



## D1.3 Ethical requirements for human participation in research

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## Executive Summary

The D1.3 (ethical requirements for human participation in research) deliverable discusses the various research methods and ethical procedures that will be used during the Möbius project. First, we give a brief description on the Möbius project and its necessity. The second chapter describes the different quantitative- and qualitative research methods, supported by the external step-by-step document. In the third chapter, we provide an overview on the ethical procedures that must be followed during the research activities. Chapter four refers to the D1.4 Initial Data Management Plan (DMP) written by Eurecat with the contribution of all partners. The fifth chapter will discuss the health and safety issues concerning living lab experiments. Lastly, chapter six gives an overview of the informed consent templates that need to be used during research activities.

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# Table of Contents

REVISION HISTORY .....	2
EXECUTIVE SUMMARY.....	3
TABLE OF CONTENTS.....	4
LIST OF FIGURES.....	5
LIST OF TABLES .....	5
TERMINOLOGY AND ACRONYMS.....	6
<b>1. INTRODUCTION.....</b>	<b>7</b>
<b>2. RESEARCH SETUP .....</b>	<b>7</b>
2.1 CONSORTIUM CONTRIBUTIONS .....	8
2.2 TECHNIQUES AND METHODS .....	9
2.2.1 <i>Living labs</i> .....	9
2.2.2 <i>Interviews</i> .....	10
2.2.3 <i>Survey</i> .....	11
2.2.4 <i>Data scraping</i> .....	11
2.3 RESEARCH TOOLS .....	11
2.4 PARTICIPANTS' INVOLVEMENT .....	11
2.4.1 <i>Passive involvement</i> .....	12
2.4.2 <i>Active involvement</i> .....	12
<b>3. ETHICAL PROCEDURES, PRIVACY AND DATA PROTECTION .....</b>	<b>13</b>
3.1 DEALING WITH PARTICIPANTS.....	14
3.1.1 <i>General guidelines</i> .....	14
3.1.2 <i>Personal data relating to children</i> .....	15
3.2 SETTING UP INTERVIEWS, WORKSHOPS AND FOCUS GROUPS SESSIONS.....	15
3.2.1 <i>Call for participation</i> .....	16
3.2.2 <i>Practicalities</i> .....	16
3.2.3 <i>Informed consent</i> .....	16
3.2.4 <i>After the research activity</i> .....	17
3.3 SURVEY.....	17
3.4 EXPERIMENTS.....	17
3.4.1 <i>Ethical board</i> .....	17
<b>4. DATA MANAGEMENT .....</b>	<b>17</b>
<b>5. HEALTH AND SAFETY.....</b>	<b>18</b>
<b>6. CONCLUSION .....</b>	<b>18</b>
<b>7. REFERENCES.....</b>	<b>18</b>
<b>8. ANNEXES.....</b>	<b>19</b>
8.1 TEMPLATE FOR PRIVACY NOTICE FOR ONLINE SURVEY .....	19
8.2 TEMPLATE FOR INFORMED CONSENT .....	20

## List of Figures

Figure 1 screenshot testing phases .....	9
Figure 2 decision tree .....	13

## List of Tables

Table 1 Consortium contributions.....	9
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## Terminology and Acronyms

<i>DMP</i>	<i>Data Management Plan</i>
<i>WP</i>	<i>Work Package</i>
<i>GDPR</i>	<i>General Data Protection Regulation</i>
<i>POPD</i>	<i>Protection of Personal Data</i>

## 1. Introduction

This deliverable describes the ethical procedures that need to be followed during any given research activity of the Möbius project. As mentioned in the Ethics Summary Report: “*There is a potential risk for profiling or data processing that could lead to the identification of the users. The strategy for data protection and ensuring the privacy of users must be defined.*” To make sure the research activities are ethically sound, we describe how we will organise participation by end users and professional users (authors, publishers, fanfic writers, etc.). All project partners agree to adhere to these ethical guidelines. Furthermore, this deliverable contains all relevant document templates (such as the informed consent form) that should be used during research activities involving human subjects. Due to the relative long timespan of the project (three years), the aim is to update the deliverable and implement it as a living document throughout the project.

