

# **D7.10** Ethical Principles and Guidelines for Responsible Research and Innovation (update)

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## **Technical References**

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<sup>1</sup> PU = Public

PP = Restricted to other programme participants (including the Commission Services)

RE = Restricted to a group specified by the consortium (including the Commission Services)

CO = Confidential, only for members of the consortium (including the Commission Services)





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## **Executive Summary**

The purpose of Ethical Principles and Guidelines is to offer a genuine rationale underlying principles and guidelines that the ULTIMATE partners need to take into consideration. The ULTIMATE project consists of a diversity of organisations, including universities, other research institutions, industrial partners, water companies, water service providers and technology providers) and other organisations. A central element in ULTIMATE are the 9 case studies. In the context of each case study a community of practice (CoP) has been formed, including operators, technology providers, regulators, municipalities, to share experiences and co-produce knowledge. The CoPs give feedback for technology development by discussing it in a wider context, addressing barriers and opportunities. Furthermore, stakeholders, including citizens, have been engaged for example through immersive environments and living labs. The ethical principles and guidelines described here are general and cover both professional and research ethical issues, and project internal as well as external dimensions. This is described in further details below.

Ethical codes of conduct across this diversity of institutions do necessarily vary according to their kind of institution: university, end user, water utility etc. There are, however, a large amount of codes and values that are important to most of them, these are mentioned in section 4, Ethics codes – participants.

Most guidelines across the diversity of partners of ULTIMATE touch upon the following:

- The ethos of science: behavioural conduct
- Concern for research subjects: protection of clients or research subjects
- Social responsibility (RRI)

For universities and research organisations in particular, there is a strong focus on research internal aspects relating to quality of research, and behaviour towards fellow colleagues and students, where integrity and honesty are pivotal. Any kind of fraud or misconduct is incompatible with the ethos of science.

Ethical principles and guidelines described in this document make up the basis for (i) identification and recruitment of research participants; (ii) obtaining informed consent for the participation of humans in project activities; and (iii) managing any ethical risks associated with their participation. Templates for the informed consent/assent forms and information sheets are provided.

The current document reiterates the processes established and includes changes and updates based on the progress in the ULTIMATE project and insights gained in the process. As such, the Ethical Principles and Guidelines are not fixed, but will continue to evolve as the project develops. More specifically, this deliverable presents the second version of the Ethical Principles and Guidelines for the ULTIMATE project and present an update on D7.5 in which they were first described. A final update on this deliverable is foreseen Month 48 (D7.11) of the project.





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## **Disclaimer**

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## **List of Abbreviations**

CoP: Community of Practice DMP: Data Management Plan EO: Ethics Officer GDPR: General Data Protection Regulation PSB: Project Steering Board PMT: Project management Team RRI: Responsible Research and Innovation WHO: World Health Organisation





## **1.Introduction**

The ULTIMATE project consists of a diversity of organisations, including universities, other research institutions, industrial partners, water companies, water service providers and technology providers). A central element in ULTIMATE are the 9 case studies. In the context of each case study a community of practice (CoP) has been formed, including operators, technology providers, regulators, municipalities, to share experiences and co-produce knowledge. The CoPs give feedback for technology development by discussing it in a wider context, addressing barriers and opportunities. Furthermore, stakeholders, including citizens, are engaged for example through immersive environments and living labs. Both the CoPs as well as the immersive environments and livings labs will be developed as part of Work Package 3. Additionally, Work Package 4 involves the general public through large scale surveys as well as interviews. All these interactions with stakeholders, as well as the conductance of the research in ULTIMATE are performed according to, and take into account, ethical principles and guidelines. Ethical principles and guidelines cover both professional and research ethical issues, and project internal as well as external dimensions. This is described in further details below.

The ethical principles and guidelines described below make up the basis for (i) identification and recruitment of research participants; (ii) obtaining informed consent for the participation of humans in project activities; and (iii) managing any ethical risks associated with their participation. Templates for the informed consent/assent forms and information sheets (in language and terms intelligible to the participants) have been provided for use by the partners. All forms and templates are provided in the English language and have been translated into local languages by the local partners when necessary.

