



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No.: 761999



EasyTV: Easing the access of Europeans with disabilities to converging media and content

EasyTV_D.9.1

EasyTV Project

H2020. ICT-19-2017 Media and content convergence. – IA Innovation action.

Grant Agreement No.: 761999

Start date of project: 1 Oct. 2017

Duration: 30 months

Document. ref.: D.9.1, H – requirement No. 1

Disclaimer

This document contains material, which is the copyright of certain EasyTV contractors, and may not be reproduced or copied without permission. All EasyTV consortium partners have agreed to the full publication of this document. The commercial use of any information contained in this document may require a license from the proprietor of that information. The reproduction of this document or of parts of it requires an agreement with the proprietor of that information. The document must be referenced if is used in a publication.

The EasyTV Consortium consists of the following partners:

	Partner Name	Short name	Country
1	Universidad Politécnica de Madrid	UPM	ES
2	Engineering Ingegneria Informatica S.P.A.	ENG	IT
3	Centre for Research and Technology Hellas/Information Technologies Institute	CERTH	GR
4	Mediavoice SRL	MV	IT
5	Universitat Autònoma Barcelona	UAB	ES
6	Corporació Catalana de Mitjans Audiovisuals SA	CCMA	ES
7	ARX.NET SA	ARX	GR
8	Fundación Confederación Nacional Sordos España para la supresión de barreras de comunicación	FCNSE	ES

PROGRAMME NAME:	H2020. ICT-2016-2017. H2020-ICT-2016-2
PROJECT NUMBER:	761999
PROJECT TITLE:	EasyTV: Easing the access of Europeans with disabilities to converging media and content
RESPONSIBLE UNIT:	UPM
INVOLVED UNITS:	UAB and UPM
DOCUMENT NUMBER:	1
DOCUMENT TITLE:	H – Requirement no. 1
WORK-PACKAGE:	WP9
DELIVERABLE TYPE:	CO
CONTRACTUAL DATE OF DELIVERY:	31 March 2018
LAST UPDATE:	01/03/2018
DISTRIBUTION LEVEL:	PU

Distribution level:

PU = *Public,*

RE = *Restricted to a group of the specified Consortium,*

PP = *Restricted to other program participants (including Commission Services),*

CO = *Confidential, only for members of the LASIE Consortium (including the Commission Services).*

Document History

VERSION	DATE	STATUS	AUTHORS, REVIEWER	DESCRIPTION
0.1	8-2-2018	Draft	Pilar Orero (UAB)	Table of Contents Definition, Document structure and first draft
0.2	19-2-2018	Draft	Sara Rovira, Irene Tor (UAB)	First correction
0.3	20-2-2018	Draft	Pilar Orero (UAB)	First correction
0.4	27-2-2018	Draft	Federico Álvarez (UPM)	Adding hyper- personalization risks
0.5	27-2-2018	Final	Pilar Orero (UAB)	Validation

Definitions, Acronyms and Abbreviations

ACRONYMS / ABBREVIATIONS	DESCRIPTION
EA	Ethical Advisor
GA	Grant Agreement
CA	Consortium Agreement

Table of Contents

List of Figures	8
Executive Summary.....	9
1. Introduction.....	10
2. Ethical considerations	10
2.1. Research ethical framework.....	11
2.1.1. Charter of Fundamental Rights of the European Union	11
2.1.2. European Code of Conduct for Research Integrity.....	11
2.1.3. Specific guidance on social sciences and humanities.....	12
2.2. Research with human subjects from vulnerable groups	13
2.3. Ethics in H2020 projects.....	13
2.3.1. Grant agreement dispositions	13
2.3.2. Ethics Appraisal Procedure	14
2.4. EasyTV Ethical Procedures.....	15
2.4.1. Recruitment processes for experimental testing	16
2.4.2. Informed consent procedures	16
2.5. Communication with vulnerable participants.....	17
2.6. Health and safety of participants	17
2.7. Personal data protection: EU regulations.....	18
2.8. Personal data protection in EasyTV	18
2.8.1. Video recordings rights	18
2.8.2. Video recordings and promotional material	18
2.8.3. Website	19
2.9. Risks of hyper-personalization	19
2.9.1. Main related risks	19
2.9.2. Measures proposed to reduce risks (according to the literature on the matter)	20
REFERENCES	21
ANNEXES	22
Annex I: Information sheet	22
Annex II: Consent form (written version).....	23
Annex III: Sample of an oral information sheet.....	24
Annex IV: Consent form in Spanish sign language (snapshots of clip)	25
Annex V: Consent form that grants photo, video and sound recording rights to UAB.....	26

LIST OF FIGURES

Figure 1 Certificate of ethical procedures for EasyTV..... 15

Figure 2 Personalization phases 19

EXECUTIVE SUMMARY

This deliverable was requested by the EC ethical committee to report a preliminary version of D.6.2.1 including at least Ethical Data Management Plan, including security; report on the risks of hyper-personalisation; Consent forms and Recruitment plan (including details on how to not affect other members of the household).

Therefore, this deliverable describes procedures implemented for EasyTV to ensure compliance with the **Ethical Considerations** in the project. It offers all the information regarding permissions and forms approved by the UAB Ethical Committee to be taken into account during EasyTV project when performing any end user interaction to gather information (focus groups and questionnaires). It also deals with the permissions required when taking pictures or filming end users.

Risks derived from the hyper-personalization have been addressed, including relevant considerations in the literature.