As requested in the ethics summary report, an independent ethical advisor, Aagje Weyler (Imec) was appointed to provide feedback on the ethical procedures and to advice on potential ethical issues that appear during the project (reported in D7.1). Complementary to this deliverable, are the Data Management Plan (DMP) (D1.3) and the Protection of Personal Data (POPD) (D1.2). First, the DMP specifies how the data collection will be handled, processed and stored. Secondly, the POPD ensures the compliance with GDPR, and is closely related to this ethical requirement report. Personal data will be collected and handled during the research activities and further analyses, in compliance with the GDPR. As soon as the personal data is no longer required for purposes for which they were initially collected - they will be either destroyed or anonymized. This responsibility applies to all consortium partners that conduct research involving personal data.

First, we discuss the research setup including contribution of consortium partners, applied research methods and participant’s involvement. Second, we summarize the ethical procedures concerning privacy and security. The last sections give a brief overview of the DMP, health and safety measures and available templates.

## 2. Research setup

The European publishing industry has a strong global foothold and is still the largest cultural industry in Europe. Book sales in Europe are steady, but the decline of readers – especially the younger generations, is rapidly growing. Traditional publishers need to adjust their value chains, business models, consumption formats and user engagement to stay relevant within the digital era. Due to the digital transformation, traditional players must break out of their comfort zone and embrace innovation. Yet, successful innovation will only occur through the combination of several strategies, which will offer new experiences.

Möbius will tackle the bottlenecks of the European publishing industry with innovative solutions – aimed at using the potential of the prosumer and creating new enriched media experiences.

User-centric and user-driven perspectives are the backbone of Möbius and will be part of the three key innovations. As stated on the website<sup>1</sup>:

1. Prosumer intelligence toolkit, built upon living labs methods and the analysis of a dataset containing several hundred thousand of prosumer online works and interactions.
2. Prosumer business models, grounded in thorough analysis of IP law, for steering a fair and sustainable ecosystem.
3. Möbius book, allowing cross-media, interactive and immersive book experiences. Möbius will be developed and validated through large scale piloting activities mobilizing 2.500 relevant user groups, including prosumers, and publishing and media professionals.

To reach our goal – various partners spread across Europe will engage and share their expertise. This will happen concretely by our project partners and via the involvement of living labs across Europe, facilitated by project partner ENOLL, the European Network of Living Labs. Hereby different disciplines (technology, business modelling, literature and research) strive towards unique innovations that will alter the course of the European publishing industry.

## 2.1 Consortium contributions

Various research activities are planned, spread over the work packages, where humans are the research subject within a living lab environment. It's important that all consortium partners are aware of their obligations towards these participants. In table 1 below, we give a brief overview on the research activities involving human participation per partner. As this is a living document, the table will be updated as the project progresses over time.

Partner	Description
Imec	Imec will <b>apply a living lab methodology (qualitative and quantitative methods)</b> to support the prototype development and evaluation. The first intelligence toolkit will be tested by Imec – involving consortium partners, board members and other trusted third parties. Later stages of the Möbius prototypes will be tested by a wide variety of participants, including professional users, prosumers and consumers. These participants will be engaged via diverse user research activities, including interviews, focus groups, observations, co-creation workshops and surveys.
EnoLL	EnoLL will use its wide network of living labs, spread across the EU – to <b>set up pilot test environments</b> . Participants will test and evaluate different prototypes that will contribute to the final product.
Eurecat	Eurecat will <b>scrape data</b> from fandom platforms such as Archive of Our Own (AO3) or FanFiction.net – to gain insight on the fanfic community. The data collection aims

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<sup>1</sup> Möbius. (n.d.). *Our story – Möbius*. Möbius-Project. <https://mobius-project.eu/our-story/>





	to obtain data about user interaction on the platform; personal data will not be collected nor mentioned in any deliverable.
KKW	KKW will create <b>a unique Möbius experience that will be presented</b> on various occasions. The goal is to present the new book experiences to a wider audience, data collection isn't a priority. Yet, people who participate in the experience should be informed about the Möbius project.
Bookabook	The <b>open call for manuscripts</b> will be organized by Bookabook. During the open call, writers can upload their manuscripts that could transform into an immersive experience. It's important to write a proper disclaimer concerning the goals of Möbius, IP rights, use cases, authors rights, etc.
IN2	IN2 will collect various sorts of <b>data from the Möbius application and social media</b> to improve the user experience and the final product. User data, experimental data, user feedback, etc. will be handled.

Table 1 Consortium contributions

## 2.2 Techniques and methods

Throughout the project, a mixed set of data gathering techniques will be applied, in a living lab setting. User participation is required in every stage of the development process. The living lab approach combines quantitative- (surveys, data scraping) and qualitative tools (co-creation workshops, interviews, experiments, focus group interviews). Figure 1 gives a visual overview of pilot testing phases.