The current document reiterates the processes established and includes changes and updates based on the progress in the ULTIMATE project and insights gained in the process. As such, the Ethical Principles and Guidelines are not fixed, but will continue to evolve as the project develops. More specifically, this deliverable presents the second version of the Ethical Principles and Guidelines for the ULTIMATE project and present an update on D7.5 in which they were first described. A final update on this deliverable is foreseen Month 48 (D7.11) of the project.





## 2. Ethical aspects and dimensions

## 2.1. The ethos of science

The first dimension to be mentioned has to do with *good research conduct*, which relates to the '*ethos*' of science. This dimension is internal to research itself, and concerns quality aspect. The *ethos* of science and research rules out any kind of plagiarism, cheating and misconduct, and the norms regulating science are well described by Merton's ethical norms CUDOS:

- Communism Universalism Disinterestedness Organised Scepticism
- (1) Communism, which emphasizes that scientific validity should be independent of the socio-political status or personal attributes of its participants. This also implies that the products of science should be accessible by all, cf. also ideals of open science and open access. Knowledge production should be shared with others, and is thus comparable to *commons*, something owned by everyone, not only the knowledge producer, or those who are able to pay for it.
- (2) Universalism, a norm requiring that all scientists should have common ownership of scientific goods (intellectual property), to promote collective collaboration. Secrecy is the opposite of this norm. This norm is of particular relevance to projects like ULTIMATE, as the products from the project (such as technologies and methods) should be shared with the rest of the *research society* in order to contribute optimally to the research community at large. This norm is also stressed by EC, when repeatedly pointing out the need to cooperate with similar research projects on water management and circular economy.
- (3) Disinterestedness, meaning that scientific institutions should act for the benefit of a common scientific enterprise, rather than for the personal gain of individuals within them. This norm implies that science should be independent of special interests of particular partners or stakeholders. As an example, this norm rules out that research and science itself is biased in the sense of advancing some particular stakeholder's interests. This norm further conflicts with research funded by a client who asks for particular results.
- (4) Organized Scepticism, a norm which emphasizes that scientific claims should be exposed to critical scrutiny before a project starts running. This applies both to *methodology* and *institutional codes of conduct*. Organised scepticism is based on the premise that close relations might prevent the researcher(s) from discovering flaws in the setup of a project. The main point of this norm is that research projects needs to be scrutinized by a committee, an ethics officer or other bodies that are themselves independent in the sense of not having any stakes connected with the project. For some projects, particularly medical research, there will be a research ethics or clinical ethics committee that are assigned the task of approving a project





before it can start. Organised scepticism in ULTIMATE is partly taken care of by the appointment of an ethics officer.

In order to decide whether a scientific research project complies with the CUDOS norms, it is necessary to see how these norms apply in a particular context, in this case the ULTIMATE context. Here we want to point out a few foreseeable challenges for ULTIMATE, by critically asking some questions:

- Who owns the products technologies, reports and publications?
- Are property rights compatible with this norm, and if not, there is a need to clarify early in the project how to deal with it.
- Do any of the project partners' internal codes of conduct conflict with any of the CUDOS norms? If so, it is necessary to identify any such conflicts, and to describe how to solve it.

## 2.2. Concern for research subjects

The second dimension to mention here concerns research subjects. This dimension is relevant to any kind of research that involves human beings, but also other beings as well, for instance animals. This dimension became particularly relevant in the aftermath of the second world war, due to many inhumane experiments during the Nazi regime. Protection of research subjects has ever since been pivotal to research on humans, and later on to other creatures as well, as e.g., animal welfare has become increasingly important. No research should impose damage on the research subject. In connection with humans there are some principles that are particularly relevant. Additional to do good, i.e., beneficence, and do no harm, i.e., nonmaleficence, which are pivotal to all medical research, there are a few other principles of particular relevance: respect, autonomy and justice. These principles are commonly referred to as prima facie duties, meaning that all of them are equally important, although they may sometimes conflict. In such cases there is a need to prioritise, and to state the underpinning arguments. As an example, it might sometimes be necessary to prioritise the common good for the society at large, above protection of the individual – or vice versa.

