizes, that the potential research participants are free to ask questions about issues that remain unclear within the information process.

Project Acronym: USER-CHI

Project Name: Innovative solutions for USER centric CHarging Infrastructure

(Grant Agreement: N° H2020-875187

Start Date of Project 01/02/2020

End Date of Project 31/01/2024

Website (.....)

This project has received funding from the European Union's Horizon 2020 research and innovation programe under grant agreement No 875187.

Dear USER-CHI participant,

You have been invited to take part in a research study. Before you decide on whether you want to participate or not, please read this document carefully.

Please ask all the questions that arise, so you can be completely sure to understand all the proceedings of the study, including risks and benefits. Our intention is that you receive clear and sufficient information, that is fully comprehensible for you. Based on this information you can evaluate, if you would like to participate in the USER-CHI trials.

This information letter may include words or processes 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 piece of information you do not understand. We will be glad to solve the possible questions that you may have. At all times, we assure compliance with applicable legislation on data protection

Project goals

The aim of USER-CHI is to unlock the potential of transnational and inter-regional electromobility in Europe. Therefore, different charging technologies will be integrated to achieve interoperability for users. This process includes, for example, charging technologies, e-roaming, billing, authentication and reservations of parking slots in front of charging infrastructure. The user will be put at the center of the project in order to be empowered.

Moreover, the synergies between electromobility and smart grids will be fostered to contribute to the European energy transition. The developed technological tools, and business models will be put into practice and demonstrated in five areas: Barcelona metropolitan area (Spain), Rome (Italy), Berlin (Germany), Budapest (Hungary), and Turku (Finland).

Besides, replication cities have been included in each of the TEN-T corridors involved in the project: Murcia (Spain) in the Mediterranean corridor and Florence (Italy) in Scandinavian-Mediterranean corridor.

In this context, it is necessary to collect data concerning the following topics:

- the use of electromobility services (e-car sharing, smart park & charge, smart charging, etc.)
- related information including EV geolocalisation,
- charging infrastructure status,
- charging operations,
- energy consumption,
- booking,
- billing and payment transactions,
- logistics
- municipal fleets operations.

The collected data will enable the demonstration of the USER-CHI envisioned solutions. Personal data that is collected, will be available exclusively for the end-users and researchers that participate in the USER-CHI-project. The information will be used for data analytics, as well as long term forecasting.

Procedure, duration and implications

The project activities will last for 48 months. Users who agree to join the trials will participate through the continuous use and assessments of the USER-CHI solutions. Throughout the period of trials, questionnaires, interviews, workshop and focus group will be applied. The questions aim at the assessment of the practicability, ease of use and benefits of the USER-CHI-solutions. The trials do neither cause any health risks for the participants, nor do they cause any other disadvantages.

Use of data and guarantee of confidentiality

The responses you provide in the questionnaires, interviews, workshop and focus group will be recorded. All your data will be coded under a pseudonym instead of using your real name, that will be neither stored nor transmitted to third parties. All your personal data will be treated according to the national data protection laws. 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 specific trial participants as the source of the information. The results of this study may be published in scientific journals or conferences and may be used in further studies. Nothing of the provided personal data will be handed out to third parties.

Voluntary participation and right to withdraw the consent

Your authorization for the use and access to the information is valid until the end of the USER-CHI project, unless you decide to withdraw it before. If you should decide to withdraw your consent, please contact the leading researcher (.....) and let her/him know of your intention to leave the study. Your decision of whether or not to give your authorization for the use and diffusion of the information provided by you is completely free. You can decide not to participate or change your decision and withdraw your consent at any time. However, if you do not authorize the researchers to use the information provided by you or if you withdraw your consent at a later time within the duration of the project, you will not be able to participate anymore.

Questions and doubts

You have the right to ask any questions that arise and raise concerns you might have regarding the project before, during and after the tests. Therefore, feel free to contact the responsible researcher (.....) of the USER-CHI-project at any time.

Confirmation

Your participation in this study is only possible, if you freely and independently sign the attached “Informed Consent Form” to authorize us to use the data you provide. If you do not wish to do so, please do not participate in the USER-CHI trials.

4.2 Template II – Informed Consent Form

The following *Template II* needs to be handed out to and signed by the potential research participants in order to guarantee, that they provide their informed consent for the participation in USER-CHI. Moreover, it needs to be signed by the responsible researcher of the project partner, who is in charge of managing the research participation process.