The following subsections address the ethical guidelines for each possible research activity. Where needed, we refer readers to our step-by-step guide that clarifies which actions to take when setting up such an activity. This allows us to expand these sections below should other activities occur yet allows us to provide templates and guidance in a very comprehensive and accessible way.

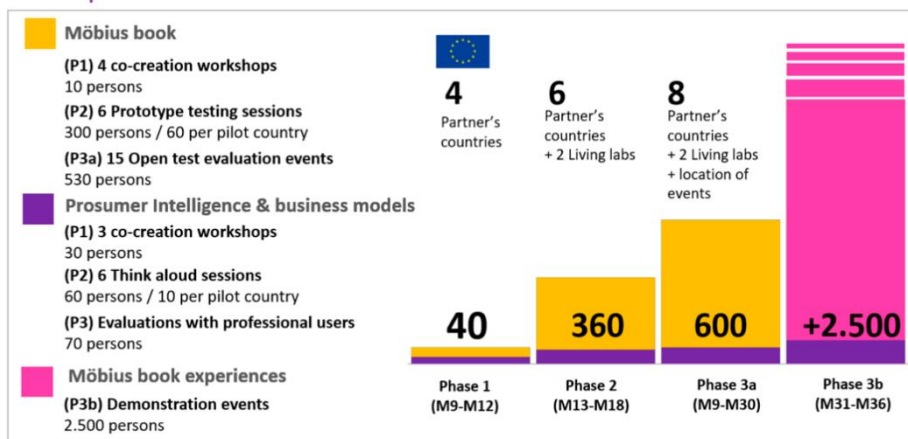


Figure 1 screenshot testing phases

### 2.2.1 Living labs

The living lab methodology aims to involve end-users (and professional users) iteratively throughout innovation processes. Lievens & Kilpi have defined Living Labs as “*user-driven open innovation ecosystems based on a business-citizens-government partnership which enable users to take an active part in the research, development and innovation process*”<sup>2</sup>. In addition, Ballon & Schuurman<sup>3</sup> describe living labs as environments for research and experimentation that involve large groups of users over a longer time period. As such, living labs aim to actively study users’ interaction with innovations within their natural use context. This approach is suitable for Möbius as the project depends on user-driven research where living labs play a crucial role throughout the different work packages. For Möbius, we will use both the living lab methodology as well as living lab infrastructure. This means that we will apply a living lab research methodology including different phases of user involvement alongside the development and increased maturity of the proof-of-concept and that we will work together with existing living lab infrastructures across Europe to engage these participants in evaluation activities.

The involvement of living labs will grow alongside the Möbius prototypes, where the number of participants will increase during later project phases. For the first phase, only consortium partners, experts and trusted third-parties can test the intelligence toolkit. Here, Imec will host a co-creation workshop within a living lab environment. In a co-creation workshop, users together with developers co-create or co-design potential solutions. The outcome of a co-creation session is typically a set of first prototype ideas together with first user requirements. Later phases will allow participants to test the Möbius Book Experiences. Here EnoLL will play a crucial role, by using its wide network of living labs across Europe. As part of the living lab research methodology, also experiments will take place in which users will test immersive experiences. For these experiments, specific health notifications will be added to the consent forms and the approval by an ethical committee will be foreseen (see section 5).

### 2.2.2 Interviews

For individual- or group interviews organized by any consortium partner, a step-by-step guide is available together with example text and informed consent templates (see Annex 8). The informed consent is mandatory and needs to be signed on paper or via a digital signature (or verbally accepted if online and recorded) before the interview can officially start. It’s important that the participant understands the necessity of the interview and knows that he/she can stop the interview at any given moment. Also, the informed consent will explain why their personal data is required, for which purposes their data will be used (e.g. age comparison, demographic

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<sup>2</sup> Kilpi, K., Lievens, B., Stamatelatos, M., Aguilar Santiago, M., & Osstyn, D. (2013). *Deliverable D2.2.Methodological Approach*. (Deliverable D2.2. Methodological Approach in Smart Platforms Enabling the Creative Industries for Future Internet (SPECIFI)). Unknown.

<sup>3</sup> Ballon, P. and Schuurman, D. (2015), "Living labs: concepts, tools and cases", info, Vol. 17 No. 4. <https://doi-org.myezproxy.vub.ac.be/10.1108/info-04-2015-0024>

analysis, etc.), who will handle and store their data and that their data will be anonymized or destroyed when it's no longer required for further research.