The research carried out in ULTIMATE does not involve humans in a context comparable to medical research. It is hard to foresee any case where humans could be harmed for the sake of a greater common good in the ULTIMATE context.

One question that *is* relevant to ask for the ULTIMATE project, however, concerns *respect*: Are the humans involved in the project being respected? The most obvious and basic requirement is the request for informed consent ahead of including participants (research subjects) in the project.

Principles of *autonomy* and *justice* do probably not apply to humans being included in ULTIMATE, unless their autonomy could possibly be compromised by the very design of the consent form, the questionnaire, the interview or other methods being applied. We do not foresee that any such instance is likely to occur. The overarching question to ask is always whether the methods and design of the project might in any way compromise the individuals being included in the project.







## 2.3. Social responsibility

Dimensions I and II mainly apply to research internal issues relating to quality of methods, research conduct and respect for research subjects. The third dimension does, however, concerns a broader perspective, including the relationships between the research project and external partners, such as politicians, interest groups, and the society at large. Key concerns are *trust* and *responsibility* in a broader context. This is commonly referred to as *Responsible Research and Innovation*, RRI, which is of the utmost importance to all Horizon 2020 projects.

Some of the norms and principles mentioned above are also integrated in RRI, which is described in terms of elements of thematic actions:

- Public engagement
- Open access
- Gender equality
- Ethics
- Science education

Below we will briefly explain how these RRI keys become relevant to ULTIMATE.

## 2.3.1 Public engagement

### **Public engagement** in Horizon 2020 is grounded in the following:

- Enhancing creativity in research and innovation design process and results
- The likelihood that research and innovation outcomes are more societally relevant and desirable.
- Achieving shorter time to market and greater consumer acceptability of research and innovation outcomes.
- Providing a breeding ground to foster a more scientifically literate society of knowledge-driven and empowered citizens, able and interested to participate in and support democratic processes, including on decisions of Research and Innovation financing, and evidence-based policy making.

In ULTIMATE there are immersive experiences/playbooks and living labs that will seek interaction with the public, and thus contribute to this goal.

## 2.3.2 Open science

### **Open science (open access)** is motivated by the following:

- It is widely recognised that making research results more accessible contributes to better and more efficient science, and to innovation in the public and private sectors.
- As other challenges need to be addressed such as infrastructure, intellectual property rights, content-mining and alternative metrics, but also inter-institutional, interdisciplinary and international collaboration among all actors in research and





innovation, the European Commission is now moving decisively from 'Open access' into the broader picture of 'Open science'.

For ULTIMATE there is a strong motivation for open access, although there might be some issues to resolve concerning diversity of ethical guidelines with respect to intellectual property concerns. However, there are a substantial number of private companies, who will not necessarily be prepared to follow the open access principles. ULTIMATE will identify and describe what company internal principles that do not comply with open access principles, and decide how to deal with any such controversies. This is a task for the PMT and Project Steering Board (PSB).

## 2.3.3 Gender equality

### **<u>Gender equality</u>** strategy is underpinned by the following objectives:

- Fostering gender balance in research teams, in order to close the gaps in the participation of women.
- Ensuring gender balance in decision-making, in order to reach the target of 40% of the under-represented sex in panels and groups and of 50% in advisory groups.
- Integrating the gender dimension in research and innovation (R&I) content, helps improve the scientific quality and societal relevance of the produced knowledge, technology and/or innovation.

The ULTIMATE project is highly concerned about gender equality and intend to have a gender balance across the project, as indicated in the proposal.