I, Mr./Ms....., have received the information concerning the Horizon2020 project "USER-CHI". I will participate in the USER-CHI project by assessing the solutions and technologies that will be developed within its framework.

I have been sufficiently informed about the tasks which will be carried out, as well as its conditions. Furthermore, I have received information about the goals of the project and the use of data gathered through my participation. I accept the conditions of the trials, which require my participation for a lengthy period of time. I understand that my participation is voluntary and that I can withdraw from the study at any time according to Art. 7 III 1 GDPR.

The legal basis for the processing of the personal data is the informed consent in accordance to Art. 6 I a) GDPR.

Therefore, I give freely my consent for:

- Participating in the USER-CHI-project
- Recording images (photographs and videos) of my participation in the study by USER-CHI-project-staff
- Publishing the recorded images in scientific publications and promotional material in the scientific field

I hereby declare:

• I am 18 years old or older and able to give consent; /

- *(In case the research participant is not 18 years old, or not able to give consent: (.....)*
- *My legal guarding has explained the relevant information to me and has understand the scope of my participation in USER-CHI. My legal guardian will sign this form on my behalf.)*

• I have been fully informed about the aims and purposes of the USER-CHI-project (according to the USER-CHI Information sheet). I understand that it is not obligatory to participate in the USER-CHI trials and, if I choose to participate, I may at any stage withdraw my participation;

• I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. Furthermore, I understand the description of the research that is being provided to me;

• I agree that my data (collected by smart meters, surveys, questionnaires, interviews or focus groups) is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity;

• 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 and I am fully aware of 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;

• I understand that 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 complies with the relevant national, European and international data protection laws and regulations and personal data treatment obligations. Special care was given to the obligations of the EU General Data Protection Regulation (GDPR) for the protection of individuals with regard to the processing and the free movement of personal data.

.....

Name and surname of participant

.....

Place, date and signature of participant

Statement of researcher's responsibility:

I have explained the nature and purpose of the USER-CHI-project, as well as the procedures to be undertaken and any risks that may be involved to the participant. I have offered to answer any questions and fully answered the questions that arose. 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:

In order to receive information about your personal data or withdraw your consent to the participation in the USER-CHI project you can contact the responsible researcher or the Data Protection Officer of the institutions through the modes of contact indicated at the foot of this page.

(.....)

USER-CHI partner in charge of the evaluation: address, telephone number, e-mail address:

Data Protection Officer:

.....

Name and contact details of the institution's DPO

5. Vulnerable individuals/groups

This chapter explains the concept of vulnerable individuals and groups and its relevance for the involvement of research participants in USER-CHI.

Therefore, this chapter will first define the different categories of vulnerable groups.

Secondly, it will highlight which categories of vulnerable groups might be involved as research participants within USER-CHI.

5.1 Relevance of the categories of vulnerable groups within research projects

The procedure involving Informed Consent, which is described above, is needed within the USER-CHI project, because personal data of the project participants is collected.

However, if vulnerable individuals or groups are involved the "usually established" informed consent procedure might not be enough.[33] It depends on the research participants autonomy and vulnerability in order to decide if special attention throughout the consent procedure is needed.[34]

The adaptation of the "usual procedure" through additional requirements might be indicated.

5.2 Different categories of vulnerable groups/individuals

The key elements that all vulnerable groups have in common is „a higher risk of harm or exploitation than others would be in a similar situation and/or is less able than others to protect themselves from harm or exploitation."[35]

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[33] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.14.*

[34] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.14.*

[35] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.52.*

In order to provide practical examples, vulnerable groups of people include:

- *Children*
- *vulnerable adults (such as elderly, prisoners,* intellectually disabled , *and severely injured patients)*

5.3 Involvement of vulnerable groups within USER-CHI

This chapter analyzes the potentially vulnerable groups, which could be involved in USER-CHI as research participants.

5.3.1 Involvement of children as research participants

This sub-section outlines the potential involvement of children as research participants in USER-CHI.

Children are legally defined as people under the age of 18.[36]

The requirements of the focus groups for the different demo site partners provided by IBV do not impose any minimum age. On the contrary, it states that 33% of the research participants should be under the age of 25.

However, the potential involvement of children as research participants is not closely linked to the focus of USER-CHI. As USER-CHI analyses the needs of EV users the research participants are required to have a driver's license.

Therefore, the applicable minimum age for driver's license for the different demo site partners needs to be clarified.