### 2.2.3 Survey

When a survey is set-up, it will include a brief description of the project, the goal of the research activity, and a privacy statement, including the researcher(s)' contact information. Participating in the survey shall only be possible when participants have consented with the privacy statement and the processing activities. Yet, it is important to clarify that participants have the right to stop the survey at any given moment; this should be part of the description. Lastly, the privacy statement will be a brief explanation of why the personal data of the participant is required, for which purposes the data will be used (e.g. age comparison, demographic analysis, etc.) and that the data will be anonymized or destroyed when it's no longer required for further research, will be added.

### 2.2.4 Data scraping

No personal data that can be linked to users (usernames, gender, location, etc.) will be collected or stored during the data scraping activities. Only users numeric IDs and server interaction data will be collected and stored, which can be seen as personal data -if the data can be linked to existing usernames. If in any case, numeric IDs or other information can refer to users - the data will be considered personal data, in compliance with the GDPR principles. All personal data must be anonymized or deleted if it's no longer required for research activities or analysis.

## 2.3 Research tools

This section addresses the tools that will be used throughout the project. It includes research tools as well as prototypes and immersive media. Because at this stage of the project (starting phase), the Möbius tool is in development and the living lab activities are planned and designed iteratively with this development process, this section will be updated regularly.

Various tools will be used during the ongoing data collection and experiments. Some instruments are straightforward like surveys, recording equipment for interviews, brainstorm tools, etc. Participants' consent for the use of these tools is part of the informed consent (see template in Annex 8).

In addition, during the living labs, participants will experiment with different prototypes, which are based on immersive media technology. So, our testers may use VR-headsets, 3D audio headsets or other immersive tools. If participants sign up for these tests, they will receive the needed information concerning health related risks. For example, some people experience nausea during VR experiences, but also more serious conditions like epilepsy must be taken into consideration. More information is available in the health and safety section.

## 2.4 Participants' involvement

The research activities require different forms of participants' involvement. Below we differentiate between active- and passive involvement.

### *2.4.1 Passive involvement*

The Möbius project aims to involve prosumers in the project in different ways. Because many prosumers are active online, it is interesting to gather insights about prosumers related to the publishing industry - fan fiction communities are an excellent starting point. Websites such as Fanfiction.net and Archive of Our Own (AO3) will be data scraped and structured into data sets. In this section, it's important we clarify how this can be done while respecting GDPR regulations, assuring anonymity and web host approval.

Personal data will be gathered; hereby **respecting the GDPR**. In addition, **respecting the web hosts guidelines, terms and conditions**, towards data scraping is important to collect data in accordance with legal requirements, and not to overwhelm the website's traffic. As mentioned in the Data Management Plan, project partners involved will take measures to secure the gathered data. No personal information will be mentioned in future reports, blog posts or any sort of external communication. At the end of the project, all handled personal data will be destroyed or anonymized from every data collection point. However, in order to ensure the reproducibility and replicability of the research conducted some of this data could be published in online repositories. The data shared is always anonymized and aggregated, and there is no personal information.

**AO3** allows third parties to scrape data without a formal consent. The data scraping begins in June 2021, starting with the Harry Potter (HP) fandom on AO3. The scraping process can take several weeks until completion, due to the enormous amount of HP fanfic. It is important to stress that only data necessary for deliverable D3.1 will be scraped:

- number of fanfic stories
- number of kudos (likes) per story
- number of bookmarks per story
- interactions between authors and readers through comments

**FanFiction.net** does not allow third parties to scrape data, which is why the Möbius consortium is currently asking for permission to scrape data to strengthen our research.

If the consortium deems it necessary to scrape any other (fan fiction communities) websites, this section of the deliverable will be updated.

### *2.4.2 Active involvement*

Complementary to scraping existing data online, new data will be gathered through user participation, by both qualitative- and quantitative methods. Throughout the project, various experiments will take place, organized by different consortium partners. Participants across Europe will engage with Möbius prototypes in a living lab environment – testing new applications and immersive formats. Still, it's important to mention that the requirements

concerning guidelines, GDPR and informed consent are equal for all partners. A step-by-step guide is available via this link and must be followed by all consortium partners. Figure 2 below shows the steps to follow for each of the research activities.