## 2.3.4 Ethics and integrity framework

<u>Ethics</u> and integrity framework is the general policy objective of Horizon 2020 projects. It is envisaged that the following will promote such a framework:

- Ensuring a dialogue between the EU countries' ethics and integrity bodies and the respective communities.
- Promoting the use of <u>European Code of Conduct for Research Integrity</u> and whenever necessary initiate the update of the code.
- Improving the knowledge base on and understanding of ethics and integrity issues through Framework Programme activities.
- Enhancing international cooperation in the context of the NEC (National Ethics Council) Forum, UNESCO, WHO and national initiatives.
- Developing the ethics and research integrity dimension in Education and Open Science.

The ULTIMATE project is highly concerned about the ethics and integrity dimension of RRI, particularly reflected in the way the ethics officer of the project is included in the Project management team (PMT). This set- up enables a view from an independent partner, cf. also Merton's norm *organized scepticism* described above.





## 2.3.5 Science education

## <u>Science education</u> is important and requires cross-cutting interaction between the relevant people in the field:

• Education system (teachers, pupils), universities (professors, students), research and innovation funding and performing organizations, civil society organizations and NGOs, industry and policymakers.

Interaction across these institutions and people is crucial, and is motivated by the impact it is expected to have:

- Develop scientific citizenship by promoting innovative pedagogies in science education, attracting more young people towards science, with a special emphasis on girls, and addressing the challenges faced by young people, in pursuing careers in science, technology, engineering and innovation.
- Develop responsible research and innovation in higher education curricula.
- Ease the access to scientific careers by increasing the service level of the <u>EURAXESS Services Network</u>

The ULTIMATE project will, at least indirectly, enable contribution to this goal, as the diversity of partners represent several of these stakeholders. In order for knowledge transfer from the project to education institutions to happen open access is a crucial prerequisite, along with well-functioning communication and dissemination. A number of our consortium partners are educational institutions (universities, including Exeter, Cranfield, NTNU, UNIVPM, NTUA) and as a part of the project a number of students, in particular PhD students, will be trained.

## 2.3.6 Comments on RRI keys for ULTIMATE

These RRI keys - public engagement, open access, gender equality, ethics and science education – are basic to the set-up of ULTIMATE. An important task relating to ethics is to make sure that all stakeholders of the project are aware of, and well informed about, these keys.

The different dimensions of ethics – the ethos of science (CUDOS), concern for research subjects, and social responsibility (RRI) – are ethics tools that are implemented in the ULTIMATE project. Since these tools necessarily have to be general, it is of the utmost importance to decide how they translate to this particular project. There is in ULTIMATE very high awareness of the external dimension of ethics (dimension III), i.e., interaction with stakeholders, partners and the rest of society, is well taken care of. This is also an ethics dimension that is easy to deal with, as there is a joint interest among the partners, and all partners can easily contribute, each in their own way.

With respect to dimension II (concern for research subjects) it is also easy to come to terms with. Not all partners are equally involved with this dimension, but all partners





need to reflect on it. Informed consent is probably the most relevant aspect of this dimension.

Dimension I – *ethos of science* – is demanding, and one issue that might be a concern has to do with a potential conflict between property rights and the ideal of open access. Ideally any foreseen problems should be resolved in a very early stage of the project. As yet no conflicts are identified, but it is important to have a preparedness for how to deal with it in case internal ethics norms between partners may conflict.

# 3. Ethics officer role and tasks – methods and procedures

The ethics officer (EO) of ULTIMATE is a member of the PMT. There are three dimensions in which the EO engages in the project:

- Discussions of methodological enablers and barriers;
- Governance and communication issues;
- RRI related relations between stakeholders/ partners/citizen engagement.

There are several contexts in which the EO is informed about the project:

- Pre-kick off meeting (all partners)
- Kick-off meeting (all partners)
- Monthly PMT meetings (Project management)
- Regular meetings with the NTNU team
- Annual project meetings with all partners

These are contexts of information exchange. The PMT meetings are the prime context for identifying and discussing any controversies or diverging (research) ethical norms between partners. The regularity of the meetings, which are characterized by a high level of trust and open access mentality, offers a very good space for information flow and updates of the project.