The appendices gather all the original documents approved and ready to be used when interacting with end users in English. Documents have also been translated into Catalan, Spanish, Greek and Italian, the four languages which will also be used during consultation with end users and pilots. For the Deaf end users a translation was performed from the Spanish documents to Spanish Sign Language. These videos are available in the intranet.

1. INTRODUCTION

Ethics is a vital part of research for all projects funded by the European Union. The EasyTV project will carry out research involving work with human beings and will generate data, therefore ethical procedures need to be followed. Special care needs to be taken when dealing with ethical considerations because the project deals with human participants, mostly from vulnerable groups, which will participate in different tests. They will be volunteers for social or human sciences research, which does not involve physical interventions on study participants.

EasyTV research will comply with ethical principles and applicable law, guaranteeing that the rights of research participants are ensured and that research methodologies do not result in discriminatory practices or unfair treatment. Special attention will also be paid to privacy, data protection, data management, and health and safety of participants. Every project team needs to plan in advance every action that needs to be performed in order to develop an ethically correct and integral research in all aspects of its process. An ethical approach must be adopted from a legal point of view, but also regarding quality of research and excellence.

In the project's kick-off meeting the project leader (UPM) allotted the task of drafting this document UAB, since this partner is already EasyTV's Ethical Advisor (EA). The EA is responsible for the proper management of all ethical aspects, and most specifically of:

1. Ensuring the proper management of all ethics procedures
2. Supervising all actions related to users
3. Providing advice and recommendations on ethics to all Parties and the Coordinator.

The choice of UAB as responsible partner for Ethical consideration is based on the fact that UAB has already been successfully carrying out this task in two previous EC funded projects (DTV4ALL and HBB4ALL). Moreover, UAB has an Ethics Committee on Animal and Human Experimentation (CEEAH)¹ which guarantees that any research conducted by UAB's researchers complies with EU's ethical requirements.

CEEAH was set up by the UAB Governing Board on 25 January 2001, and is responsible for lending support to the scientific research performed at the UAB. This committee evaluates animal experimentation procedures and procedures that involve experiments or research with humans, and it trains and advises research staff on the ethical dimension of their work. For example, the CEEAH was behind the ruling of the Governing Council on 30 January 2013 which approved the Code of Good Practice in Research: a set of recommendations to ensure rigour, honesty and responsibility in research carried out at the UAB.

The CEEAH has been a member of the Network of Ethics Committees in Universities and Public Research Centers in Spain (RCE)² from its beginnings.

2. ETHICAL CONSIDERATIONS

The following sections present an overview of the research ethical framework and the specificities of dealing with human subjects from vulnerable groups. It also describes how ethical procedures are approached in H2020 projects, and more specifically in EasyTV. Special emphasis is put on communication with vulnerable participants and health and safety issues.

¹ See <http://www.uab.cat/web/ethics-committee-on-animal-and-human-experimentation-1of345735628829.html>.

² See <http://www.ub.edu/rceue/>.

2.1. Research ethical framework

Ethics is an integral part of research and is given a high priority in EU funded research.³ EasyTV will comply with existing regulations and codes of conduct. Some of the most relevant documents are the following.

2.1.1. Charter of Fundamental Rights of the European Union⁴

This document gathers the fundamental rights to be shared, fostered and protected by every Member State of the European Union. The first draft was created by the European Convention in 2000 and was solemnly proclaimed by the European Parliament, the Council of Ministers and the European Commission during the same year. However, it was not legally binding until the entry into force of the Treaty of Lisbon, on 1st December 2009. The Charter contains 54 articles divided in seven titles: dignity, freedoms, equality, solidarity, citizens' rights, justice and general provisions governing the interpretation and application of the Charter. This Charter must be abode by Member States when applying European Union law.

The Charter sets the starting point for any research or action conducted within the context of the European Union. Every article needs to be taken into consideration in order to develop a study within an ethical framework, such is the case of any project supported and funded by the European Union. There are certain specific articles that are of high importance when developing the methodology to conduct a research in Social Science. For example, Article 8, Title II (European Parliament, Council and Commission, 2012), on Protection of personal data, which literally states that:

1. Everyone has the right to the protection of personal data concerning him or her.
2. Such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law. Everyone has the right of access to data which has been collected concerning him or her, and the right to have it rectified.
3. Compliance with these rules shall be subject to control by an independent authority.

Also, in relation to EasyTV project, the Article 26, Title III on integration of persons with disabilities needs to be considered when defining the general vision of the project and its entire development (European Parliament, Council and Commission, 2012): "[t]he Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community." In sum, any action taken within EasyTV project needs to be compliant with all fundamental rights enshrined in this Charter.

2.1.2. European Code of Conduct for Research Integrity⁵

The Code of Conduct for Research Integrity was created by the European Federation of Academies of Sciences and Humanities and has been recently revised and republished in 2017. This document contains a set of rules to self-regulate academic research through European territories and it is designed to be used across all scientific fields, without distinction. It includes the principles to preserve research integrity, a list of good practices and some guidelines about violations of research integrity (the most serious being fabrication, falsification and plagiarism) and procedures to be followed in the event of those violations.

³ See <http://ec.europa.eu/research/swafs/index.cfm?pg=policy&lib=ethics> (retrieved 8/2/2018).

⁴ See <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:12012P/TXT&from=EN> (retrieved 8/2/2018).