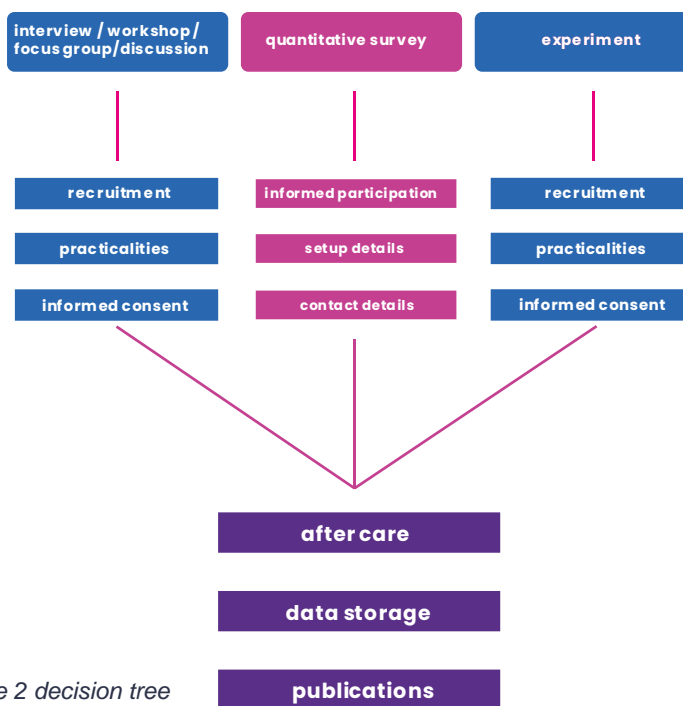


Figure 2 decision tree

The informed consent procedures are mostly identical for both interviews and experiments - templates in English are available in Annex 8. Depending on the location of the testing and experimenting, the templates can be translated to the native language of participants. The ethical requirements concerning active research methods will be discussed in the next section.

### 3. Ethical procedures, privacy and data protection

All consortium partners will ensure that all research activities during Möbius will take into account ethical principles, such as the non-discrimination principle, voluntary participation principle, ensuring the integrity of the research by applying good research practices and privacy principles.

This chapter will mainly focus on the privacy principles, considering these are the most relevant for the Möbius project. For other ethical principles, the consortium partners rely on European guidelines such as the of European Code of Conduct for Research Integrity, or European and national anti-discrimination laws. During the life span of the Möbius project, this chapter can be updated, if e.g. it becomes clear that certain research activities are subject to other specific ethical requirements or legislation.

Consortium partners guarantee the safety of our participants' personal- and acquired data. This by strictly following the European GDPR and national legislation concerning protecting personal data, data collection, usage and storage. Under no circumstances will personal data be shared with third parties or consortium partners that don't need (certain) personal data for their deliverables. The collected personal data will be anonymized when the personal data is no longer necessary for the purposes for which the personal data was initially collected. In any case, no personal data will be used in publications. Statements or quotes may only be used in a pseudonymized manner, with the permission of the participant (via informed consent).

## 3.1 Dealing with participants

It is important that consortium partners are equipped with the right tools and knowledge concerning participant recruitment and how to respect GDPR regulations.

### 3.1.1 General guidelines

Before we go into the different ethical considerations per research activity, we give a brief overview of the general guidelines the consortium partners take into consideration when they process and collect personal data.

#### Transparency

Participants should be informed about:

- their participation in the project being on a voluntary basis, hereby, they have the right to stop the experiment, workshop, interview or survey at any given moment, and demand to delete their personal- and collected data
- the purpose of processing and collecting their personal data and what personal data will be processed.
- how their data will be used, processed, stored and handled during and after the project duration
- who has access to their data
- participants need to be aware of their rights as a data subject according to GDPR, chapter 3: <https://gdpr-info.eu/chapter-3/><sup>4</sup>
- personal data will not be stored longer than required for the purposes for which the personal data is collected in the first place.
- the nature of their input, the timing and location of the research activity
- potential health hazards

#### Data minimization and purpose limitation

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<sup>4</sup> European Parliament. (2018). *Chapter 3 – Rights of the data subject*. Gdpr-Info. <https://gdpr-info.eu/chapter-3/>



Consortium partners will ensure that they have a specific, legitimate and explicit purpose for which they process personal data and ensure that they only process relevant information for this purpose.

### **Data retention and security**

Consortium partners will only handle and store the personal data for as long as this is necessary for the purposes for which the personal data is collected. After this period, all personal data will be anonymized or deleted. Consortium partners will also ensure the safety of the personal data collected by implementing technical and organizational measures securing the personal data.

We understand that some participants would like to be kept up-to-date about the project progress. They can follow Möbius via various channels: Linked-In, Instagram, the Möbius website and the newsletter. These channels will be provided in the informed consent. Participants can also indicate that they are interested in participating in subsequent research activities. Their contact information will be stored on a separate file and can only be accessed through consortium partners that manage the Möbius communication channels.