Besides participating in regular meetings, a particular task for EO is to produce ethical principles and guidelines for the project in M6, to be followed up with updates in M30 and M48.

The role and tasks of the ethics officer, which is mainly to deliver ethical principles and guidelines, and to follow the project in a diversity of meetings, is to oversee how the following is developing in the project:

- Reporting and communication procedures between partners, and between project and society outside project.
- Knowledge production and publications from project.
- Procedures for solving controversies.

Additionally, a main task is to give advice whenever requested, or needed.





## 4. Ethics codes – participants

The ethical principles and guidelines described above apply to all partners of ULTIMATE. As there is a variety of *kinds* of partners with an equivalent amount of ethics codes, we will only give some examples of highlights, based upon several of the beneficiaries' Codes of Conduct.<sup>1</sup>

Most guidelines across the diversity of partners of ULTIMATE touch upon the following:

- Behavioural conduct
- Protection of clients or research subjects
- Social responsibility (RRI)

Additionally, for universities and research organisations, there is a strong focus on research internal aspects relating to quality of research, and behaviour towards fellow colleagues and students, where integrity and honesty are pivotal. Any kind of fraud or misconduct is incompatible with the ethos of science.

Many of the beneficiaries, both universities as well as water companies and utilities, have submitted their ethics codes to the EO. There is a large degree of overlap between them, although the focus varies according to the main mission of the beneficiary. For universities a main focus is on principles and guidelines for research, whereas for water companies and utilities the relations with clients and other companies (partners and competitors) are highlighted. However, independent of the main mission of the beneficiary, there are some core values that dominate, to which all consent. The following is a list of the most important aspects covered by most of the beneficiaries' codes of conduct:

Integrity and honesty, respect, fairness, avoid conflict of interests, transparency, loyalty, confidentiality, privacy protection, report irregularities.

Some further aspects are particularly prevalent to competing companies (but are also mentioned by other beneficiaries):

community well-being; zero tolerance for bribery and corruption; honest and open competition; environmental protection, health and safety.

Thus, there is a large amount of codes and values that all parties of ULTIMATE mention explicitly in their codes of conduct. These codes and values further cover dimensions I-III presented above. Some of these codes and values may still conflict *internally* (cf. *prima facie duties* mentioned under II), i.e., equally important values or duties may still conflict internally in any set of Codes of Conduct.

*Prima facie* duties does not only apply to the context of concern for research subjects (as presented above under II). These duties may fruitfully be extended to other

<sup>&</sup>lt;sup>1</sup> The following project partners have submitted their Codes of Conduct: KWR, NTNU, Alberta, Eurecat, Water Europe, FCC Aqualia, KWB, Novozymes, Aitasa, Cranfield, KWB, Suez, PTM, Mekorot, NTUA (only available in Greece), West Systems, Pentair, Aquabio/ Freudenberg.





contexts, as well, relating to either internal or external relations where ethics codes may conflict internally. As an example, transparency is a core value in most codes of conduct, but so is also loyalty and confidentiality. These are not always possible to take equally into account, and one of them may override the other.

For ULTIMATE the following might conflict at some point and require preparedness for resolving them. The most obvious ones:

- Transparency and competition.
- Open competition and privacy protection.
- Transparency and loyalty.

Preparedness rather than strict rules is recommended, as potential tensions between these core values may only emerge in a particular context. And there is no reason to anticipate that *potential* conflicts *necessarily* will arise.

## 5. Ethics tasks and connection to DMP

Deliverable D7.5 (M6) is linked to Task 7.7 – Ethics, a deliverable that will be updated in M30 (D7.10) and M48 (D7.11). Additional to this deliverable (D7.5), ethics issues are also involved in the DMP, section 6 (deliverable D7.3). Comprehensive information and description of protection of humans, non-EU countries and GDPR is offered in DMP. The current deliverable D7.5 focuses on the ethos of science, concern for research subjects, and the social responsibility of science. The ethical principles and guidelines described here further explain the rationale why informed consent, respect for freedom and protection are basic to research where humans are involved.