⁵ See <http://www.allea.org/wp-content/uploads/2017/05/ALLEA-European-Code-of-Conduct-for-Research-Integrity-2017.pdf> (retrieved 8/2/2018).

According to this Code of Conduct, the principles to preserve research integrity are (ALLEA, 2017):

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

The document describes good research practices in various contexts: research environments; training, supervision and mentoring; research procedures; safeguards; data practices and managements; collaborative working; publication and dissemination, and reviewing, evaluating and editing.

Among other good practices and recommendations, the document establishes that “[r]esearchers handle research subjects, be they human, animal, cultural, biological, environmental or physical, with respect and care, and in accordance with legal and ethical provisions” (ALLEA, 2017: 6).

An explicit mention of ethical practices is also made under the section “Violations of Research Integrity”, where the document states:

It is of crucial importance that researchers master the knowledge, methodologies and ethical practices associated with their field. Failing to follow good research practices violates professional responsibilities. It damages the research processes, degrades relationships among researchers, undermines trust in and the credibility of research, wastes resources and may expose research subjects, users, society or the environment to unnecessary harm. (ALLEA, 2017: 8)

This document is especially important for all researchers participating in Horizon 2020 funded projects, since it has become a reference document.

2.1.3. Specific guidance on social sciences and humanities⁶

The interdisciplinarity inherent in Social Science and Humanities (SSH) research hinders the elaboration of clear patterns to develop an ethical framework to be followed by every researcher in this field. The methodologies vary from one discipline to another and the ethical implications also differ. This discussion has been held for many years in international fora, worldwide and within the European Union. On a document which provides specific guidance for the SSH field, it is stated that the basis to ensure an ethical research is provided by the following tools: informed consent, data protection and privacy, and impact of the research results (European Commission, 2010).

The document acknowledges that “[w]hile in some instances, the research activity itself could produce psychological discomfort or harm, in most cases the biggest risk in SSH research relates to the disclosure of a person’s identity and insufficient protection of private information which may then lead to discrimination or stigmatization” (European Commission, 2010: 9).

⁶ See http://ec.europa.eu/research/participants/data/ref/fp7/89867/social-sciences-humanities_en.pdf (retrieved 8/2/2018).

2.2. Research with human subjects from vulnerable groups

EasyTV will carry out research with human subjects, some can be considered to be part of vulnerable groups. According to the European textbook on ethics research (European Commission, 2010: 53),⁷ vulnerability is a very complex concept and the following indicators could be used to define vulnerable groups:

- “1. Subjects who lack competence will be unable to protect their interests by choosing to give or withhold consent (as discussed in Chapter 2).
2. If the voluntariness of the subjects’ consent is compromised, this may similarly prevent them from choosing to give or withhold consent in a way that would protect their interests.
3. The physical (or psychological) condition of some subjects leaves them especially liable to harm, for example as a result of frailty through age, disability, or illness.”

Part of the participants in the pilots for the EasyTV project (i.e., people with disabilities or the elderly) will fall within the third group, hence special care should be taken to guarantee their rights, which has been done in the EasyTV ethical forms and consent, and the data protection provisions elaborated to this aim. Special attention has been taken to Sign Language interpretation with ad hoc videos to all the documentation.

2.3. Ethics in H2020 projects

Ethical compliance is seen as fundamental in research projects funded by the European Union. As explained in the webpage of the Science with and for Society (SwafS),⁸ ethics is dealt with in the Horizon 2020 legislation at various levels. There is also a specific Ethical Appraisal Procedure in Horizon 2020 projects. The Horizon 2020 Rules for Participation⁹ determine that proposals cannot contravene ethical principles and that the Commission shall systematically carry out ethics reviews for proposals (Article 14). The Horizon 2020 Regulation of Establishment, establishes in Article 19 (Ethical principles) that:¹⁰

1. All the research and innovation activities carried out under Horizon 2020 shall comply with ethical principles and relevant national, Union and international legislation, including the Charter of Fundamental Rights of the European Union and the European Convention on Human Rights and its Supplementary Protocols. Particular attention shall be paid to the principle of proportionality, the right to privacy, the right to the protection of personal data, the right to the physical and mental integrity of a person, the right to non-discrimination and the need to ensure high levels of human health protection.

More specific dispositions are found in the GA, as described in the next section.

2.3.1. Grant agreement dispositions

Article 34 in section 4 of Grant Agreement No. 761999 establishes the obligations concerning “Ethics and research integrity”. Its subsections discuss (1) obligation to comply with ethical and research integrity principles, (2) activities raising ethical issues, (3) activities involving human embryos or human embryonic

⁷ See <https://publications.europa.eu/es/publication-detail/-/publication/0f37f142-c333-40a8-90a7-bba25c314720/language-en> (retrieved 08/2/2018).

⁸ See in <http://ec.europa.eu/research/swafs/index.cfm?pg=policy&lib=ethics> (retrieved 08/2/2018).

⁹ See http://ec.europa.eu/research/participants/data/ref/h2020/legal_basis/rules_participation/h2020-rules-participation_en.pdf#page=10 (retrieved 08/2/2018).

¹⁰ See http://ec.europa.eu/research/participants/data/ref/h2020/legal_basis/fp/h2020-eu-establact_en.pdf#page=11 (retrieved 08/2/2018).

stem cells, and (4) consequences of non-compliance (GA, 51-53).

Summaries of the respective subsections are provided below, but project participants are encouraged to read the relevant sections in the GA.

Article 34.1. puts forward the obligation of the beneficiaries to carry out the action in compliance with (1) ethical principles, and (2) applicable international, EU and national law. It also stresses when funding will not be granted. It addresses the question of research integrity, already discussed above, and enumerates principles that the beneficiaries must respect, namely: honesty, reliability, objectivity, impartiality, open communication, duty of care, fairness, responsibility for future science generations. It also discusses how these values should be implemented while conducting research activities (see GA, 52).

Article 34.2 tackles the question of activities raising ethical issues. It states that they need to comply with ethical requirements considered as deliverables presented in the Annex 1 (Description of the action) of the Grant Agreement. It also states obligations before beginning any activity raising an ethical issue, namely obtaining ethics committee opinion required under national law or obtaining notifications or authorisations required by national/European law (see GA, 53). These documents must be kept on file and submitted if requested, as indicated on GA (ibid. 53).

Article 34.4 refers to the consequences of non-compliance, which may result in reduction, termination of the grant, or other measures (ibid. 53).

Article 41.2 also establishes that each beneficiary must submit to the coordinator in good time the “ethics committee opinions and notifications or authorisations for activities raising ethical issues” (ibid. 59).

2.3.2. Ethics Appraisal Procedure

The Ethics Appraisal Steps in H2020 projects include:

- Ethics self-assessment
- Ethics pre-screening/screening
- Ethics assessment (for specific proposals)
- Ethics Checks/Audit

Horizon 2020 rules also establish that all proposals considered for funding also undergo an Ethics Review. It starts with an Ethics Screening and, if needed, an Ethics Assessment is performed. It may result in ethics requirements that become contractual obligations. In the EasyTV project no contractual obligations are set forth in the GA (see previous section).

During the Ethics Screening/Assessment, some projects are considered to be in need of an Ethics Check during the course of the project, and it will be the role of UAB to check if the technical developments and tests and pilots fulfil the initial provisions drafted in the Ethical Consent and project Information forms. If changes are identified, all relevant forms will be changed accordingly.

Concerning ethics audits, the European Commission can check, review, investigate the proper implementation of the EasyTV project and its compliance with the Grant Agreement both during the implementation of the project and afterwards. For this all signed forms and data will be stored up to two years after the completion of the project locked in UAB.

According to the H2020 website and to the provisions of the Grant Agreement (Article 22 of the Grant Agreement, p. 36), an audit of the grant can be ordered by the European Commission up to 5 years after the final payment.¹¹ This includes ethical principles and research integrity.

¹¹ See <http://ec.europa.eu/research/participants/docs/h2020-funding-guide/grants/grant-management/checks-audits->

2.4. EasyTV Ethical Procedures

Section 5 of Annex 1 in the GA describes the general ethics approach in EasyTV, which is developed and specified in the next sections.

Ethical procedures in EasyTV have adopted a holistic approach. EasyTV will implement different methodological approaches and tools, mainly focus groups, interviews, and questionnaires. However, a unified approach to ethical procedures has been favoured as a general framework for the project. The different possible users, some considered as vulnerable groups, are also taken into consideration, as well as the fact of the different languages and ways to interact with the consent form. For example, for persons with sight or low sight conditions spoken information and consent forms have been designed, and approved. When interacting with persons with sign language as their mother language, this will be the language of interaction.

After understanding who will be the users in both interactions at WP1 and, permission was requested and obtained from the UAB Ethical Committee on 24/11/2017 obtaining the reference CEEAH 4036 (see figure 1).



Comisión de Ética en la Experimentación Animal y Humana (CEEAH)

Universitat Autònoma de Barcelona
08193 Bellaterra (Cerdanyola del Vallès)

La Comisión de Ética en la Experimentación Animal y Humana (CEEAH) de la Universitat Autònoma de Barcelona, reunida el día **24-11-2017**, acuerda informar favorablemente el proyecto titulado **"EasyTV"** presentado por **Pilar Orero Clavero**

<p>Elaborado:</p> <p>Nombre: Nuria Perez Pastor Cargo: Secretària de la CEEA de la UAB Fecha:</p> <p>NURIA PEREZ PASTOR</p> <p><small>Firmado digitalmente por NURIA PEREZ PASTOR Número de reconocimiento (DN): cn=ES, ou=Viqués https://www.ucc.cat/CAT/Cat/ Regulacio, cn=PEREZ PASTOR, givenName=NURIA, serialNumber=351092387, cn=NURIA PEREZ PASTOR Fecha: 2017.11.29 16:27:59 +01'00'</small></p>	<p>Aprobado:</p> <p>Nombre: José Luis Molina González Cargo: President de la CEEAH de la UAB Fecha:</p> <p>MOLINA GONZALEZ, JOSE LUIS (FIRMA)</p> <p><small>Firmado digitalmente por MOLINA GONZALEZ, JOSE LUIS (FIRMA) Fecha: 2017.11.29 15:51:07 +01'00'</small></p>
---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Figure 1 Certificate of ethical procedures for EasyTV

UAB Ethical Commission requested the following information:

- Title of action
- Short description of the project
- Research area for human experimentation
- Personal data from the researcher responsible
- Research objectives of the experiment
- Research methodology
- Information to participants
- Compensation
- Gathered Data Management
- Feedback to participants
- Data registration

2.4.1. Recruitment processes for experimental testing

Participants in EasyTV tests will be volunteers that will be recruited through end user associations representing persons with disabilities, which are partners in this project, namely, UICI (Italian blind association) and Fundación CNSE (Spanish confederation of the deaf and hard of hearing). Other partners, such as CERTH and ENG have also contacted other associations of persons with disabilities in their respective countries to recruit users to test the new technological components to be implemented. Therefore, recruitment channels for experimental testing are well established.

Testing with persons with disabilities is a taxing activity due to the interaction with end users and the need to personalise from travelling to and from the place for testing, to communicate or explain and read the information, and to help with the tests. From our experience in other EU funded projects, before a test starts a period of over 15 minutes is spent welcoming each user prior to testing, and the same can be said after the test is finished. Specific details about the recruitment processes for experimental subjects and about the inclusion and exclusion criteria will be defined for each specific test.

In the first meeting, it was decided to generate a group named super users. Therefore, two very different recruitment processes for experimental testing have been followed in EasyTV. On the one hand, recruitment of super users who will take part in controlled focus groups to gather information about their expectations on the technology to be developed (WP1). On the other hand, recruitment of regular end users with different profiles and disabilities to test the technology developed (WP6). In both cases, recruitment will be performed through end user associations.

2.4.2. Informed consent procedures

All participants in tests and focus groups will be given a detailed information sheet and an informed consent form. Both documents will be written in terms participants can understand. They describe the aims, methods and implications of the research, and any risks or discomfort that may happen. Participation in EasyTV tests will always be voluntary and participants will explicitly be informed that they can refuse to participate or withdraw their participation at any time without any consequences. Steps will be taken to ensure that participants are not subjected to any form of coercion and alternative communication means will be provided if necessary. Participants will also be informed that they can request additional information about the project results in case they are interested. The information sheets and informed consent forms have been approved

by UAB's ethical committee, and must be used for any types of user testing (focus group, experiments, interviews, etc.). They were approved in English and were translated into the other languages used for user's information gathering (Spanish, Spanish signed language, Italian and Greek).

The procedures that will be followed to obtain informed consent are:

- Participants will be welcomed;
- Participants will be informed about the project and the specific test in which they are involved through the information sheet (Annex I), in an appropriate format according to their needs and the approved models of UAB's ethical committee;
- Participants will be requested to give their explicit written consent through the consent form (see Annex II).

The consent form and information sheet should be included on a single piece of paper (both sides, if needed). Once the test is finished, both the information sheet and the signed consent form will be sent by recorded mail to Pilar Orero, or taken to her at the next EasyTV project meeting. All forms will be kept in a locked room in a secure building at UAB.

In the project meetings that have already taken place, UAB has informed the rest of partners about all the ethical issues involving tests with users and has stressed the need to use all forms when interacting with humans to gather information for the project.

2.5. Communication with vulnerable participants

Information sheets and informed consents will be generally provided in writing. However, if consent cannot be given in writing, non-written consent will be formally documented. Appropriate efforts will be made to ensure fully informed understanding of the implications of participations, providing alternative communication means if necessary. Information sheets and consent forms have been written in a way that participants can fully understand. However, specific adaptations will need to be made to adapt to the specific user needs. More specifically,

- An oral information sheet and consent form can also be administered orally if this is better suited for end user needs (a sample is provided in Annex III).
- Sign language versions have been provided (see Annex IV).

2.6. Health and safety of participants

Avoiding any harm that might occur and ensuring the participants' health and safety is a priority in EasyTV testing. Partners have been asked to identify any potential risks their technological developments might have for different user profiles. If any risk is identified, participants will be informed about them through the information sheet and the consent forms. Appropriate measures will be taken to guarantee the participants' safety and well-being. Participants thought to be unstable or under the influence of drugs or alcohol will not be admitted to the experiments.

2.7. Personal data protection: EU regulations

Data protection regulations in EasyTV are in line with the General Data Protection Regulation (GDPR). The project takes on board EU data protection policies following the European Directive 95/46 with date 24/10/1995, and also national policies for the three countries where tests will be performed.

2.8. Personal data protection in EasyTV

Regarding personal data at EasyTV we shall follow for the time being, and until the new EU law is published, the Spanish Organic Data Protection Law 15/1999, since UAB is under Spanish jurisdiction and we are following guidelines from the UAB Ethical Committee which fulfils EU guidelines. The Law requires files containing data to be declared to a data protection agency and guarantees the rights of access, rectification, cancellation and objection (known as ARCO) rights:

- **Right of information:** When the personal data is collected, the interested party must be previously informed in an express, precise and unequivocal manner of, among others, the existence of a file, the possibility of exercising their rights and the person in charge of the treatment.
- **Right of access:** The right of access allows the citizen to know and obtain free information about their personal data subjected to treatment.
- **Right of rectification:** This right is characterized because it allows correcting errors, modifying the data that prove to be inaccurate or incomplete and guaranteeing the certainty of the information being treated.
- **Right of cancellation:** The right of cancellation allows the deletion of data that prove to be inadequate or excessive, without prejudice to the blocking duty included in the LOPD.
- **Right of opposition:** The right of opposition is the right of the affected party not to carry out the processing of their personal data or to cease it.

EasyTV has taken the approach to anonymise personal data. In the Focus Group end users (WP1) filled in and signed the Consent Form, but this information will not be associated to any comment made by any user during the focus group. When end users take part in the pilots (WP6) they will be asked to reply a questionnaire usually containing questions to be replied in Likert scales. These written forms will be anonymous, hence following ARCO rights. Fake identities will be used whenever we present information obtained from end users.

2.8.1. Video recordings rights

The European Union adopted in February 2014 the Directive on collective management of copyright and related rights and multi-territorial licensing of rights in musical works for online uses in the internal market (CRM Directive). The CRM Directive is an essential part of Europe's copyright legislation. The CRM directive (2014/26/EU) aims at ensuring that right holders have a say in the management of their rights, and at improving the functioning and accountability of Collective Management Organisations (CMOs). EasyTV will follow CRM directive using exclusively videos for testing produced by the project partners, as well as other open access audiovisual content.

2.8.2. Video recordings and promotional material

It has been established in WP7 (Dissemination) to generate at least one EasyTV short movie, but EasyTV aims at creating many short movies to follow the development of the services and offer different types of content. Anyone being recorded for dissemination processes will sign a release and consent form that grants photo, video and sound recording rights to UAB (see Annex V). This form will be stored at UAB for the duration of the project and five years after the end of the project in a locked room in a secure building.

2.8.3. Website

Only project information considered as PUBLIC will be published on the EasyTV website.¹² The project's website is still a work in progress and needs to be further defined by project's partners.

2.9. Risks of hyper-personalization

Hyper-personalization technologies offer a good approach to improve user satisfaction and experience, especially in the media domain. However their use raised privacy concerns and risks which should be further studied in EasyTV [4].

The personalization phases, according to [1][2], include data collection, user model creation, and adaptation. Each of the three phases impose different challenges on privacy and require different measures to address these challenges.

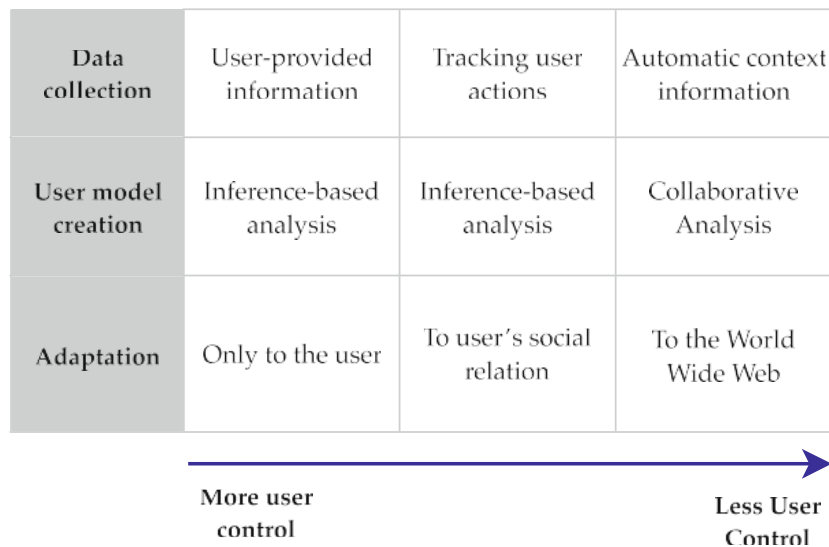


Figure 2 Personalization phases

- The data collection phase represents privacy risks that originate from new types of data collection and analysis.
- The user model creation phase represents risks that originate from new technologies for analyzing the data.
- The adaptation phase originates from distributing the adapted and personalized content in new ways.

2.9.1. Main related risks

According to [3], which is a good survey of privacy risks, well-adapted to the aims of EasyTV, indicates that there are different risks which should be contemplated. EasyTV will take them into account and will provide in D6.2.1 a full coverage and plans to mitigate that risks.

- a) Behavioral profiling and data aggregation:

¹² The website can be accessed at <http://easytvproject.eu/>.

Behavioral profiling is the practice of collecting longitudinal data about a person's activities and tailoring the user experience based on those activities. Unlike systems that rely on data actively provided by the user, in most instances of behavioral profiling the system tracks a wide range of user behaviors, with little or no consent of users. In recent years, behavioral profiling has become common in many domains, including Internet advertising.

Although EasyTV is not going to offer advertisement, the profiling will be done, so risks for using the profile for other reasons not to improve the access to AV services will be contemplated.

b) Location-based personalization

Personalized location-aware services are becoming more and more widespread. Development has been triggered by the adoption of GPS-enabled phones and WiFi positioning technologies, as well as the increase in mobile data bandwidth.

EasyTV will use 2nd screen devices such as Mobile phones or tablets. Although EasyTV is not going to use that data for another uses not related to the project objectives, will control and inform the use of location.

c) Social-based personalization

Most of the social networks store rich information about their users, including real names, email addresses, list of friends, demographics, personal photos, location, inter-personal communications, and more. This information is used for various means of personalization, in domains such as application customization, social search, and online marketing.

EasyTV will collect in the way presented in this document the information, with the solely aim of improving the experience in EasyTV services. Nevertheless we will follow the guidelines proposed to ensure a correct management of the user data.

2.9.2. Measures proposed to reduce risks (according to the literature on the matter)

In [3] and [4] different authors propose measures to reduce the risks which will be contemplated in the implementation, in case they can be technically feasible:

- Pseudonymous personalization: Pseudonymous personalization allows users to use pseudonyms in a personalized system. This approach enables the system to track the same pseudonym across different sessions and provide personalized services without knowing the true identity of the pseudonym.
- Client-side personalization: The key idea behind client-based personalization is that users' data are stored at the client side (e.g., users' computers or mobile phones) and subsequent personalization processes also take place at the client side. Since data collection and processing occur at the client side rather than the server side, users may perceive more control over their data and perceive less privacy risk.
- Distribution, aggregation and other privacy-preserving techniques: A number of distribution, aggregation, perturbation and obfuscation techniques have been proposed to help protect user privacy in recommender systems.
- User controls and feedback: In [5][6] authors suggested putting scrutability into user modeling and personalized systems. The term "Scrutability" signifies the ability of users to understand and control what goes into their user model, what information from their model is available to different services, and how the model is managed and maintained.
- Privacy-preserving location tracking: Research on privacy-preserving location tracking has built on existing privacy preserving techniques such as anonymity and perturbation techniques.

REFERENCES

- [1] Kobsa, A. : Generic user modeling systems. *User Model. User Adapt. Interact.* 11(1–2), 49–63 (2001)
- [2] Kobsa, A.: Generic user modeling systems. In: Brusilovsky, P., Kobsa, A., Nejdl, W. *The adaptive web: methods and strategies of web personalization.*, pp. 136–154. Springer Verlag, Heidelberg (2007a)
- [3] Toch, E., Wang, Y., & Cranor, L. F. (2012). Personalization and privacy: a survey of privacy risks and remedies in personalization-based systems. *User Modeling and User-Adapted Interaction*, 22(1-2), 203-220.
- [4] Volokh, E.: Personalization and privacy. *Commun ACM* 43, 84–88 (2000)
- [5] Kay, J.: Scrutable adaptation: because we can and must. In: *Adaptive hypermedia and adaptive web-based systems*, pp. 11–19. Springer, Berlin (2006)
- [6] Kay, J., Kummerfeld, B., Lauder, P. Managing private user models and shared personas. In: *Workshop on user modelling for ubiquitous computing, 9th international conference on user modeling*, pp. 1–11. Johnstown (2003)

ANNEXES

Annex I: Information sheet

Project: EasyTV (*Easing the access of Europeans with disabilities to converging media and content*)

Main researcher: Federico Álvarez (UPM)

Ethical adviser: Pilar Orero

The aim of the tests is to get feed-back on the interaction between end users and access services and its technology. This will allow us to identify the needs and expectations of diverse audiences and research how the quality of experience, the quality of the service, and personalisation can be improved.

During the test, which can take various forms (experiment with questionnaire, focus groups, interviews, etc.), you will be asked to provide some demographic data. Then, you will be asked to watch an input, perform a task or give your opinion on various aspects. If needed, objective data will be recorded during the session. The researcher will give you more details of the specific test assigned to you and the data collection methods. Please ask as many questions as needed to clarify the procedure.

If your specific test can cause you any type of discomfort, the researcher will explain it thoroughly and you can stop at any time without prior justification.

Now please read the consent form.

Annex II: Consent form (written version)

Project: EasyTV (*Easing the access of Europeans with disabilities to converging media and content*)

Your participation in the tests is absolutely voluntary.

You can discontinue your involvement in the study at any time without prior justification. This shall have no repercussions or negative consequences of any sort.

The information you provide will be used in the project but it will remain anonymous.

Easy TV is a European project led by Federico Álvarez, from the Universidad Politécnica de Madrid (Spain). The ethical adviser responsible of ethical procedures in this H2020 EC funded project is Pilar Orero. You can contact Pilar Orero at pilar.orero@uab.cat and ask her for more information about the project and the project results.

In the case that some physiological or eye-tracking apparatus are used to gather data, you will not experience any discomfort, since the apparatus used are the latest generation and are not invasive. Tests will be mostly developed in the project partner premises (research rooms, etc.) but other spaces will be considered (for instance, end user association premises) if this guarantees a better comfort and access for participants.

If the session is recorded, you will be asked to sign an additional consent form to this aim.

The researcher administering the test is ((NAME and SURNAME)).

If you are willing to participate, please confirm the following statements by signing at the end of this document.

- I have read and understood the information given for this research or have had the information read to me,
- I have had the opportunity to ask questions about the research.
- I consent to take part in the research sessions.
- (if applicable) I consent to being recorded in audio/video/(...) form.

Name of the participant	Date	Signature
-------------------------	------	-----------

Name of the researcher	Date	Signature
------------------------	------	-----------

Name of the ethical adviser	Date	Signature
-----------------------------	------	-----------

Annex III: Sample of an oral information sheet

CONSENT FORM (alternative oral version, to be recorded)

Project: EasyTV (*Easing the access of Europeans with disabilities to converging media and content*)

Your participation in the tests is absolutely voluntary.

You can discontinue your involvement in the study at any time without prior justification. This shall have no repercussions or negative consequences of any sort.

The information you provide will be used in the project but it will remain anonymous.

If the session is recorded, you must sign an additional consent form to this aim.

Easy TV is a European project led by Federico Álvarez, from the Universidad Politécnica de Madrid (Spain). The ethical adviser responsible of ethical procedures in this H2020 EC funded project is Pilar Orero. You can contact Pilar Orero at pilar.orero@uab.cat and ask her for more information about the project and the project results.

In the case that some physiological or eye-tracking apparatus are used to gather data, you will not experience any discomfort, since the apparatus used are the latest generation and are not invasive. Tests will be mostly developed in the project partner premises (research rooms, etc.) but other spaces will be considered (for instance, end user association premises) if this guarantees a better comfort and access for participants.

The researcher administering the test is ((NAME and SURNAME)).

If you are willing to participate, please reply at the end of each question:

- Have you been read the information about the project and have you understood it? Please reply yes or no. (oral reply)
- Have you had the opportunity to ask questions about the research? Please reply yes or no. (oral reply)
- Do you consent to take part in the research sessions? Please reply yes or no. (oral reply)
- (if applicable) Do you consent to being recorded in audio/video/(...) format? Please reply yes or no. (oral reply)

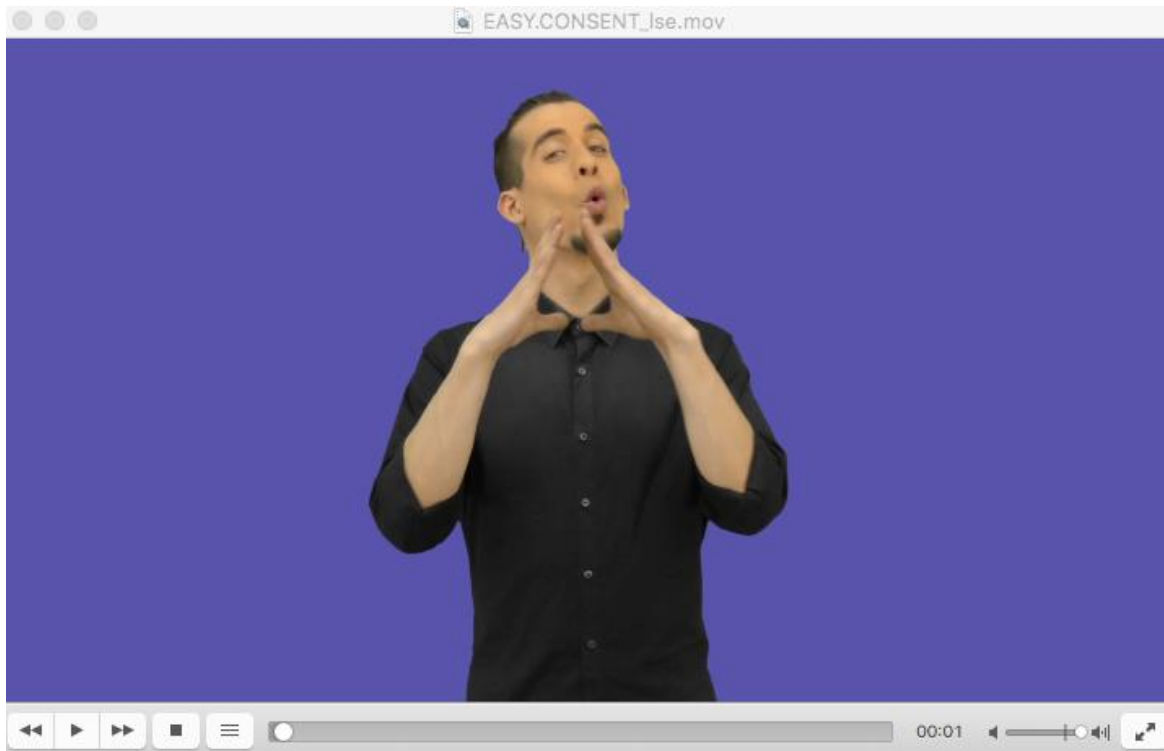
Please indicate your name: (oral reply)

Please indicate the date: (oral reply)

Please indicate the researcher's name: (oral reply)

Please indicate the ethical adviser's name: (oral reply)

Annex IV: Consent form in Spanish sign language (snapshots of clip)



Annex V: Consent form that grants photo, video and sound recording rights to UAB

UNIVERSITAT AUTÒNOMA DE BARCELONA PHOTO, VIDEO AND SOUND RECORDING RELEASE AND CONSENT FORM

By signing this Photo, Video and Sound Recording Release and Consent Form, I am irrevocably giving permission to the Regents of the UAB officers, agents, employees, successors, licensees, and assigns to take and use photographs, video or sound recordings of me for the following project: EASYTV. This is completely voluntary and up to me.

My consent to the use of the photographs, video and sound recordings and your image, likeness, appearance, and voice is for forever. I will not receive compensation for the use of my image, likeness, appearance, and voice now or in the future. The University may use the photographs, video and sound recordings containing my image, likeness, appearance and voice in any manner or media, including use on web pages. The photographs, video and sound recordings may be used in whole or in part, alone or with other recordings. The photographs, video and sound recordings may be used for any educational, institutional, scientific or informational purposes whatsoever, but not for any commercial uses. The University has the right and may allow others outside the University to copy, edit, alter, retouch, revise and otherwise change the photographs, video and sound recordings at the University's discretion for not commercial purposes. All right, title, and interest in the photographs, video and sound recordings belong solely to the Regents of the UAB.

I further give permission to the University to use my name, biography, and any other personal data, events, or other material in or in connection with any such uses of the photographs, video and sound recordings under the Spanish personal data protection legislation.

I understand and agree to the conditions outlined in this photograph, video and sound recording release and consent form. I irrevocably give consent to the Regents of the UAB and the University's officers, agents, employees, successors, licensees, and assigns forever to make use of my image, likeness, appearance, and voice in photographs, video and sound recordings as described above. I acknowledge that I am fully aware of the contents of this release and am under no disability, duress, or undue influence at the time of my signing of this instrument.

Printed Name of Participant

Signature of Participant

Date

<END OF DOCUMENT>