The following table describes the minimum age in order to obtain a driver's license for passenger cars in the regarding EU-member states (Hungary, Italy, Germany, Finland and Spain):

Demo site partner:	*Minimum age for driver's license (passenger cars):*

[36] *European Commission, "EU actions on the rights of the child", < https://ec.europa.eu/info/policies/justice-and-fundamental-rights/rights-child/eu-action-rights-child_en>, accessed 15 April 2020.*

Hungary (Budapest)	18 years[37]
Rome (Italy)	18 years[38]
Berlin (Germany)	18 years[39]
Turku (Finland)	18 years[40]
Barcelona (Spain)	18 years[41]

This table shows, that the minimum age for obtaining a driver's license for a passenger car for the participating demo sites is at least 18 years.

This implies that children will not be involved as research participants regarding the research on electric-cars within USER-CHI.

5.3.2 Exception: The possible involvement of children as LEV users

The involvement of children requires further attention to special ethical and legal measures of protection, which will be addressed in Chapter 6. Therefore, legal issues may arise in theory. In cases where there is no explicit added value through the involvement of children in the USER-CHI project, children should not be included. Nevertheless, the final decision is left to the individual researcher's within USER-CHI.

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[37] *European Union, "Getting a driving license in the EU – Hungary", https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/hungary/index_en.htm, accessed 15 April 2020.*
[38] *European Union, "Getting a driving license in the EU – Italy", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/italy/index_en.htm>, accessed 15 April 2020.*
[39] *European Union, "Getting a driving license in the EU – Germany", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/germany/index_en.htm>, accessed 15 April 2020.*
[40] *European Union, "Getting a driving license in the EU – Finland", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/finland/index_en.htm>, accessed 15 April 2020.*
[41] *European Union, "Getting a driving license in the EU – Spain", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/spain/index_en.htm>, accessed 15 April 2020.*

As Ethics Advisor IKEM advises against the involvement of children as research participants within the USER-CHI project in principle.

However, this sub-section explores how children could be potentially involved as research participants through the use of LEVs (Light electric vehicles).

According to the USER-CHI focus groups requirements LEVs are motorcycles, scooters, as well as e-bikes. Those requirements provided by IBV state that at least 5 participants in the focus groups in Rome, Turku and Budapest should be LEV users.

The minimum age for a driver's license for scooters in the relevant EU-member states:

This table describes the minimum age in order to obtain a driver's license for different types of scooters and motorcycles in Hungary, Italy and Finland.

Demo site partner:	*Minimum age for driver's license (scooters/motorcycles):*
Hungary (Budapest)	below 55cc displacement 14 years; over 122cc 16 years; over 395 cc displacement 18 years; over 595cc displacement 24 years[42]
Rome (Italy)	up to 125cc displacement 16 years; up to 35kW 18 years; over 35kW 21 years[43]
Turku (Finland)	up to 125cc displacement 16 years; up to 35kW 18 years; over 35kW 24 years[44]

Conclusively, this table shows that children might be involved as research participants regarding the use of e-scooters or e-motorcycles within the demo site in Budapest, Rome and Turku.

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[42] *European Union, "Getting a driving license in the EU – Hungary", https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/hungary/index_en.htm, accessed 15 April 2020.*
[43] *European Union, "Getting a driving license in the EU – Italy", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/italy/index_en.htm>, accessed 15 April 2020.*
[44] *European Union, "Getting a driving license in the EU – Finland", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/finland/index_en.htm>, accessed 15 April 2020.*

The minimum age for a driver's license for e-bikes in the relevant EU-member states:

The Directive 2006/126 imposes the need for an AM driving license for two-wheel vehicles with a maximum design speed of more than 25 km/h but not more than 45 km/h. On the other hand, the use of e-bikes with a maximum speed of 25 km/h is not linked to a driving license.

Accordingly, relevant end-users of e-bikes might not need to have a driver's license in order to use the e-bikes.

In conclusion, children under the age of 16 could be potentially involved as e-bike users in the demo site of Rome, Turku and Budapest.

5.3.3 Involvement of vulnerable adults as research participants

This sub-section analysis the potential involvement of vulnerable adults as research participants within the USER-CHI project.

The category of vulnerable adults includes the elderly, prisoners, intellectually disabled persons, and severely injured patients.[45]

Prisoners and severely injured patients will not be involved in USER-CHI as research participants. The focus groups, online surveys, and demonstration require that the research participants can move freely and use electronic vehicles. Moreover, USER-CHI is not a clinical research study and will therefore not involve severely injured medical patients.

