

### GDPR Protection of personal data and ethics human requirements compliance

EU project SENSEI hereby acknowledges that ethics and personal data protection is given the highest priority in EU funded research and that activities carried out under Horizon 2020 must comply with ethical principles and relevant national, EU and international legislation, such as the Charter of Fundamental Rights of the European Union and the European Convention on Human Rights and The EU Personal Data Protection Regulation (GDPR).

# The EU Personal Data Protection Regulation (GDPR)

Regulation (EU) 2016/679 sets out the new General Data Protection Regulation (GDPR) framework in the EU, notably concerning the processing of personal data belonging to EU citizens by individuals, companies or public sector/non-government organizations, irrespective of their localization.

The GDPR has replaced the previous Data Protection Directive (95/46/EC) and its national implementations. The GDPR text is available on the Eur-Lex website.

The legislative definition of personal data is quite broad, as it includes any information relating to an individual, whether it relates to his or her private, professional, or public life. It can be anything from a name, a home address, a photo, an email address, bank details, posts on social networking websites, medical information, or a computer's IP address.

### Informed consent procedures

Participants must get information about the research and the participation must be consented. Informed Consent is the decision, which must be written, dated, and signed, to take part in research, taken freely after being duly informed of its nature, significance, implications, and risks. The consent also includes how data is stored and used for future research.

SENSEI will fully inform participants about the project, its evaluation and what is being asked of them. Information to be provided to participants will include:

- Aim of SENSEI: Develop and test pay-for-performance (P4P) schemes What data will be collected: Your name, your title, your email, and company name
- How data will be stored, analyzed, and destroyed: Data will be stored in a excel-file and kept by the WP leader in Communication and Dissemination. Data will be collected for supporting actions. Data will be destroyed by the end of the project, 30 September 2022.
- Confirmation of the right for participants to request that their data is deleted: Participants can anytime ask for deletion of their data, by sending an email to info@senseih2020.eu. Deletion will be done promptly.
- Possible risks to project partners, participants in engagement activities or any third parties: Partners in SENSEI will un request get access to the data and will be informed not to keep the data.





Data will only be kept one place.

- Confirmation of the right to step back from participation without any consequences at any time of the study: SENSEI will inform participants upfront that they can redraw their consent at any time without any consequences.
- Access to the analysis of the data collected and any resulting recommendations: SENSEI will give participants access to all analysis of data at the stakeholder platform EngageSuite protected by login. The purpose of the informed consent is to verify that participants: understand that taking part is voluntary and they are free to withdraw
- fully have understood the information about the research have been given the possibility to ask questions about the study to researchers
- recognize that the data they provide with will be de-identified agree that the research team have the right to access the data recognize that the data will be stored for use in another future research

#### TEMPLATE OF THE INFORMED CONSENT

You have been invited to take part in HORIZON 2020 project SENSEI. Before deciding on whether you want to participate or not, please read these lines carefully. Please direct any questions you may have to the following email address: info@senseih2020.eu.

The Horizon 2020 guidelines on research ethics define ethical standards for research carried out in Horizon 2020 projects. These include standards on privacy and data management. In compliance with these standards, we are happy to:

- provide the necessary information on the project
- provide information on the necessary informed consent

### Information on the project

The objective of the SENSEI project is to develop and test pay-for-performance (P4P) schemes. Data acquisition in the project may consist of surveys, questionnaires, interviews and focus groups.

### **Data protection**

Responses you give in SENSEI's surveys will be recorded and stored on secure servers. Your recorded data will not include any personal identification; hence it will not be possible to identify you as the source of information. Data will be processed for scientific purposes during the phase of data analysis. Data will be shown in project reports, scientific journal publications, conference presentations or other project-related outputs in anonymized form only. Results may be used in further studies. Nothing of the provided personal data will be handed out to third parties.

#### Risks or inconveniences

No risk is foreseen. You are only requested to be available to participate.





### Informed consent

Your participation in this study is voluntary. You can choose not to participate or to leave the survey at any point. However, once you submit your completed survey, there will be no way to withdraw your responses from the study because the survey contains no identifying information.

By participating in SENSEI, you confirm that:

- you are 18 years or older and competent to provide consent.
- you have read the above information about this research and this informed consent procedure. you have been fully informed about the aims and purposes of the SENSEI Project www.senseih2020.eu.
- you give your consent for project SENSEI to send you Newsletters during the duration of the project.
- you give your consent to receive invitations to partake in workshops, events and other initiatives set up in project SENSEI.
- you give consent for project SENSEI to sign you up to EngageSuite which is a login protected extranet with supporting material.
- you give your consent for project SENSEI to send you direct mail in case of specific feedback on content related to project SENSEI.
- you have been given the opportunity to ask questions regarding the purpose of the study.
- you understand that your participation is fully anonymous and that no personal details about you will be recorded.
- you agree that your data collected in e.g. a survey is used for scientific purposes and that you have no objection that your data is published in project-related publications in a way that does not reveal your identity;
- Information may be shared between any of the other researcher(s) and partners participating in this project in an anonymous form. All information you give will be treated as confidential.

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 EU General Data Protection Regulation (2016/679) on the protection of natural persons with regard to the processing of personal data and on the free movement of such data.

### Applicable ethics human requirements compliance

## **Ethics principles**

In the conduct of the study, SENSEI will observe the following principles of responsibility toward research participants:

- respecting the integrity and dignity of persons
- voluntary nature of participation provision of information on the context of the study
- provision of a project information sheet





- the right to withdraw from the study
- anonymity respecting the principle of proportionality not to impose more than necessary on the participants, as well as not going beyond stated objectives
- considering the concerns research raises and building an understanding that all benefits of this research are for the good of society
- protection from harm and discomfort

SENSEI's research will be performed on qualitative and quantitative data generated during the case development process. In addition, we will analyse data collected in a broader context by using data from questionnaires. Key ethical issues concerning the planned research activities are recruitment of participants, information to participants and informed consent during the planned research activities.

## Procedures to identify / recruit research participants

Recruitment of research participants involves presenting potential participants with information about the study in order to make them interested and willing to serve as research subjects. No children or adults not able to give an informed consent will take part. It is important that the information is presented in an accurate and understandable way and that ethical issues in the recruitment process is taken into consideration. Participation in research must be voluntary. To assure that participation is voluntarily, the investigation will be introduced in a way that allows participants adequate time to ask questions and to freely consider whether they wish to take part.

The recruitment of participants will involve the following steps:

- In the case studies, researchers will meet potential participants in groups in order to recruit and inform them of the research, e.g. at the introduction of a course.
- The participants will be provided with adequate information in their native language about the study. Researchers contact details will be provided, for participants to contact the researchers for information and decide whether they wish to join in.
- When making surveys, participants will be given the necessary information in a foreword to the questionnaire.
- Participants in the case studies will be asked to sign the informed consent form. In surveys, participants will give their consent by ticking a box.
- The researcher who is responsible for the investigation is also responsible for storing the signed forms for future reference.
- Participants can withdraw from the study at any point; it will be made clear that participation is voluntary.