#### *3.1.2 Personal data relating to children*

At this time, no special categories of personal data, as mentioned in article 9 GDPR, will be processed by any consortium partner during the Möbius project.

**Children:** The Zoomer generation (kids and teenagers) is crucial for Möbius. Yet, to assure their privacy and safety, all consortium partners will be extra cautious with their data. First, minors can only participate in the interviews or surveys with consent from their parents or legal guardian. Minors cannot sign their informed consent; this can only be signed by their parent(s) or legal guardian. It's important to guide the parent(s) or legal guardian through informed consent. Both the parent(s), legal guardian or the minor can stop the research activity without reason or any given moment; and demand to delete their personal- and acquired data.

As mentioned above, it is not the goal of data scraping to collect and process personal data. It is, however, not possible to exclude personal data during data scraping, because of the numeric IDs and server interaction data. For this reason, we cannot guarantee that the data sets from the data scraping includes personal data relating to minors. The consortium partners do guarantee that if personal data is collected during the data scraping, this personal data will also be handled and stored in accordance with the data protection principles as detailed in this chapter and guaranteed by the GDPR.

## **3.2 Setting up interviews, workshops and focus groups sessions**

In this section we discuss the different steps to set up an interview, workshop or focus group session compliant with ethical guidelines.

### 3.2.1 Call for participation

Recruiting potential participants is an important and delicate task that needs to be taken seriously. Developing a trustworthy relationship with participants will have a positive impact on the Möbius research and its final product(s). Hereby, it's crucial that every consortium partner follows the needed steps during recruitment process. It's also mandatory to mention that we will only contact the participant for a particular research activity, he/she will not receive newsletters nor will he or she be contacted for further research activities - only if the participant explicitly confirms that he/she would like to participate in further research activities.

- Open communication towards the participant
- What is Möbius
- What is the purpose of the research activity
- What sorts of data will be collected
- Information on data privacy
- Who will store, and has access to the data
- Participants rights (see section 3.2 *Guidelines*)
- Where to find Möbius published articles, blogpost and deliverables

### 3.2.2 Practicalities

When participants have responded to a call for participation, the organising partner will contact these participants individually and provide all information the participant needs to take part in the activity:

- Time and location
- Nature of the activity
- Goal of the activity

### 3.2.3 Informed consent

Before the start of the interview, workshop or focus group session, the Informed-consent-document must be signed in twofold. This can be either physical or digital (signed via Word document or PDF) copy. The document should be in the native language of the participant and provides a brief overview of the project, its objectives and mentioning if the research will be recorded (notes, video, audio). It also contains the research activity including timing and location and what is expected from the participants. Most importantly, it mentions the rights of the participants; hereby he/she has the right to stop the activity without reason at any given moment. It states our data processing plan, stressing the importance of privacy and anonymization. Any other form of data gathering, like pictures, can only be used with the permission of the participants, especially if they will be used in deliverables (blogs, articles, social media, etc.). The English template of the informed consent form is available on Annex 8.2. Please translate the needed sections of the informed consent into your native language to inform your participants.



### 3.2.4 After the research activity

When the research activity is finished, it's important to carefully handle the informed-consent-documents. The documents must be uploaded or stored on to a central online- or offline facility. In no case should informed-consent-documents be shared or uploaded to personal storage facilities.

## 3.3 Survey

When setting up a survey, two major steps need to be considered:

- The participants need to know that the survey links to the Möbius project, what the project stands for and how the survey results will help the Möbius project. This can be done by adding a brief explanation to the start-screen of the survey. In addition, participants need to be made aware that by filling out the survey and agreeing to the privacy statement, they are automatically giving consent for the use of this data, including their personal data. However, they can stop participating at any time and can request at any time throughout the project to have their data removed from the data set.
- After the survey is completed, participants must get the opportunity to leave additional comments and to reach out to the consortium directly. This can be done by adding a free text survey question where participants are asked for additional remarks and by stating the contact details of the organising researcher on the final screen of the survey.

## 3.4 Experiments

The Möbius project will most likely set-up experiments including different immersive technologies. It is mandatory to receive approval from an ethical board, which is discussed in the next section *3.4.1 Ethical board*. Most experiments allow participants to be fully informed about the research activity. Yet, some experiments don't fully inform or explicitly mislead participants - as part of the experiment. If this is required for the experiment, imec-smit, Vrije Universiteit Brussel will submit an ethical approval request to the VUB ethical board.