Open science and protection of individuals included in the study are equally important to realise the ethos of science. This implies that participants need to be correctly informed about their rights to their own data, the right to withdraw, and to be informed about how the data are stored. A consent form, including information about the study, is made available to all participants (Annex 1). Particular rules apply to data that are identifiable, and all sensitive data need to be safely stored, and only those who are eligible will have access. The participants that are included have a right to be informed about the details concerning access to and storage identifiable data. Tools are developed for a common online system for updating and storage of data for ULTIMATE, and the project will encourage project partners to store datasets produced in open research repositories and obtain Digital Object Identifiers (DOIs).





## 6. Conclusion

ULTIMATE will comply with the ethical principles and guidelines that are outlined in this document. Should any instance of conflicting norms be identified, this will be discussed by the PMT, and necessary action will be taken to resolve the problem. The setup of the project involves active participation by all parties, including frequent PMT meetings. The start-up of the project, both the pre-kick off meeting in June 2020, and the kick-off meeting with all partners in September 2020, has ensured a promising future for the remaining years of the project.





## **Annex 1: Sample information sheet and**

## consent form template

This is a standard consent form to be used for inclusion of research participants. Details about the particular study need to be filled in.

## Appendix: Sample Information sheet and consent form

This is a sample template - you must adapt this template to the requirements of your particular study.

### [Title of research study] [Name of researcher]

### Information for participants

Thank you for considering participating in this study which will take place [*insert approximate dates*]. This information sheet outlines the purpose of the study and provides a description of your involvement and rights as a participant, if you agree to take part.

### 1. What is the research about?

[Set out the aim of this project/research, and also the methods to be used to collect information. **It is** *important that you use language that will be understood by your intended participants*. If applicable, state who the funder of the research is.]

### 2. Do I have to take part?

It is up to you to decide whether or not to take part. You do not have to take part if you do not want to. If you do decide to take part [*I/we*] will ask you to sign a consent form which you can sign and return in advance of the [*interview/focus group meeting*] or sign at the meeting.

### 3. What will my involvement be?

[Be clear about what participation will involve and how long this might take. E.g. 'You will be asked to take part in an interview/focus group/survey about your experience/knowledge of... It should take approximately...]

### 4. How do I withdraw from the study?

You can withdraw from the study at any point until *[insert date, e.g. when you will begin analysis of the data, or until publication of the data]*, without having to give a reason. If any questions during the *[interview/focus group]* make you feel uncomfortable, you do not have to answer them. Withdrawing from the study will have no effect on you. If you withdraw from the study we will not retain the information you have given thus far, unless you are happy for us to do so.





### 5. What will my information be used for?

[*I*/*we*] will use the collected information for.... [*a research project, academic paper, future research, etc.*]

### 6. Will my taking part and my data be kept confidential? Will it be anonymised?

The records from this study will be kept as confidential as possible. Only [*myself/others*] will have access to the files and any audio tapes. Your data will be anonymised – your name will not be used in any reports or publications resulting from the study.<sup>2</sup> All digital files, transcripts and summaries will be given codes and stored separately from any names or other direct identification of participants. Any hard copies of research information will be kept in locked files at all times.

**Limits to confidentiality:** confidentiality will be maintained as far as it is possible, unless you tell us something which implies that you or someone you mention might be in significant danger of harm and unable to act for themselves; in this case, we may have to inform the relevant agencies of this, but we would discuss this with you first.

#### 8. Data Protection Privacy Notice

The LSE Research Privacy Policy can be found at: https://info.lse.ac.uk/staff/divisions/Secretarys-Division/Assets/Documents/Information-Records-Management/Privacy-Notice-for-Research-v1.1.pdf

The legal basis used to process your personal data will be *[Please select one of the following: Staff* "Public Task"; *Students* "Legitimate interests"]. The legal basis used to process special category personal data (e.g. data that reveals racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, health, sex life or sexual orientation, genetic or biometric data) will be for scientific and historical research or statistical purposes.

