

# Deliverable 7.3 Ethics requirements and forms

Lead: IHE

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# **Project Deliverable**

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Authors (organisations)

Angeles Mendoza-Sammet (IHE)

**Reviewers (organisations)** 

Lydia Vamvakeridou-Lydoudia (KWR) Lorena González Duarte (IHE)





#### Abstract

Deliverable 7.3 "Ethics requirements and forms" is a public report, developed within WP7 - Project Management.

This document presents the NEXOGENESIS ethics plan, which specifies the responsibility of project partners to ensure that researchers are aware of the ethical implications of research involving human subjects. The Ethics plan also indicates that researchers should be familiar with the guidelines and standards for research integrity and research involving human subjects to conduct research activities according to the ethical standards set by the European Union. The ethics plan also provides a review of ethical concerns of conducting research during the COVID-19 pandemic. The second part of this document includes specific guidance to create consent forms for face-to-face and online activities aimed to obtain information for the project, including information for research participants on the risks associated to COVID-19.

<u>Related Deliverables</u>: D7.2 Ethics requirements and forms (M6); D4.6 Data Management Plan (M3) for stakeholder data management procedures.

#### Keywords

Quality Assurance; ethical considerations; ethical forms



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# 1. Introduction

# 1.1 Purpose of this document

This report has been developed within Task" 7.3 in WP7 (Project Management) in NEXOGENESIS. It complements Deliverable 7.2 Scientific quality assurance plan and ethical considerations" (D 7.2), and serves two purposes:

To present the ethics plan indicating how the activities involving humans will be conducted in a way that protects the rights and freedoms of subjects participating in workshops or interviews aimed to collect personal data and other information from stakeholders for the project.

To specify the information to be included in the forms and communications with participants to comply with the ethical standards set by the European Union and ensure they are informed, among other, of their rights and freedoms and research-associated risks.

To specify considerations related to the COVID -19 pandemic, for the organization of activities where there will be gathering of people for data gathering or communication of results.

#### 1.1.1 Definitions

In this document, the definitions in the 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, EU General Data Protection Regulation (EU GDPR hereafter, EP 2016) are used, for example these:

Personal data is any information that directly or indirectly could be used to identify a natural person involved in the research, including "…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;" (EP 2016: Art. 4[1]).

Processing refers to all the operations done with personal data: "... 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, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction;" (EP 2016: Art. 4[2]).

## 1.2 Structure

The document is structured as follows:





- Section 2 specifies the ethics plan according to the ethical considerations specified in section 3 of D 7.2. and EU Guidance.
- Section 3 presents the elements and information to be included in printed or online forms that will be used for inviting stakeholders to participate in the research, for obtain their consent, and for gathering data or information from participants in a way that protects their rights and freedoms and informs them about the research and researchassociated risks, including information regarding COVID-19.

# 2. Ethics plan

# 2.1 Scope of the ethics plan

As specified section 3 of D7.2, NEXOGENESIS activities involve human participants as informants who provide information about the case studies. There is no involvement of children or persons who cannot give consent. The same section provides the guidelines for the identification and recruitment of participants, obtaining their consent, and managing related ethical risks. Section 3.2 of the same deliverable specified the measures for protection of personal data.

"The research will not involve children (or other persons unable to give consent) or human experimentation. Participation will not entail any psychological, social, legal or any other type of harm. All sampling methods and recruitment processes will be fully transparent, non-discriminatory and ethically sound." D7.2 sec. 3.2

Building on that, this ethics plan specifies the process to follow when creating or modifying the forms that will be used when engaging stakeholders, knowledge requirements for researchers (including research assistants), and quality assurance for ensuring compliance with the European standards such as the European Code of Conduct for Research Integrity (All European Academies [ALLEA] 2017) and the EU GDPR (EP 2016).

# 2.2 Creation and updating of Forms

Following the guidance in this document, each project partner is responsible for creating the forms that will be required for its specific activities that involve humans and processing of personal data. The Ethics Officer will review that the forms include the information necessary.

- 1. The forms will have to include, as applicable, the information specified in section 3 of this plan.
- 2. Before a form will be used, the draft version should be submitted to the project's Ethics Officer for verification that all the elements necessary for free, prior, specific, unambiguous and informed consent are included and that participants are aware of any potential risk, including those related to COVID-19.
- 3. Within one week, the Ethics Officer will indicate if changes are required. The final version should be submitted to the Ethics Officer for record keeping.
- 4. To support equity, transparency and diversity, the forms should be translated to the local language. If an informant belongs to an ethnic minority and is not fluent in the







local language in which the forms have been translated, a person that he/she trust could act as a translator to understand the information in the consent form and consent to all the points included in it.

If during the use of the forms it is deemed necessary to modify the text in the forms, an updated version should be sent to the Ethics Officer for verification.

# 2.3 Review for receiving ethics clearance for research

Applications for ethic clearance should be submitted to NEXOGENESIS Ethics officer for approval. The Ethics officer will provide the corresponding form by request from the partner's researcher who is leading the activity. If the partner has obtained ethic clearance from the ethics committee in its home institutions, or from an organization in the country where the research takes place, copy of the proof of ethical clearance should be send to the NEXOGENESIS Ethics Officer for archival.

If the partner does not have a research ethics committee, then the researcher responsible for the activity will submit the application to IHE's research ethics committee and contact the Ethics Officer to get the application form and guidance to fill it in.

### 2.4 Consent

Section 3.1 of D 7.2 indicates that informants will give written consent. However, if new waves of COVID-19 emerge and activities are moved online because of measures to control the pandemic, the researchers should distribute consent forms with sufficient time, depending on local conditions, for informants to send the signed consent forms back to researchers before the activity starts.

If there is a situation in which getting written consent is not feasible but oral consent is feasible, participants still should be given the same information and record should be made on how and when consent was given. A script should be prepared for that and it should be reviewed by the Ethics Officer. Participants should receive a copy of the consent form (or script for oral consent) and information sheets. The way in which consent is obtained should be appropriate to the culture and context of participants.

Section 3.1 of D 7.2 indicates that participants will not be video-recorded nor audio recordings will be made of their interventions. If at any moment is considered necessary to take pictures, consent from participants must be obtained using the guidance included in section 3.

In research, consent forms need to comply with the EU GDPR (EP 2016), including the need to give specific consent and to minimize the processing (and collection) of personal data, according to Arts. 4 [11], 5[c] and 7. This implies the following:





- Consent should be given by a statement or 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.
- Participants should have the freedom to consent to specific parts or activities of the project or purposes. Either in print form, in digital formats (e.g. internet surveys) or verbally, research subject should agree to each different purpose for which data will be used.
- The principle of data minimization, which specifies that only data that is necessary for the purposes of the research should be processed.

Lobe et al. (2020) indicate that for online activities consent it must be clear for participants to what do they consent and how they can exercise their rights. Therefore, section 3 indicates what information should be communicated to participants before they answer surveys.

# 2.5 Storage of forms, quality assurance and ethical issues

In the same way that each partner is responsible for processing data, each partner is responsible for processing any materials (printed on in digital format) in which participants consent to be involved in the research.

If for quality assurance is considered important to verify that consent has been given, the documents should be available for the Ethics Officer to review.

Documents should also be available for the Ethics Officer if participants raise ethical concerns about their participation and/or the use of their personal data.

# 2.6 Measures for COVID-19

Although at the time this document is written new cases of COVID 19 are reported in most European countries by the European Centre for Disease Prevention and Control (ECDPC 2022), new variants have emerged and the risk of exposure continues. One of the aspects of ethics in research is to ensure the safety and well-being of people participating in research informants and volunteers (EUREC 2020).

The European Code of Conduct for Research Integrity (ALLEA 2017) specifies the responsibilities of researchers to safeguard the health, safety and wellbeing of any person involved in the research, such as research subjects (informants), volunteers and collaborators for NEXOGENESIS.

The pandemic does not change the process to obtain the free, specific and informed consent of research participants (op. cit.). It brings an additional requirement with respect to the





responsibility to inform participants of the risks associated to the research activity (Newman et al. 2021).

In this case, for workshops, information sessions, project meetings and other activities that involve the gather of people gatherings the ethical implications for NEXOGENESIS in relation to COVID-19 are to increase the risk of exposure, infection and transmission of the virus because of participation in workshops where people will gather or by transmission from one person to another during an interview. The risk will vary depending how the waves of the pandemic develop (Newman et al. 2021). It also should be noted that the researcher also may at risk of exposure to COVID by being in proximity to an informant that unknowingly may transmit the virus.

The planning of activities should be adaptive because it will take place weeks or months in advance. Therefore, feasible alternatives should be considered during the planning in case new waves modify the level of risks and the implementation or modification of control measures. The Project Coordinator and leads of the Work Packages involved should analyse the alternatives as information becomes available:

- Alternative locations (also depending of country requirements for internal and international travel),
- Alternative dates,
- Alternative modes of interacting with participants: gathering in smaller groups, using social media or online interviews or other means to gather data, or
- Other.

If information is not available online, local health authorities must be contacted to get information about procedures in case a participant gets sick and tested positive for COVID within a time that reasonably could be related to the activity. Under the advice of health authorities, if needed, all possible efforts should be made to inform other participants that could be considered to have been in close contact, of the measures that should be taken, depending on local or national requirements.

Researchers must follow all the measures that health authorities prescribe to prevent the spread of COVID in the country and location where project activities will take place. Any person involved in the research should follow the recommendations form health authorities when the person experiences any symptoms or signs that may suggest an infection with COVID-19 -or other transmissible respiratory disease such as the flu or a cold) and not to participate in face-to-face activities.

To protect the health of people involved in project activities, all communications for people attending the activity must include information about the measures that public health authorities have in effect and how they will be strictly followed, for example these:

- Physical distancing for sitting arrangements (e.g. 1.5 or 2.0 meters),
- Vaccination requirements for gatherings,
- · Curfew and scheduling of the activity,
- Restrictions on number of people attending gatherings,
- Hygiene and safety measures (e.g. have available hand sanitizer),





#### Use of face masks:

- If the use of face masks is obligatory in the country or locality, when available protective FFP2 masks should be used. Otherwise non-surgical medical masks should be preferable or other masks designed for the pandemic and that cover nose and mouth.
- If the use of face mask is not required, still their use should be encouraged for all researchers and for participants.

Previous to the organization of any workshop or other activity in which there will be gathering of people, including gatherings in which several partners will meet, the Leader of WP7 and leaders of other WPs will be responsible for reviewing the latest information about new cases of COVID and the spread of its variants in the place where the activity is planned. For that, information may be obtained from official sites such as the country statistics published by the European Commission on the website of the European Centre for Disease Prevention and Control. (ECDPC 2022), at the *ECML Covid* portal (EC 2022), which reports daily cases and the measures in effect per country, for example, for international travel.

# 2.7 Ethics training for researchers and research assistants

Each partner is responsible for ensuring that all persons involved in the project, especially researchers and research assistants involved in activities that involve human subjects and/or processing of personal data, have received ethics training. Researchers affiliated to an academic or research institution in which training in research ethics is available should take it before engaging in research activities. If it is not available, lead researchers and/or Work Package leaders should contact the Ethics Officer to access training available at IHE.

Lead researches should be familiar with the content of the following guidance documents:

- NEXOGENESIS' Privacy Policy (for processing of personal data and recruitment and engagement of participants).
- The European Code of Conduct for Research Integrity (ALLEA 2017) and codes for research integrity in the country where research activities will take place.
- EU Guidance on Ethics in Social Science and Humanities (EC 2021).

Based on those documents, ethics training should cover, as minimum, these points:

- Research integrity
- Ethical consideration of research,
- Ethical considerations for internet-based research (online research)
- Informed consent,
- Protection and processing of personal data
- Misuse of research and/or its results
- Research misconduct





#### Deliverable 7.2

If research is going to be conducted in a country that is considered as low or middle-income, Work Package leaders and lead researchers should also adhere to the Global Code of Conduct for Research in Resource-Poor Settings (Trust Project 2018) and conduct research according to the standards set for research in high-income countries.



# 2. Templates

# 2.1 Guide for writing a consent form

IHE Delft has produced a template for a consent form that can be used for project partners and adapted as needed. The guidance has also been reviewed by IHE's Data Protection Officer and the Research Ethics Coordinator (who is also NEXOGENESIS Ethics Officer). The text included bellow, modified for NEXOGENESIS, still will need to be adapted for the specific purpose (e.g. interviews or participation in workshops). The text in blue font should be included in the corresponding form. It can be adapted to the local language but its meaning should not change.

# 2.1.1 Guide for preparing a consent form for research involving human subjects

For questions about using this guide, contact NEXOGENESIS Ethics Officer (Dr. Angeles Mendoza Sammet) at a.mendoza@un-ihe.org.

Each project partner is responsible for creating the information sheets and consent forms needed for the activities it is carrying out (e.g. workshops and interviews). Consent form people involved in the research must be explicit for the specific research project or activity. A consent form should have three distinguishable sections. Headings have to be used to distinguish them. The consent form, including the debrief (information sheet), should no more than 2 pages long, so it is important to write concisely and using clear and plain language

Sections 1 and 2 constitute the debriefing protocol. Printed versions should be given to participants. Only if consent is obtained orally, the guide can be used to write the script that will be read to participants for obtaining their consent.

Section 3 is the consent part in which participants indicate their consent to different purposes and sign. This section could be included in the same document that contains the previous two sections or can be a separate form in which participants give their consent.

If a participant does not read and/or write), she/he can give oral consent after having been explained all the points and having understood them. In that case, the researcher needs to document the details of how the consent was given, e.g. by who, how, where, and when.

The following guidance applies to different purposes. Remove all elements that do not apply to the specific need. For written consent, include the text that is in blue font.

#### Section 1: information about the researcher and research project

In this section introduce the researcher and the research. The information should be succinct and the points should be described in a few lines.





The use of logos in consent forms for printed, digital or verbal material (scripts for oral consent) must be used in accordance with agreements set for the consortium and be authorized by the Leader of the corresponding Work Package, notifying the project leader.

- Include a header: Consent Form for" and a title clearly related to the activity
- Introduce researcher's name and affiliation. If applicable, add the URL for the organization or project's website.
- Inform about the NEXOGENESIS project (include website address) and its context, sponsor.
- Indicate the purpose of the activity and how it helps achieve the NEXOGENESIS purpose.

#### Section 2: the research process and participation of individuals

Explain how the informants are expected to participate in the corresponding activity, what measures are taken for protection of personal data, and communicate the rights of informants. Try to write only 1 clear sentence per applicable point and cover all the points in one or two paragraphs (Based on EC 2021):

- Describe research process or intervention: what will be done and what will subjects have to do, e. g participation in a focus group or interview, answer a questionnaire, or discuss how practices or activities.
- Explain participation in the study. Tell how participants are selected or recruited, for example, the person has specific knowledge that will help NEXOGENESIS fulfil its purpose, or person belongs to a stakeholder group that is going to benefit from the project, etc.
- Explain if there are any incentives (material or non-material) and/or costs (e.g. to attend workshops) and reimbursements for participating and what they are.
- Tell how much time and effort is needed for the participation (e.g. the interview will last X minutes, or it will take around X minutes to answer this survey).
- Inform participants about the purpose of each activity involving processing personal data and for which consent is sought.
- Clarify if there is need for confidentiality of the information provided for the research.
- If any personal data is going to be collected, see Annex 2 Requirements on the EU GDPR to obtain valid consent for processing of personal data. Ask agreement for each specific item using check boxes (no pre-ticked check boxes).
- Explain how the Inform participants what (type of) personal data will be collected and used how it will be processed (from collection to storage and/or disposal), including how it will be kept secure and confidential.
  - o for how long personal data will be stored and
  - how it will be destroyed (if that is the case).
- Inform participants about their rights before to obtain consent:
  - participation is voluntary (without coercion);
  - a participant has the right to withdraw his/her consent at any time without any
    repercussion (and how; e.g. If you want to end the interview at any moment, tell
    me and I will stop immediately). Explain situations in which the researchers would
    stop or interrupt the participation;
  - participants have the right to withdraw and can request to have their data erased, including information that they have provided. (see annex 1).
- Explain if there are any risks and/or benefits that the research may have for participants (include the text for COVID-19).
- Explain how will results be disseminated, or made public, and how participants can access them.

#### Section 3: Consent and additional information





Include the different items to which participants need to give their consent. It is easier to make it in the form of a check list that has the items that apply to the specific research. Agreement of subject to participate. Include a check list with all the elements participants have to consent to. These are only examples. The same item could be written in different ways if that does not modify the meaning. It must be clear to what right or element for consent each item applies to.

According to the General Data Protection Regulation of the European Union, I/we kindly ask for your consent to use of your personal information by ticking yes or no to each one of these uses of personal data:

| I agree to being photographed                                  | ☐ Yes ☐ No |
|--|------------|
|  |            |
| I agree pictures in which I appear are used in the publication | ☐ Yes ☐ No |
| related the research   |            |
| I agree to have my name disclosed in the research,             | □ Yes □ No |
| I agree to have the name of the organization for which I work  | □ Yes □ No |
| disclosed in the research,                                     |            |
|  | □ Yes □ No |
| of the experts that contributed to this research               |            |

NOTE that the items listed above must be adapted to the specific need.

- Include fields for the participant to give written consent: name, signature and date.
- Include fields for the researcher's name, signature, and date.
- Include information of who else to contact for questions about the research, data protection, or their rights as research participants:

If you have any questions about how personal data is processed (collected, used, stored, discarded), you can contact NEXOGENESIS Data Protection Officer, Xavier Domingo, at <a href="mailto:xavier.domingo@eurecat.org">xavier.domingo@eurecat.org</a>. If you have any concerns or questions about your rights as participant in this research activity, you can contact NEXOGENESIS Ethics Officer, Angeles Mendoza Sammet at: a.mendoza@un-ihe.org.

### 2.1.2 Statement of risk related to COVID-19

Participation of research subjects in NEXOGENESIS is expected to not result in any psychological, social, legal or other type of harm. However, as long as there are concerns from public health authorities at European and/or local level, about the COVID-19 pandemic, consent forms and information for face-to face activities (e.g. interviews, workshops, or other events) must include statements about the risk of infection. This is a suggested text (based on American Psychological Association 2020):

The participation in this [specify the activity, e.g. interview, workshop, or event] may pose risk of exposure to the COVID-19 virus, for example by being in proximity to a person who is participating in the same activity and who may be an asymptomatic carrier of the virus, and by using public transport to attend the activity. However, for the organization of this activity, the following measures indicated by health authorities to control the spread of the virus have been considered to minimize the risk:



[include description of the measures observed when organizing the activity, for example limits to the number of participants, arrangement of chairs and other furniture to observe physical, etc.; see section 2.6].

We encourage the use of face mask even if it is not required. We ask for your cooperation observing these measures to minimize the risk of exposure for you and other people. Please abstain from attending the activity if you do not feel well and/or have any symptoms that could indicate that you may be infected with the virus.

[For interviews] Feel free to indicate if you prefer to participate in the interview in a virtual modality and we will make the necessary arrangements.

Please be aware that if it is known by the organizer of this activity that any person that participated had tested positive with a timeframe that could be related to the date in which the activity took place, the advice of local health authorities will be sought about the need to inform other participants of a potential close contact with a person that tested positive for the virus, without disclosing any information that could identify the individual or other participants.

### 2.1.3 Consent for online surveys

When informants will answer a survey, for example NEXOGENESIS – Questionnaire Stakeholder Engagement Evaluation, the first page a respondent access must be the equivalent of the information and the consent form. Therefore, it must include concise statements specifying the points indicated for consent.

1) The purpose of NEXOGENESIS and how the survey supports it.

NEXOGENESIS intends to pursue its goals through a participatory, multi-actor approach. Stakeholders are identified through consortium members and other stakeholders. The following survey is part of the stakeholder\* engagement evaluation for the project. It will be answered by representatives from the project team and stakeholders. The evaluation will help elicit priorities, expectations, and experiences for and with the stakeholder engagement process\*\*. Responses will be collected regularly throughout the duration of the project. Throughout the project, the evaluating team will analyse the information gathered and recommend adjustments to the process, if necessary. There are no right or wrong answers.

- \* 'Stakeholder' means a person or institution with an interest in and that affects or is affected by the governance of a river basin. In the survey, you will also read 'most influential stakeholders'/least influential stakeholders', which refers to stakeholders that have significant/very little control over how resources in the river basin are governed, distributed, and used. Whether you consider yourself or someone else to be (not) influential is for the purposes of this questionnaire up to your own judgement.
- \*\* 'Process' or 'stakeholder engagement process' here refer to the activities (e.g. drafting policy packages, developing a conceptual model for the river basin) and interactions (e.g. quality or form of discussions) during the workshops as well as interactions you may have with other stakeholders and the NEXOGENESIS project team between the workshops.





Even if it is expected that survey respondents should be stakeholders that have agreed to be included in the stakeholder registry and the processing of specific personal data A message should indicate the following:

All stakeholders are asked to consent to be included in the registry and to have the personal information they provide in the storage and use of their personal data through this present form. Before filling in this survey, please review NEXOGENESIS Privacy Policy. If you have not given your consent to be included in the stakeholder register, please do so before answering the survey. No additional personal information will be collected in this survey.

There are [X] questions and it will take approximately [X] minutes to complete it. Answering this survey will be taken as your consent to use the information you provide for this project.

If you have any questions about this survey, please contact [name of researcher] at [e-mail address]. In addition, if you have any questions about how personal data is processed (collected, used, stored, discarded), you can contact NEXOGENESIS Data Protection Officer, Xavier Domingo, at <a href="mailto:xavier.domingo@eurecat.org">xavier.domingo@eurecat.org</a>. If you have any concerns or questions about your rights as participant in this research activity, you can contact NEXOGENESIS Ethics Officer, Angeles Mendoza Sammet at: <a href="mailto:a.mendoza@un-ihe.org">a.mendoza@un-ihe.org</a>

The GDPR specifies that only the data that is necessary for the specific objectives of the research should be collected. Therefore, research participants should not be asked to consent to aspects that are not essential for the research. Also, there is no need to ask consent twice for the same purpose if for the same activity there is overlap between the requirements to obtain consent for processing of personal data under the GDPR and the requirements to obtain consent the rights of participants and obtaining their consent to participate in research. If any other personal data is going to be processed, besides to what was included in the register, based on the principle of data minimization (Article 5 [c], EU GDPR), only information that is necessary to achieve the objectives of the project should be processed, previous consent from respondents. In that case, survey respondents must be informed of the purposes for processing the data requested. Optional information should not be collected.

The survey should include links that respondents could use to review information on the project, the privacy policy, and the consent form in case they have not signed it. Links to other information that would be useful can be included.



### 2.2 Consent forms

# 2.2.1 Consent form for Interviews – H2020 EU project NEXOGENESIS

Before being presented with the consent form, research subjects should be provided with the information indicated in section 2.1.1. This text is an example for the consent form to be used for interviews conducted by researchers from the University of Tours. The text should be adapted for the specific case.

You have been contacted to participate in an interview within the framework of the H2020 EU project NEXOGENESIS that is being implemented by University of Tours, KWR Water Research institute, BEF Latvia in Latvia and Lithuania.

To establish an agreement on how the data collected will be dealt with in the project, and in accordance with the EU General Data Protection Regulation\*, we ask you to carefully read the following sentences and to tick the box for each item you agree with.

Once again, thank you very much for participating!

| I confirm that I have received, and understood, oral information about the project and the objectives of this interview and have had the opportunity to ask questions.   | □Yes □ No |
|--|-----------|
| I was informed about any risk and benefits related to my participation in this activity  | □Yes □ No |
| I agree with, and understand, that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without any negative consequences. In addition, should I not wish to answer any question or questions, I am free to decline.                             | □Yes □ No |
| I agree with my name or the name of the company I represent not being linked with the record of the interview or any written documentation or valuation in the context of the interview, and that I will not be identified or identifiable in the report or reports that result from the research. | □Yes □ No |
| I agree with having this interview to be recorded to be used only for analysis by NEXOGENESIS. I understand that no other use will be made of the recording without my written permission, and that no one outside the research team will be allowed access to the original recording.             | □Yes □ No |
| I agree with the use of written extracts from my interview for conference presentations, reports or journal articles developed because of the research   | □Yes □ No |
| I agree that my data (audio recordings, written extracts) will be kept for future research purposes, which could lead to such as publications related to this study after the completion of the study.   | □Yes □ No |
| I agree that the audio recordings of the interview will only be kept for 5 years after the project finalization.   | □Yes □ No |
| I agree to take part in this interview.  | □Yes □ No |





If you have any questions about how personal data is processed (collected, used, stored, discarded), you can contact NEXOGENESIS Data Protection Officer, Xavier Domingo (xavier.domingo@eurecat.org). If you have any concerns or questions about your rights as participant in this research activity, you can contact NEXOGENESIS Ethics Officer, Angeles Mendoza Sammet (a.mendoza@un-ihe.org).

| Name of participant | Date     | Signature     |  |
|---------------------|----------|---------------|--|
| Name of researcher  | <br>Date | <br>Signature |  |

**Copies**: Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, and the information sheet. A copy of the signed and dated consent form should be placed in the main project file which must be kept in a secure location.

# 2.2.2 Consent form - Placement in the NEXOGENESIS Stakeholder Register

1. The purpose of NEXOGENESIS and the registry.

NEXOGENESIS pursues two societal goals: 1) develop locally adapted river contracts that satisfy the needs of stakeholders, and 2) inform and influence local, national or supranational policies in relation to sustainable resource management. NEXOGENESIS also pursues the scientific goal of enhancing the academic knowledge on the Water-Energy-Food Nexus.

NEXOGENESIS intends to pursue its goals through a participatory, multi-actor approach. Stakeholders are identified through consortium members and other stakeholders.

Being placed in the NEXOGENESIS stakeholder register allows the research consortium to tailor their interaction to the stakeholders needs and interests. Stakeholder engagement to understand their needs and interest is critical for the success of the project, but we understand that participation in a research project may not be the interest of each one of the stakeholders. We have created a stakeholder registry to know which stakeholders are interested in participating, and what they expect form NEXOGENESIS. This registry will help us target communications about activities and results of the project according to what each stakeholder has expressed be interested in.

The registry is used for these purposes:

- a. communicating and disseminating information in relation to the NEXOGENESIS project,
- b. processing of your requests,





<sup>\*</sup>To review the General Data Protection Regulation, please consult this link: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679.

- c. inviting to partake in NEXOGENESIS engagement workshops, consultation workshops related to NEXOGENESIS solutions, events relating to outreach and advocacy that highlight the policy importance of NEXOGENESIS outputs and outcomes, and other similar events that foster NEXOGENESIS societal goals,
- d. the invitation to provide comments and or feedback on NEXOGENESIS scientific outputs such as publications, technical briefs and assessments, conferences and other similar activities that foster NEXOGENESIS academic goals,

This will help reduce stakeholder fatigue and provide us with a means to keep interested stakeholders informed, interacting or being more involved in specific activities.

If any personal information will be collected, it must be only what is strictly needed. Survey respondents must be informed of the purposes for each personal data processing operations for which consent is sought, and agree to each different purpose. Indicate that individuals have the <u>right to withdraw</u> their consent at any time and provide an easily accessible way for that, for example by communicating that in person to the researcher or by sending a message to the lead researcher that will process the data, indicating that the individual wishes to withdraw from the research. Provide the name the person and the corresponding e-mail address. Note that this is different from the right to not answer questions they are not comfortable answering.

Through this form, we ask each individual that participates on his/her behalf or as representative of a stakeholder group, to consent to be included in the registry. For that, we ask that you indicate which information you agree to be processed (which includes from collection, to storage and disposal).

Before giving your consent, please review NEXOGENESIS Privacy Policy [include link or attach the document] to know how your personal data will be used and protected, in compliance with EU Data Protection Regulation, 2016.

Please provide your consent to being placed in the stakeholder register.

| I agree to be included in NEXOGENESIS stakeholder registry and to have in it my name, my e-mail and the name the company or organization I represent.   | □Yes □ No |
|---|-----------|
| I understand that my participation is voluntary and there is no remuneration.   | □Yes □ No |
| I understand that I am free to withdraw my consent at any time without need to give any explanation and without any negative consequences. In that case, I can request to have all my personal data erased or destroyed from the registry and other storage media, together with any other information I have provided. | □Yes □ No |
| I agree to have my gender recorder for the purpose of reporting gender equality in NEXOGENESIS activities.  | □Yes □ No |
| I agree with, and understand, that my personal data and responses will be kept strictly confidential and  | □Yes □ No |
| agree to have it stored until the end of the project  | □Yes □ No |





| agree to have it store other purposes without   | ed for an indefinite time, but not to be used for out my consent  | □Yes □ No   |
|---|---|-------------|
| I would like to sign up for th  | ne NEXOGENESIS newsletter   | □Yes □ No   |
| Frist Name  | Last Name   |             |
| Signature   | Date  |             |
| Other information for the refiling in) Organization E-mail Gender □ Female □ Male □ Other/wish not to state | egistry (you can leave empty any field you are not  | comfortable |
| category  ☐ Tier 1 (direct engagement)  | and classification: select your most pertinent on project implementation and/or outcomes) results and products for application) on project) | stakeholder |
| Please provide a brief state  | ement about your expectations from NEXOGENSIS   | ı           |
| Please rate your INTEREST in NEXOGENESIS (your amount of (desired) involvement in the project)              |   |             |

# 2.2.3 Attendance lists for workshops and other faceto face activities

Please rate your POWER in NEXOGENESIS (your ability to change or stop the project)

Attendance list for face to face activities should include the information of the consortium and clearly identify the specific event. The information about the workshop and consent form should follow what is specified in section 2.4.

Participants should have signed a consent form to participate in workshops will usually be those that have been included in the stakeholder register. Following the principle of data minimization, attendance list should not require persons to sign. If it is needed to verify the identity of the attendant, an alternative can be to have the person at the registry ask the participant to only show an Identification Document (ID) to verify the name without making a copy of the ID





A potential participant that is not in the register should freely choose to be included in the register or just participate in the corresponding activity after signing the consent form.

For general dissemination activities, a list for participants to include name and e-mail if they wish to be contacted later should be prepared. However, it should not be required to register or sign. The same will apply if face to face activities have to be moved to an online format.



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# 5. Annexes

### **Annex 1 Rights of participants**

The rights of research participants aim to prevent harm, protect the integrity of the person, his/her personal data, respect personal and family live and give free and informed consent (EC 2013).

The guidelines for research in social sciences and humanities (European Commission 2021, European Data Protection Board. 2020) indicate the rights of participants:

- Have enough time to freely decide to participate in the research
- Withdraw from the study at any time, or not to answer one or more of the questions, without repercussions.
- · Be informed about
  - The nature of the study and benefits for society or scientific relevance.
  - What the participation entail.
  - Any physical or non-physical risks or harm that could results directly or indirectly from their involvement in the research.
  - Direct or indirect benefits they may get form participating.
  - Any costs for them for participating in the research and any compensation for that
  - The information that will be collected,
  - How their personal data will be processed,
  - o How the information they provide will be used and any matters of confidentiality
  - When, how and where the results of the research will be available.
- Ask any questions they may have and receive information for who to contact for questions or concerns related to the research or how it was carried out.
- Receive a copy of the consent documents they sign

## **Annex 2 Protection of personal data**

Personal data is any information that can be used to identify -directly or indirectly- an individual (natural Person). This include, for example name, age, date of birth, place of residence, gender, identification numbers, place of origin, education level. ethic origin, affiliation, photographs, of other factors related to genetic, mental, cultural, social or physical identity (Article 4, EP 2016). The GDPR prohibits the collection of special categories of personal data, for example data about health or specific beliefs or opinions (Article 9, EP 2016).

Please note that consent must be freely given, specific, informed and unambiguous. Below is a summary of the GDPR requirements to obtain valid consent.

- Specify researcher and her/his partner organization,
- Ask for consent <u>prior</u> to the intended processing of personal data.
- Describe the <u>purpose</u> of each of the data processing activities for which consent is sought in a specific and explicit manner. Describe other relevant information needed





for individuals to make an informed decision and not to be surprised by the processing of their personal data.

- In case of different purposes, please require consent for each purpose. For instance, providing a different tick box for each purpose.
- Indicate <u>what type of data</u> will be collected or used and if the data will be shared with third parties.
- Specify for how long the data will be stored (e.g. only during the time the research or other activity is ongoing, for a specific no. of time (months, years) after the completion of the activity, for indefinite time).
- Indicate that individuals have the <u>right to withdraw</u> their consent at any time and provide
  an easily accessible way for that, for example by sending a message to the lead
  researcher that will process the data indicating that the individual wishes to withdraw
  from the research. Provide the name the person and the corresponding e-mail address.
  Note that this is different from the right to not answer questions they are not comfortable
  answering.
- Giving a real choice and control to individuals to decide, reassuring that there are no negative consequences in case of refusal.
- If the individual's consent is given in 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.
- Indicate the possible risks of data transfers due to absence of an adequacy decision and of appropriate safeguards as described in Article 46 EP 2016.

Refer research subjects to NEXOGENESIS Privacy policy.



# Annex 3 Request of Consent for use of photographs, images, video and/or voice recording

Note: this is a general template to be modified based on the specific needs of a project or activity. The text in red colour should be replaced with the necessary information.

Name of Project Partner Name of Lead Researcher Contact information

#### Subject matter:

Include one or a few sentences about the event and other relevant circumstances and their relation with the project

Identify when you will take photograph(s), images, or video with or without audio.

#### Intended use:

Describe, concisely and in plain language, the <u>specific purpose(s)</u> of using photographs, images, video and/or voice recording. Please describe these reasons in a way that the person is able to take an informed decision and to prevent the person from being surprised for the use of their personal data. It is important to manage properly his/her expectations.

Indicate if the photographs, images, video and/or voice recording will be made public through social media such as Facebook, LinkedIn, YouTube, Twitter, Instagram, or NEXOGENESIS website

(If the photographs, images, video and/or voice recording will be used for joint publications with our partner or other stakeholders in the sector, please name them).

#### Request consent

#### Sample text:

The NEXOGENESIS Consortium asks to Indicate your consent to the unremunerated use of [specify the media: photographs, images, video, etc] in which you appear, for the purposes described and for [specify for how long or if it will be indefinite time]. At any time, you have the right to withdraw your consent by requesting that to [Name of activity lead] and/or by emailing [name of the person] at [e-mail address] with heading: Withdrawal of consent for photography of [name and date of event]. Please read the privacy statement and indicate your consent (or not) to each point.

#### Note: Consent must be obtained separately for each purpose. Example:

#### Tick yes or no

| Describe the consent you are asking for                            |             | ☐ Yes ☐ No |
|--|-------------|------------|
| I agree to being photographed                                      |             | ☐ Yes ☐ No |
| I agree to have my photo used for NEXOGENESIS materials or reports | information | ☐ Yes ☐ No |
| Name   | Date        |            |