### 3.4.1 Ethical board

Specific research activities such as experiments need to be approved by an ethical board before they can be set up. The Vrije Universiteit Brussel, of which research partner imec-SMIT is part, will act as the ethical board in case ethical approval is required. If certain project activities need specific ethical approval, Imec will file a request with the ethical board of the Vrije Universiteit Brussel (VUB). This is a living document. So, adjustments to this section are possible.

## 4. Data Management

Keeping personal- and collected data secure is a key priority to build lasting relationships with the participants. Hereby, it is important to build a secure Data Management Plan (DMP). In the

DMP further instructions will be discussed concerning data security, management and when certain data must be deleted. Yet, it's important to mention that consortium partners are responsible for the data they collected. Also, personal data of participants shouldn't be shared between consortium partners, but exceptions can be made. If personal data needs to be shared, please contact Eurecat to discuss the needed procedures. The DMP is built by Eurecat as part of D1.3.

## 5. Health and safety

Most research activities will not involve any health or safety risks for participants. The only exception might be activities that involve the use of head-mounted displays for immersive media experiences. For this type of activities, we will provide additional health information to the participants.

## 6. Conclusion

The ethical requirements report provides a brief overview of the ethical procedures when conducting research with human participants. It is mandatory that every consortium partner is informed about the ethical guidelines, before conducting any research activity. This report covers different research methods that will be applied in the Möbius project and the mandatory preparation concerning: contacting participants, informed consents, after care, etc.

Lastly, the importance of handling personal data according to the GDPR is stressed throughout the report. Personal data will be gathered during numerous research activities and shall be treated following the GDPR. When the personal data is no longer required for further research activities or analysis, the data will be deleted or anonymized.

This is a living document that will be adjusted during the lifespan of the Möbius project. The final version of the report will be available in M36

## 7. References

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Kilpi, K., Lievens, B., Stamatelatos, M., Aguilar Santiago, M., & Osstyn, D. (2013). *Deliverable D2.2. Methodological Approach*. (Deliverable D2.2. Methodological Approach in Smart Platforms Enabling the Creative Industries for Future Internet (SPECIFI)). Unknown.

Möbius. (n.d.). *Our story – Möbius*. Mobius-Project. <https://mobius-project.eu/our-story/>

## 8. Annexes

The templates hereinafter are to be adapted and modified depending on the type of research being carried out.

### 8.1 Template for privacy notice for online survey

#### PRIVACY NOTICE MÖBIUS

[COMPANY, address], is/are responsible for processing your personal data for this online survey within the Möbius project. COMPANY will process your feedback and data in accordance with the General Data Protection Regulation (EU) 216/679 (GDPR) and other applicable privacy legislation. Below is explained how and for what purposes your personal data is processed for the online survey.

#### Participation

##### **What is the goal of the project?**

Möbius is an initiative funded under the European Commission Horizon 2020 programme (grant agreement 957185) that aims to modernize the European book publishing industry by remodelling the traditional value chains and business models uncovering the prosumer potential and delivering new enriched media experiences.

##### **What does your participation entail?**

**Your participation to our projects is of course entire voluntary.**

As participant, we will ask you to complete our online survey. At the end of the survey, we will ask you for some contact information to be able to contact you with information about next phases in the Möbius project.

##### **What personal data will we collect from you?**

[Complete what personal data is collected during the online survey]

- *Identification data (eg name, first name, ...)*
- *Contact details (eg address, email address, telephone number, ...)*
- *Financial information (eg Bank account number, salary, ...),*
- *Demographic information (civil status,...)*
- *Location data (eg GPS, ..)*
- *Professional data (eg profession, education, studies, ...)*
- *Sensitive data (sexual orientation, religion, political preference, race and ethnic background, trade union organization, ...)*
- *Medical data (eg ECC, medical history, ...)*
- *Biometric data (eg fingerprint, ...)*
- *Connective data (IP address, ...)*
- *Log data (eg Mobile DNA)*
- *Information about behaviour and habits (smoking habits, user experience, purchasing behaviour, ...)*

### **Who will have access to your personal data?**

1. Our own researchers will have access, but also other researchers within the Möbius project, only when they require access for the purposes as described above.
2. Your personal data can be shared with organisations and companies who support us during the execution of the Möbius project, such as Qualtrics.

Some of these recipients can be located outside the EEA. [COMPANY] will ensure that your personal data will only be transferred to countries where similar protection as the GDPR is guaranteed.