To request a copy of the data held about you please contact: <a href="mailto:glpd.info.rights@lse.ac.uk">glpd.info.rights@lse.ac.uk</a>

### 9. What if I have a question or complaint?

If you have any questions regarding this study please contact the researcher, [X], on [email address]. If you have any concerns or complaints regarding the conduct of this research, please contact the ULTIMATE coordinator.

If you are happy to take part in this study, please sign the consent sheet attached.



<sup>&</sup>lt;sup>2</sup> There are some circumstances in which you may – with their agreement – name your participants in your research; however, caution should be exercised, and you are advised to discuss this with other researchers in the project.



## CONSENT FORM

### [Title of research study] [Name of researcher]

### PARTICIPATION IN THIS RESEARCH STUDY IS VOLUNTARY

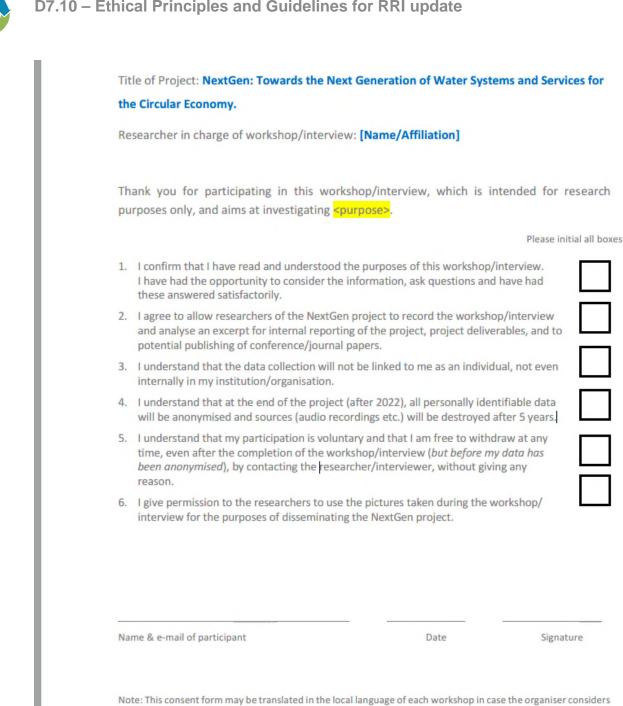
I have read and understood the study information dated [DD/MM/YY], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	YES / NO
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and that I can withdraw from the study at any time up until XXX, without having to give a reason.	YES / NO
I agree to the [interview/focus group] being audio recorded [delete if not being audio recorded]	YES / NO
<i>[If conducting focus groups]</i> I agree to maintain the confidentiality of the focus group discussions	YES/NO
Add additional statements for e.g. video recording, photographs, etc. if relevant	YES / NO
I understand that the information I provide will be used for <i>[my dissertation, thesis, research publication, etc.]</i> and that the information will be anonymised.	YES / NO
<i>If you want to use quotes in research outputs, add:</i> I agree that my (anonymised) information can be quoted in research outputs.	YES / NO
<i>If you want to use named quotes, add:</i> I agree that my real name can be used for quotes.	YES / NO
<i>If written information is provided by the participant (e.g. diary), add:</i> I agree to joint copyright of the [specify the data] to [name of researcher].	YES / NO
I understand that any personal information that can identify me – such as my name, address, will be kept confidential and not shared with anyone [other than myself / beyond the study team].	YES / NO
I give permission for the (anonymised) information I provide to be deposited in a data archive so that it may be used for future research.	YES / NO
[Note that for some funders it is a requirement to ask participants this]	

Please retain a copy of this consent form. Participant name:

Signature:	Date
Interviewer name:	
Signature:	Date

For information please contact: <<name and email address of researcher>>





it necessary for the participants; otherwise the English version will be used