5.3.3.1 Involvement of elderly as research participants

This chapter outlines the potential involvement of elderly as research participants in USER-CHI.

Elderly are adults who are 65 years old or older.[46]

First of all, there is no upper age limit for research participants of USER-CHI defined within the focus groups criteria, provided by IBV. On the contrary, the requirements for the focus groups state that optimal 33% of the research participants are 56 years and older and for a minimum three users should be older than 56 years.

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[45] *European Commission, Directorate-General for Research and Innovation, Directorate B – European Research Area Unit B.6 – Ethics and gender, "Ethics for researchers – Facilitating Research Excellence in FP7", 2013, p.14.*

[46] *European Commission, Eurostat, Infographs, "A look at the lives of eldery in the EU today", 2017.*

Moreover, there is no upper age limits within the EU-member states for holding a driver's license.[47] As long as adults are medically fit to drive, they are able to keep their driver's license.[48] In some EU-member states the fitness to drive needs to be attested by a doctor.[49]

Conclusively, the elderly might be involved as research participants within USER-CHI.

5.3.3.2 Involvement of intellectually disabled persons as research participants

This chapter analyzes the potential involvement of intellectually disabled persons as research participants in USER-CHI.

USER-CHI is not a clinical study with the aim to provide research on the topics of mental illnesses. Therefore, there is no focus on acquiring intellectually disabled individuals as research participants.

However, intellectually disabled individuals should not be excluded as research participants per se.

The European Union and all its Member States are parties to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), which entered into force in 2011.[50]

Art. 2 of the UN CRPD states,

- that discrimination on the basis of disability" means any distinction, exclusion t or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field (...)."

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[47] *European Union, "Getting a Driving license in the EU", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/index_en.htm>, accessed 15 April 2020.*
[48] *European Union, "Getting a Driving license in the EU", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/index_en.htm>, accessed 15 April 2020.*
[49] *European Union, "Getting a Driving license in the EU", <https://europa.eu/youreurope/citizens/vehicles/driving-licence/get-driving-licence/index_en.htm>, accessed 15 April 2020.*
[50] *European Commission, Employment Social Affairs and Inclusion, "Persons with disabilities", <https://ec.europa.eu/social/main.jsp?catId=1137>, accessed 15 April 2020.*

Accordingly, it would be discriminatory to exclude intellectually disabled individuals as research participants merely on the basis of their disability.

Moreover, the European Disability Strategy 2010-2020 includes the goal to "eradicate discrimination on grounds of disability within the European Union."[51]

Intellectually disabled persons are excluded from participating as research participants, if the intellectually disabled is too severe to obtain a driver's license. Yet, the exclusion in these cases is not based on the intellectually disability itself, but on the ability to be fit to drive. The ability to be fit to drive is a necessary requirement in order to protect the individuals themselves and other traffic participants.

However, as shown above, the demo sites in Turku, Budapest and Rome also include research participants as users of LEV's next to electric vehicles. Whereas the requirement of a driver's license counts for scooters and motorcycles as well, it is not applicable to the use of e-bikes, with a maximum speed of 25 km/h.

In conclusion, intellectually disabled individuals might be involved as research participants in the USER-CHI project.

[51] *European Commission, Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, "European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe", 2010, COM (2010) 636 final, p.6.*

6. Measures of protection / avoidance of stigmatization

This chapter analyzes the measure of protection which should be carried out while involving vulnerable individuals as research participants in USER-CHI.

As analysed in Chapter 5 potential vulnerable research participants in USER-CHI might be children, elderly and intellectually disabled persons.

6.1 Measures of protection for the involvement of children

This chapter analyzes the measures of protection which should be carried out while involving children as research participants in USER-CHI.

„Competence can be defined as the ability to understand relevant information, to evaluate that information and make a reasoned decision, to decide without undue influence, and to communicate consent or refusal."[52]

„Although children are commonly viewed as a vulnerable group in relation to research, the fact that they mature at different rates means that we can- not assume that someone who is legally a minor is necessarily incompetent or vulnerable; thus, even in a jurisdiction in which a minor's consent is not legally recognised or required, there may be a moral requirement to obtain consent from an older child who is capable of understanding the risks and benefits of participation."[53]

The information process might be needed to be adapted in order to make sure, that the involved children understand the scope of the research activities correctly.

[52] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.55.*

[53] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.68.*

This could be achieved through explaining the Information Sheet *(Template I)* orally in easier language and particularly encourage the children to ask questions, which they might have in regard of USER-CHI activities.

However, the competence of the child itself is not enough in order to render the consent valid.

The parents (or other legal guardians) need to be included as well, in order to provide consent on behalf of the child.[54]

6.2 Measures of protection for the involvement of elderly

This chapter analyzes the measure of protection which should be carried out while involving the elderly as research participants in USER-CHI.

The categorization of elderly people as vulnerable groups does not mean that every elderly person automatically lacks competence in order to give valid consent.

Hence, special protection measures in order to achieve valid consent is only needed, if the elderly research participants have a deficient competence.

This might be difficult to determine. Therefore, it is the responsible researcher's duty to apply either a procedure of "improving the quality of consent" or consider "alternatives to the standard consent processes."[55]

Improving the quality of consent in order to gain valid consent:

- Additional help to aid the understanding of the research
- Retention of relevant information [56]

Limitations to this approach:

- *No unnecessary stressful and harmful interactions with the potential research participants*

[54] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.70.*
[55] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.63.*
[56] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.63.*

- *Attention needs to be paid to the adaptation of the process as sensitive issue: Over-simplification may also be taken as "affront to their dignity"*[57]

Another means of providing an additional safeguard for an incompetent subject's welfare is to consider alternatives to the standard consent processes.

Alternatives:

- gaining their assent to requiring the absence of dissent if the subject is capable;
- the use of a proxy to make decisions on their behalf; or
- relying on an advance statement, where one has been prepared."[58]

The most suitable alternative for the involvement in USER-CHI research activities will most likely be the second option, which implies the use of a proxy.

However, it is the project partner's responsibility to choose the protection measures, which most effective for the individual case at hand.

In case any questions arise, researchers can contact IKEM in their role as *Ethics Advisor* in order to clarify which actions are needed.

6.3 Measures of protection for the involvement of intellectually disabled persons

This chapter analyzes the measure of protection which should be carried out while intellectually disabled individuals as research participants in USER-CHI.

The measures of protection for the involvement of intellectually disabled persons are similar to the measures, which are described in regard to the involvement of the elderly.

Again, the special protection measures are needed, if the research participant lacks competence in order to give valid consent. Therefore, responsible researcher needs to either apply a procedure

[57] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.63.*
[58] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.63.*

of "improving the quality of consent" or consider "alternatives to the standard consent processes."[59]

Regarding the implementation of either the *improving of the quality of consent*, or the *alternatives to the standard consent processes*, *see Chapter 6.1*.

In case any questions arise, researchers can contact IKEM in their role as *Ethics Advisor* in order to clarify which actions are needed.

[59] *European Commission, Directorate-General for Research Science, Economy and Society, "European Textbook on Ethics in Research", 2010, p.63.*

7. Conclusions

This report provides an overview of the most relevant ethical guidelines and legislation, which apply to the USER-CHI research activities.

Furthermore, it presents the criteria and procedure, which should be considered during the recruitment of research participants and the collection of their personal data.

The use of the templates for the information sheets and informed consent are essential in order to ensure that the procedures concerning the data collection will be executed in accordance with both the EU and national legislation.

Moreover, the deliverable shows that vulnerable individuals might be involved within USER-CHI as research participants. Therefore, the project partners must give special attention to the outlined protection measures, if vulnerable individuals are involved.

The main dependencies and synergies with other deliverables are:

- D1.1 User requirements for USER-CHI solutions: This report will collect the user requirements analysed through the Big Data analysis and the User-Driven Innovation approach.
- D6.1 Demonstration Concept and Implementation Plan: This deliverable summarizes the demos' approach and focus for USER-CHI demonstrations and will specify the pilot demonstration activities with regard to technical and organizational tasks, in which the ethical requirements and defined procedures must be taken into account.
- D11.3 Data Management Plan: This deliverable includes information required in the guidelines on Data Management in Horizon 2020 and the data management lifecycle for the data to be collected, processed and/or generated by the project.
- D11.4 Protection of Personal Data Report: This deliverable describes the actions conducted to protect the personal data collecting and processing processes, from an ethical point of view. It will also provide templates and documents regarding the use of personal data.
- D12.1H – Requirement No. 1: This deliverable includes confirmation that the opinions by ethics committees or competent authorities have been obtained and are kept on file.

- D12.2 POPD – Requirement No. 2: This deliverable includes a description of the technical and organizational measures that will be implemented to safeguard the rights and freedoms of the data subjects/research participants.

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