### **Your rights**

For processing your personal data, we rely on your consent. You have the right to withdraw your consent at all times and end your participation in our research activities, without having to give a reason.

In addition, you can request us to obtain a copy of the personal data collected by us and / or to correct or delete this information in our files.

You can do this by sending an email to: <Project contact>.

### **Technical and organisational measures and data retention**

[COMPANY] has taken appropriate technical and organizational measures, which are incorporated in internal information security documents, to protect your personal data.

Your personal data collected will be stored for up to 5 years after the last collection. Your personal data will be removed from our systems after 5 years. <OR> After 5 years, your personal data will be anonymised so that it can no longer be traced back to you.

### **Contact**

With all your questions and / or comments about the processing of your personal data, you can contact

- [COMPANY] via the email address \_\_\_\_\_ or consult the privacy statement on the website \_\_\_\_\_.

## **8.2 Template for informed consent**

We invite you to participate in Möbius, an initiative funded under the European Commission Horizon 2020 programme ((grant agreement 957185) that aims to modernize the European book publishing industry by remodelling the traditional value chains and business models uncovering the prosumer potential and delivering new enriched media experiences.

In this particular study we focus on <aim of study>. This study is carried out by <researcher> on behalf of [COMPANY].

## What does your participation entail?

As a participant you participate voluntarily in the following research activity(ies):

*Explain how the participants are expected to participate in the study. [Interviews, focus groups,...]*

## PRIVACY

[Name controller/joint controllers] is/are responsible for handling your personal data in accordance with the General Data Protection Regulation (EU) 216/679 (GDPR) and other applicable privacy legislation.

### What data do we collect?

The following personal data are processed in the context of this study

*Select the personal data that will be collected during the focus groups.*

- *Identification data (eg name, first name, ...)*
- *Contact details (eg address, email address, telephone number, ...)*
- *Financial information (eg Bank account number, salary, ...),*
- *Demographic information (civil status,...)*
- *Location data (eg GPS, ..)*
- *Professional data (eg profession, education, studies, ...)*
- *Sensitive data (sexual orientation, religion, political preference, race and ethnic background, trade union organization, ...)*
- *Medical data (eg ECC, medical history, ...)*
- *Biometric data (eg fingerprint, ...)*
- *Connective data (IP address, ...)*
- *Log data (eg Mobile DNA)*
- *Information about behaviour and habits (smoking habits, user experience, purchasing behaviour, ...)*

[Company] can use the collected data in pseudonymised form for further scientific research in the same research domain as this study for which you have given permission. The pseudonymised data is stored for up to 5 years after collection.

### Why will we process this data?

The personal data collected during this study will only be used in the context of our research studies as described here:

- *The identification data and contact information are used to be able to contact you about the planning of the interviews and focus groups.*
- *The demographic data and professional information are used in the context of the research to*  
...
- *Behavioural information ...*
- *Log data*
- *Physiologic data*
- *Health data*

### **Who will have access to your personal data?**

The researchers of the Möbius project have access to the necessary personal data for carrying out their assignment within the planned research.

Your personal data can be shared in a pseudonymised form with employees of the companies and organizations we work with in the context of Möbius for the implementation of the project or assistance and support. [Include limit list]

If a party is involved that is located outside the European Economic Area (EEA), imec will ensure that your data is always adequately protected and therefore only uses countries or organizations or sectors that guarantee equivalent protection.

### ***Technical and organisational measures and data retention***

[COMPANY] has taken appropriate technical and organizational measures, which are incorporated in internal information security documents, to protect your personal data.

Your personal data collected will be stored for up to 5 years after the last collection. Your personal data will be removed from our systems after 5 years. <OR> After 5 years, your personal data will be anonymised so that it can no longer be traced back to you.

### **Your rights**

We collect your data on the basis of your consent, which means that you have the right to stop your cooperation at any time without having to give a reason. This can easily be done in writing by e-mail to <project manager>, after which imec will process your cancellation as soon as possible. In addition, you can request us to obtain a copy of the personal data collected by us and / or to correct or delete this information in our files.

You can do this by sending an e-mail to **<contact information of project responsible>**.

### **Questions**

With all your questions and / or comments about the processing of your personal data, you can contact

- [COMPANY] via the email address \_\_\_\_\_ or consult the privacy statement on the website \_\_\_\_\_.

### **Consent**

I declare that I have read all the information and that I agree to participate in the <study> as described in this brochure. I consent to the collection and processing of my personal data as described in this information brochure

Name participant:
Date:
Signature: