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## Executive Summary

The present document is a deliverable of the Easy Reading project which is funded by the European Union's Horizon 2020 Programme under Grant Agreement #780529.

Deliverable 8.4 deals with the first phase of WP 8 (Ethics, Safety, Privacy, Security – Sensitive personal information and data). The aim of this deliverable is to formulate and discuss considerations for safety, privacy and ethics related to the project and its users. The deliverable builds upon the set of ethics requirements established in D8.2 and is closely related to the risk assessment in D8.3.

The deliverable will have three main focuses. Firstly, the background on and the aims for the people of the target group will be described. Secondly, aims related to the research carried out in the project will be discussed in terms of ethics. Thirdly, aims in relation to the technology development and design will be in focus. The report will also discuss data collection and ethical regulations. Both research ethics and more general ethical considerations when developing for users with disabilities will be discussed.



## Table of contents

Executive Summary .....	6
1. Introduction.....	8
2. The target group and their challenges .....	9
Participation in society .....	9
Considering different abilities – a note .....	10
3. To research with the target group .....	11
Ethical regulations .....	11
Recruitment and Informed consent .....	12
Peer researchers and their tasks .....	14
To test together with participants .....	15
Privacy and integrity.....	16
Ombudsman .....	18
4. To develop for the target group .....	19
Basic principles – what to consider .....	19
The system should benefit the users .....	19
The users’ needs should be center.....	20
The users should be in control .....	20
Data collection must comply with data regulations.....	20
The system must be transparent.....	21
To test systems that are under development – what to think of .....	21
References.....	23
Appendix A: Information and informed consent to be used for peer researchers.....	25
Appendix B: Information and informed consent with pictures to be used for testers .....	28



## 1. Introduction

People with physical disabilities has since long had the possibility to use assistive technology to access and participate in the digital area of life. For disabilities such as low sight or motor dysfunction, there are several standards and solutions to compensate. The situation looks different for people with cognitive disabilities. The needs of the group of people who has difficulties navigating, understanding and interpreting content on the web are often individual and dependent on context and support. Adapting content for poor reading skills or needs of alternative presentations of content is thus more elusive and as a consequence less standardized. The solutions that do exist do not fit all and cannot be adapted to every variation. What is more, those solution often tend to be “special solutions” that sets those users apart from the original digital content, often with restricted functionality. Special solutions like this make the users more dependent on third-party suppliers and of course limits true participation.

Cognitive accessibility is still in contradiction to the principles of inclusion according to the UN Convention on the rights of People with Disabilities. Easy Reading will be carried out in accordance with this right, particularly Articles 19 and 21 which concerns the rights to live independently and being included in the community, and to have the freedom to express opinions and access information, in the communication form of their own choices.

Easy Reading aims to provide a number of services and interface overlays to help users personalize their experience on the web. The overall goal is to help users with cognitive impairments to more effectively use and understand the web regardless of their preferred way of taking in information. The support will be based on user tracking and analysis, which means that users build personal profiles that will lay as a ground for what type of support they are offered by the system. The types of support can be for example symbols to support text, larger text, tooltips or spoken text, but the key point is that everything is done within the original content. Over time, the system will learn and adapt to the user’s preferences.

The research and development in the project will be carried out with the help of peer researchers with own experiences of cognitive impairments. Their views, needs and opinions are of utmost importance for the project’s designers and developers and they will be gathered in different ways throughout the project.

This deliverable lays out the ethics, safety and privacy considerations related to Easy Reading. The deliverable will have three main focuses. Firstly, the background on and the aims for the people of the target group will be described. Secondly, aims related to the research carried out in the project will be discussed. Thirdly, aims in relation to the technology development and design will be in focus. The report will also discuss data collection and ethical regulations. Both research ethics and more general ethical considerations when developing for users with disabilities will be discussed.





## 2. The target group and their challenges

Easy Reading is a project that aims to develop technology to facilitate for users. Our aim is to increase participation and independence. This can have an effect on many areas of life for people that needs this support, such as work, education and social life. This section provides a brief overview of the needs and challenges in these areas and how we need to think about ethics when developing our solutions.

The target group of Easy Reading is determined by the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO). The target group includes people who have such difficulties relating to memory, problem solution, attention, reading, writing and understanding of graphics that it reduces their possibilities to participate in digital channels on equal terms with others. Applying this model to the use of our information society and media channels, we can see clearly that the barriers arise when the design of the media is not accessible.

### Participation in society

In today's society, using digital channels is a prerequisite to perform many tasks – both related to work, education and social participation. To use them, the skills of reading, writing and understanding information are crucial. People that have difficulties in these areas and thus cannot access those digital channels may experience great limitations in participation. This also means that they usually experience dependency on other people to a great extent. Simple, and sometimes private, tasks like reading emails, booking appointments and simply browsing for content of interest, must be done with the help of someone else.

In a workplace setting, it is often expected to be able to use a company's intranet to access information and services such as calendars, news and logins to systems and software.

Likewise, in an educational setting, it is expected to be able to navigate school platforms to submit work, report attendance or take part of calendar events and reading materials. Moreover, it is also expected to be able to use the Internet to research information for school work and different online editors to enter information.

Accessing the Internet and different services does of course not only restrict to professional settings. Much of our time today is spent communicating with others on social media, booking appointments online, contact support services, and communicating with societal services like insurance companies or employment agencies. People who are not able to access those services are severely limited and excluded from many areas today.

Access to a personal assistive technology device doesn't always help, since systems are not necessarily compatible with their functionality or there are technical or economic restrictions in installing and adapting facilitating software. When it comes to limitations that are due to cognitive difficulties rather than physical access, there are not many assistive technologies today that are able to help, at least not any that would work with any given domain and area.

Facilitating access to these areas could mean giving people with disabilities, who would otherwise be excluded from work or education, opportunities to gain employment or be admitted to an education



and contribute equally and prove themselves. They would also to a much larger extent be able to communicate with others and contact important societal services when they need to.

Facilitating access to web content in the original setting has a lot of advantages. It means that no special measures need to be taken and that people are not dependent on a certain computer. When trying to solve these challenges, and providing solutions that gives access, it is important to consider the ethics in doing so.

Ethical considerations for specific technological issues are addressed in section 4. Dealing with the target group and offering new solutions to their challenges is much needed and welcome, but it has to be done with care. Offering a new solution also comes with a pressure to maintain and keep that service going if the user starts using it and start relying on it. Therefore, it is important to really think through the scope of what to offer and how to maintain it in a long run.

### Considering different abilities – a note

The profiles of both project participants and end users of the system are many and can range in level concerning physical and communicative abilities. No matter someone's ability, we must strive to give them the possibility to use the system.

Users that have difficulties in the cognitive area may very well be capable physically. But there are a number of people who will have physical limitations in addition to difficulties in the area that Easy Reading targets, including for example limited motor function and low vision. These limitations, requiring alternative access to devices, must not be an obstacle to make use of the functions Easy Reading provides. That means that developers must think ahead and make the system as accessible as possible.

Peer researchers and pilot participants may have limitations in their communication. They might, for example, use alternative and augmentative communication devices to express themselves. It is important that this does not become an exclusion criteria to be allowed to participate in the project. Researchers must therefore prepare and adapt the testing situations and how they receive feedback from these participants, if needed.



### 3. To research with the target group

When developing new technology, it's crucial to test it together with the users who are going to benefit from it in the end. Only by doing this, the product developed will have a chance of meeting the true needs and wants of the users – and by that, succeed.

In the work with users of the product's target group, ethical aspects have to be considered in all phases. Particularly inclusion of people with cognitive impairments in research requires careful consideration of ethical issues such as safety, consent, self-determination, privacy and well-being of participants.

In Easy Reading, ethical guidelines were drawn up in the beginning of the first project year. Those guidelines are meant as a help for both developers and researchers in their continuous work. Some of those guidelines concerned the peer researchers, the testing procedures and what to think about when carrying out research with users, and will be discussed in this section. Not all discussed here will be strictly about ethical research principles. We will also bring up the ethical and moral considerations we need to have in different situations when we interact with or develop for this target group.

#### Ethical regulations

All countries have different regulations regarding ethical practice in research. The codexes and practices may also vary depending on the nature of research. Each country within Easy Reading is obliged to abide by any institutional, professional, and legal requirements in their country regarding ethical approval.

In Austria, there are a number of regional research ethics committees, most of them dealing with medical research or animal research. Nationally, ethics assessments in scientific research are formulated as general values, for example the freedom of research. These values, however, can be restricted by fundamental rights of ECHR. Research requiring permissions or opinions of Ethics Committees is only related to clinical trials of medical products, medical devices or animal research. In case the Austrian partners need advice, the Ethics Committee of Upper Austria is to be contacted.

In Germany, there are a few Ethics Councils, where The German Ethics Council (Deutscher Ethikrat) is the most prominent. Their purpose are mainly to inform the public and prepare recommendation for political actions. They have no advisory board for specific research projects to be consider when the project is not of a medical nature.

In Sweden, the Act concerning the Ethical Review of Research Involving Humans has been in place since 2004. The purpose of the Act is to protect the individual person and ensure respect for human dignity in research. The legislation has been complemented with the establishment of ethics review boards which review research projects and decide whether they merit approval. Great importance is placed on an assessment of how informed consent has been handled and the handling of sensitive personal data.



## Recruitment and Informed consent

The first step towards user involvement is the recruitment. In this process, it is very important that no users are excluded on criteria that is not relevant. For example, if a person fits the profile for the target group – that is, difficulties reading, writing and understanding – but has additional impairments, they cannot be denied participation. When recruiting, potential participants need to know what participation will entail and what they can expect.

A challenge when it comes to conducting research with people with cognitive impairment is to ensure that they understand what it means to participate in the research. To participate, peer researchers and testers need to sign an informed consent. An informed consent is based upon a clear appreciation and understanding about circumstances, implications and consequences of an action. Information should be given so the involved persons will understand all of the content.

When we inform users in Easy Reading about the project and ask for their consent, we will do so both verbally and in writing. We will inform participant one by one and face to face and ensure that the person have understood the content. The information must include the aim and purpose of the project and what is expected on the person to perform during the research participation, procedures to be undertaken and expected duration. The consent will also include information about potential risks and benefits. It is important to emphasize that participation is voluntary and that it is possible to end the participation at any time, without any consequences.

Given the nature of Easy Reading and the target group, we need to adapt the information sheets and informed consents so that they are accessible. Many of our testers experience limitations in reading, understanding and taking in information. It is important to use a simple language to make the information understandable. Another important aspect is that the information must be provided in the participant's own language.

In the process of developing the informed consents, the peer researchers in Austria and Germany selected not to include pictorial support. It is true that not all participants in the pilot testing will need the support of pictures for reading or understanding text. However, we recommend an approach where the information and forms directed to participants are of a universal design with both texts and pictures. Such a version was developed by the Swedish team. That way, there is no need for the project members, or the peer researchers responsible for informing, to make an assessment of which participants need an alternative version. Two example of consent forms are attached as appendixes to this deliverable, one without and one with pictures. Below is an illustrations of one of them. More examples can be found in Deliverable 8.1 – Informed consent.



## Information to the **informed consent** for peer researchers.


<p><b>The informed consent</b></p> <p>This is a declaration of consent  <u>that all participants have to sign.</u></p> <p>Before you sign  you have to know and understand the details  of the research <b>Project EasyReading.</b></p> <p>The informed consent is a prerequisite  to the participation  <u>as a peer researcher within the project.</u></p>	
<p><b>Please read this writing carefully  <u>before you sign it!</u></b></p>	
<p><b>What is the <b>Project EasyReading</b> about?</b></p> <p>Many people cannot understand  <u>the information on the internet.</u></p> <p>They find it difficult</p> <ul style="list-style-type: none"> <li>• Because they cannot read well.</li> <li>• Or they are slow in reading.</li> <li>• Or quickly lose overview.</li> <li>• Sometimes the words are also difficult to understand</li> </ul> <p>On the <b>Project EasyReading</b> peer researchers and developers  research how to help people  <u>to a better understanding of the internet.</u></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• We ask questions concerning problems on the internet.</li> <li>• We look for new devices for the internet.</li> <li>• We test these new devices.</li> </ul> <p>In other words, the collection of data.</p>	

Figure 1: Part of an informed consent, developed together with peer researchers in Austria and Germany



The following checklist was prepared in D8.2 for researchers to use in their interaction with participants as a help to make sure participants' well-being are ensured.

<input type="checkbox"/>	I present materials in an accessible way, for example easy to read or with pictures
<input type="checkbox"/>	I make sure the participant has understood and consented to participation
<input type="checkbox"/>	I make sure the participant knows how to evoke consent and say no
<input type="checkbox"/>	I make sure the participants know who to contact if they have questions or concerns
<input type="checkbox"/>	I make sure the participants know how the service functions
<input type="checkbox"/>	I make sure the participants know what data is being saved and how it will be used
<input type="checkbox"/>	I make my best to make the test situation comfortable for the participant, including giving opportunities to leave

### Peer researchers and their tasks

Easy Reading has three pilot sites, in Austria, Germany and Sweden. Each site consists of research teams where users with cognitive impairment are an integrated part of the team as peer researchers. The teams in Austria and Germany will work in tandem with developers in their countries since they are in the same area and have the possibility to have a close cooperation. Since the team in Sweden is based far away and need to adapt materials and instructions, they will test the services that are possible.

The research teams started out by developing the Informed Consents described in the previous section. Following that, peer researchers did a requirement analysis, which will serve as a basis for developers in their work. For this purpose, the teams developed and adapted the IPAR-UCD methodology and discussed appropriate ways to test and evaluate.

During the project, the research teams will collaborate and develop procedures to involve the peer researchers as researchers in the development process. This is done according to the Design Based Research (DBR) methodology. The peer researchers will keep diaries and take pictures and videos as a way to give ideas, feedback and input into this process, as well as on the Easy Reading services developed. A detailed description of the IPAR-UCD methodology can be found in Deliverable 1.2.1.

Additional feedback and evaluation will at a later stage be collected from secondary participants.



### To test together with participants

As the peer researchers start working alongside researchers in the project, and as other participants start testing and evaluating, there are many aspects to consider.

It is important that participants are made aware of what the services are, how they are meant to function and why they will help them. Part of this includes informing them about potential downfalls, weaknesses and limitations. It also concerns making them understand how and why the system are tracking or collecting data and how it is used. Just as the informed consent must be accessible, all materials and information throughout the test phases need to be as well, so that every participant is able to take part. A good approach is to try to present the same information in many different formats – multimodality – so that participants can use the format they feel fits them best.

In Easy Reading, the testing will rarely be done independently by a participant, for example at home. The testing will mainly be done in the research teams or in workshops with other participants. Therefore, there will be support in case a task is overwhelming or difficult to understand.

When performing the actual testing together with participants that needs support understanding and processing information, instructions around the process must be very clear and broken down into several steps. This includes both all the information around the task – where will it be, how long time will it take, who will be there, what equipment will be used, what help is there and what is the purpose – and the test performance in itself. It is important to maximize the predictability so that the participant doesn't need to put energy on understanding and taking in everything else, but rather focus on the task ahead. This includes information to participants about the idea of peer researchers and their role. In this information, make sure to provide clear information on the persons who participants will meet. A good approach is to provide photos and if needed, a short concrete text to explain anything that might provoke questions or take focus from the task at hand.

Test leaders should make sure that the participants understand the purpose with each test, but that information has to be balanced so that they don't influence the outcomes from the participant.

One way to make sure the testing will be understandable and not stressful for participants is to let them learn by looking at others. For example, a peer researcher could start trying out and modeling how to test a specific tool before participants do it themselves.

When evaluating the tools in testing, feedback from participants and peer researchers will be collected in different ways. It is important to think about how this is formed to allow everyone to express their meaning. These methods are dependent on the participants and the researchers will need to be flexible and have many tools in their toolbox to reach the best result. In Easy Reading, these methods will be formed together with peer researchers, which is a great way to ensure the methods are suitable. The pilot sites responsible for the testing are also experienced with the target group and can provide many different ways of interviewing. It is also crucial to form the information provided and the questions so that the feedback are given regarding the tool itself and not the content on the websites that are used in testing.

Some of these guidelines are of course true for conducting research generally. However, taking the target group's needs into consideration, it is of particular importance that researchers are prepared and flexible to adapt to different changes and situations. In summary, the well-being of the peer researchers and the participants must be at the center of the research team. It must always triumph the need for data collection or feedback.





## Privacy and integrity

A very important question when dealing with research ethics is how to treat information about people that are included in research projects. Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects, is seen as the basis for positions on ethical research issues around the world. According to this declaration, every precaution must be taken to protect the privacy of the research subjects and the confidentiality of their personal information.

Easy Reading aims to ensure that no one has their privacy rights violated during their participation or by using the services. That said, both the pilot procedures and the services in themselves require us to collect data. This collection should be treated in accordance with current European regulations. In short, this means that:

- We must make sure that the person whose data we treat knows about it
- We must only use the data for the purpose we have informed about
- We must only hold and process the data we need and only save it for as long as we need to
- We must limit the access to personal data to those needing it
- We have a responsibility to make sure the data is correct and updated

An overview of the data collected in the project can be found, meant as an internal checklist, in deliverable 8.2. The list includes data such as personal data, preferences (e.g. symbol sets, device and operating system), skills, browser history and user tracking such as eye movement and keystrokes.

Data that is sensitive has an even stronger protection under this regulation. Data that concerns for example political views, ethnicity, religion, health, sexuality and criminality is as a baseline not allowed to be collected. However, if explicit consent is given, it is allowed.

Audio and video recording fall under a special category of data. It should of course be treated according to regulations, which means that particular consent must have been given beforehand. It is also important to remember that all participants must be informed if they are going to be recorded, why videotaping is used and how it is going to be analyzed and treated.

In Easy Reading's consent form, there are specific checkboxes for the permission to take photos and videos. The participants do not need to agree to this to be able to participate.

To abide by regulations concerning privacy, we need to think in advance about what data we need to collect and for what purposes – in short, what is important to know to be able to draw conclusions. In Easy Reading, there is a need to collect data on what participants experience as a problem, in order to develop appropriate solutions. As participants enroll in Easy Reading because they identify with having a disability or lack of ability that limits them, this data is in a way already present as a pre-condition. But the data can be collected in a way that does not disclose personal information about specific diagnoses. Instead, we may think about abilities and functionality, and again, this must be considered against what kind of results we want to be able to present.

There are a couple of approaches that could be used as suggestions for collecting this data without specifically ask for diagnoses:

- Let the participants describe their own difficulties. It gives no objective assessment and can't be used to compare participants, but it will measure what participants experience as a problem and to what extent the solutions will help them. It is a true participatory approach.
- Do an objective testing of participants' abilities to perform certain tasks. This poses ethical questions such as who assesses the results, and if all participants get an equal chance to prove their abilities.





- Simply use a set of inclusion criteria we use when recruiting for the project, and the individuals that are enrolled will not need to be described further than that.

In Easy Reading, we will have the opportunity to discuss and determine the optimal approach together with our peer researchers.

In a project like Easy Reading, where we develop and evaluate technology, data such as age, access to technology and technical experience may be of relevance to be able to analyze results of the testing done – both the difficulties encountered and support needed and to what extent solutions are embraced and used.

No matter *what* data we collect, it is important to remember that the *more* data we collect, the larger the risk for a specific participant to be identified, especially when it comes to information about disabilities. Just data on living area, gender, age and disability may be enough to recognize someone, even when the data is presented on a group level.

The following checklist was prepared in D8.2 for researchers to use in their interaction with participants as a help to make sure data is treated correctly.

<input type="checkbox"/>	I have made sure the person whose data it is knows about it
<input type="checkbox"/>	I have consent
<input type="checkbox"/>	I know the data I collect is not considered as sensitive data – or I know I have explicit consent for collecting it
<input type="checkbox"/>	I use it only for the purpose I have informed about
<input type="checkbox"/>	I will only save it for as long as I need to
<input type="checkbox"/>	I will only give access to it to those needing it
<input type="checkbox"/>	I have made sure data is correct and updated



## Ombudsman

To be sure that we safeguard the safety of the peer researchers and users in Easy Reading, each test site appoints an ombudsman for their peer researchers. An ombudsman is a representative for the peer researchers and participants in the project with whom they can discuss questions or complaints regarding their rights, privacy and wellbeing. If a conflict arise, the ombudsman will recommend the most suitable solutions, such as coaching of an individual, mediation or a systematic change in the project.

Peer researchers should be able to independently, or together with a support person, contact the ombudsman.

Before appointing an ombudsman, we need to think through what the role will entail and who could be suitable. The nature of the project and what kind of questions and issues could arise will determine and guide this choice.

The following requirements could be used as a starting point when selecting a suitable candidate:

Competences that are desirable are:

- Knowledge about regulations about legal rights and privacy
- Knowledge or experience of how research is done
- Experience of cognitive and communicative disabilities

Practically:

- Must speak the same language as the peer researchers
- Must be available physically in person if needed
- Should not be associated with the project
- Could be more than one person sharing the role to be able to support each other

These listed points mean that there should be one (or several) ombudsman at each pilot site, so that communication is practically possible. If participants don't know the country's language well enough, it's important to remember to plan for interpretation services in meetings between the ombudsman and the participant. Suitable people could for instance be those working in patient associations and know the target group well.

The recruitment of the ombudsman must be done carefully to make sure that the person is right for the role. These requirements can be seen as suggestions on what to look for. Equally important are the personal qualities and that the potential candidate is flexible and open to work together with people with different abilities. When a candidate is selected, it is highly recommended that he or she gets an introduction to the specific target group, communication strategies and the project's goals and processes.

It is also important to have clear guidelines for the reimbursement of the work that an ombudsman puts into the project, either directly from the project or as a part of their regular paid work.

Peer researchers and participants should get clear and precise information on the role of an ombudsman, who it is and how they can get in touch with him or her.



## 4. To develop for the target group

For everyone in today's modern society, technology is a great help in a variety of tasks; shopping online, booking appointments and travels and communicating with others. For people that need extra assistance with daily tasks, technology can also greatly facilitate and improve quality of life. Technology can also be a barrier for some individuals when it is not accessible. Many people today are closed off from things other take for granted because apps or websites are not compatible with screen readers or alternative access methods – or, most important for our target group, that the design, information load and language simply is not easy enough to use.

It is a question of ethics to design technology so that it, as far as it can, be used by everyone. This is called universal design. We also know that, for individual with disabilities, having a standard and non-stigmatizing solution is of great importance and influences the frequency of use positively.

We want our services to be of help to our target group. This means it must be intuitive and easy to use, especially when our users might have problems with cognition, ability to read and might easily reject or give up. It is also important to build the systems so that users' mistakes are allowed and compensated for. The emphasis on the services provided is to make them clean and simple, responsive and context-aware, all to make a seamless and easy tool to use when there is need.

It is also essential that the technology we offer, particularly when it is developed for a target group with particular needs, is reliable and safe to use.

### Basic principles – what to consider

Deliverable 8.2 provided a list of basic principles as a guide for developers on how to think about the designing and developing of the services. This list was based on the eFriend Framework developed by Middlesex University. In this section, we will expand on those principles. They are also closely linked to the risk assessment table in Deliverable 8.3. The principles are not strictly ethical, rather guidelines to develop appropriate services for the target group and not subject them to systems that don't work well. Of course, a lot of principles are true for all users of a system, however, the importance of user friendliness and transparency are even greater when targeting users that are vulnerable.

### The system should benefit the users

- The system should be beneficial enough so that the users want to use it
- The system must have tolerance for errors
- The system's automatic proposals to users must be of help to them

Easy Reading's aim is to improve the target users' experience in digital channels and help them overcome challenges. The risk of seriously harming users is assessed as minimal, but nonetheless, the project will strive for a beneficial and enjoyable service and take measures to make sure that the system's do not cause users discomfort.

The incorporation of peer researchers into the teams at an early stage and in close cooperation with developers is an excellent factor to discover and prevent issues with this in time.



#### The users' needs should be center

- Users' needs are in the center of the system
- The system should provide a reasonable amount of various output formats
- The system should be accessible to use even without standard input devices

It is Easy Reading's absolute aim to make the services usable for the needs of the target group. This is ensured by the joint collaboration with users in the form of peer researchers in the research teams. They will work closely together in all phases of the project and iteratively test and give feedback to developers. They will also take part in creating appropriate evaluation methods. Apart from this group of peer researchers, an extensive amount of secondary users will test the services throughout the project time.

In this way, Easy Reading will get feedback from a quite large and diverse group of users, and is thus well prepared to take on feedback and adapt services to this. By letting users both use the services over a long time, as the peer researchers will do, and let them try on new things unprepared, as the secondary testers will do, we will have a good basis to see both how intuitive the interfaces are and what users will think over time.

#### The users should be in control

- Users can preferably specify and change the level of privacy when using a system
- Users can preferably turn on and off different kinds of tracking of a system
- Users should be able to turn on and off the whole system when they want to
- Users should be able to choose which features to use in the system and when

Easy Reading's services are partly based on observations of the system to be able to determine the best help for the user. This means that systems will track the user's behaviors in some ways. To be able to completely turn the system on and off in a simple way is important, even if the aim of the project will always be to minimize the privacy intrusion when the system is active. It will also be important to clearly present to users what is being observed and why, what it means and how to edit this. How this recommendation can look in practice will of course have to be discussed and adapted in accordance to developer's possibilities over the project time.

The nature of the framework's interface will make it easy to let users select the features they prefer. A toolbar will offer a set of services and only the ones activated will be used. The selection will also adapt to the real usage and present the most relevant features according to a user's profile.

#### Data collection must comply with data regulations

- Only necessary data is collected
- Data collected is used only for known purposes
- Data is stored safely and not too long in the system
- Participants have the right to view, update and delete their data when requested
- All data is collected with consent



The nature of the services in Easy Reading will require the collection and analysis of data from users to offer relevant solutions. However, the project will strive to minimize the data needed and comply with the European regulations on storing and treating that data.

In practice, this will mean that the servers where data is stored are secure and backed up, and that data is not shared with a third party unless there is explicit consent or agreement between Easy Reading and the third party.

The participant will of course always be given access to the data stored about them (or having it removed) if they ask for it. The participants can reach out to their ombudsman or directly to the researchers or developers to make this request.

#### The system must be transparent

- The system's limitations and weaknesses should be transparent to the users
- The user should be made aware of data collection and analyses performed by the system
- The user should be informed of all the features possible in the system
- The system should respond visibly to all user interaction

To realistically understand and appreciate what a system can do, it is important to be aware of what limitations there are, particularly if the limitations are features that might be expected. It should also be clear in what way the user can change, edit and set own preferences in the system (for example select a symbol set or hide certain buttons). When it comes to data collection, it is important that this is presented in a clear and accurate way, so that the user understands what is being collected and why, but don't become apprehensive about using the service.

Easy Reading's services will strive to be as transparent as possible. The features will be labeled with symbols and text and it should be easy to understand which feature is currently activated. Documentation will also be provided so that the framework can be extended with additional components that apply with the existing.

#### To test systems that are under development – what to think of

It is necessary that the participants and the users of technology trust the system they are using. It doesn't take many failed attempts or technical failures for a user to abandon a system. When developing new technology, there will undoubtedly be technical problems, unforeseen behaviors and unstable or not ready test releases. This is a part of the process and all things discovered in the testing phases will be used to improve the final version.

It is therefore essential that participants are given the information that the system they are testing may experience bugs and unexpected errors, and that this is not due to something they did. However, it is crucial that they are not given a too unstable version to try. This will likely discourage them from further participation or useful contribution.



The following checklist was prepared in D8.2 for developers as a help to make sure their services comply with the data regulations and our principles.

<input type="checkbox"/>	I make sure the service benefit the user and don't cause harm
<input type="checkbox"/>	I have the user's need and wishes in center
<input type="checkbox"/>	I make sure the user can control the level of privacy
<input type="checkbox"/>	I make sure that collected data comply with data regulations
<input type="checkbox"/>	I design it so that features can be switched on and off by the user
<input type="checkbox"/>	I make features and functions transparent so that it is easy for the user to understand what is happening



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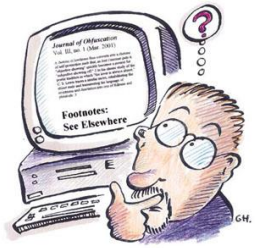
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## Appendix A: Information and informed consent to be used for peer researchers

<p><b>The informed consent</b></p> <p>This is a declaration of consent that all participants have to sign.</p> <p>Before you sign you have to know and understand the details of the research <a href="#">Project EasyReading</a>.</p> <p>The informed consent is a prerequisite to the participation as a peer researcher within the project.</p>	
<p>Please read this writing carefully before you sign it!</p>	
<p><b>What is the <a href="#">Project EasyReading</a> about?</b></p> <p>Many people cannot understand the information on the internet.</p> <p>They find it difficult</p> <ul style="list-style-type: none"> <li>• Because they cannot read well.</li> <li>• Or they are slow in reading.</li> <li>• Or quickly lose overview.</li> <li>• Sometimes the words are also difficult to understand</li> </ul> <p>On the <a href="#">Project EasyReading</a> peer researchers and developers research how to help people to a better understanding of the internet.</p> <p>For example:</p> <ul style="list-style-type: none"> <li>• We ask questions concerning problems on the internet.</li> <li>• We look for new devices for the internet.</li> <li>• We test these new devices.</li> </ul> <p>In other words, the collection of data.</p>	
<p><b>Your cooperation</b></p> <p>Participation in this project is voluntary.</p>	



<p><b>Your personal data</b></p> <p>People who want to take part in this project allow the use and collection of personal data.</p> <p>For example: personal information</p> <ul style="list-style-type: none"> <li>• name, sex, age</li> <li>• or questions about using the computer</li> <li>• or footage of personal discussions, pictures and videos</li> </ul> <p>Your name will not be used public. But pictures of you are allowed to be shown. And videos of you are allowed to be shown.</p> <p>Each participant is allowed to revoke this permission at any time. You are allowed to get to know, which of your data within the project are saved or being used.</p> <p>You are allowed to delete or put them right. In doing so you have no disadvantages.</p>	
<p><b>What is important for Peer-Researchers?</b></p> <p>This is important:</p> <ul style="list-style-type: none"> <li>• The Peer-Researchers are supposed to understand everything;</li> <li>• They are really supposed to be entitled to have a say in the sense of participation;</li> <li>• They are supposed to be discreet:</li> <li>• Everything that is a matter of the project</li> <li>• must <b>not</b> be let out.</li> <li>• The peer researchers promise, <ul style="list-style-type: none"> <li>○ that they keep everything confidential.</li> </ul> </li> </ul>	



Did you understand the information?

If yes, please answer these 4 questions:

- 1) Some people have problems on the Internet.  
Name a problem: .....
- 2) What is being researched in the **Project EasyReading**?.....  
.....
- 3) Name an example:  
What is personal data?.....
- 4) Are you allowed to talk about details of this project?.....

## The informed consent

### Agreement:

I agree to participate  
in the Research Project Easy Reading.

I provide my data,  
included pictures ☐  
include videos of me ☐  
which are produced during the project.

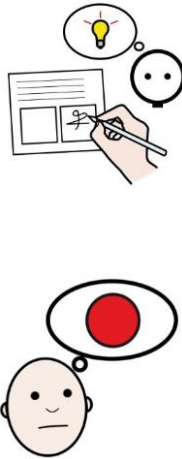


.....  
(place, date)

.....  
(signature)

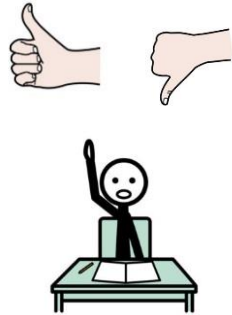

.....  
(if necessary signature legal representative)



## Appendix B: Information and informed consent with pictures to be used for testers

<p><b>The informed consent</b></p> <p>This is a declaration of consent that all participants have to sign.</p> <p>The informed consent is a prerequisite to the participation as a tester within the project.</p> <p>Before you sign you have to know and understand the details of the research <b>Project Easy Reading</b>.</p>	
<p><b>Please read this writing carefully before you sign it!</b></p>	
<p><b>What is the <b>Project Easy Reading</b> about?</b></p> <p>Many people cannot understand the information on the internet.</p> <p>They find it difficult</p> <ul style="list-style-type: none"> <li>- Because they cannot read well.</li> <li>- Or they are slow in reading.</li> <li>- Or quickly lose overview.</li> <li>- Sometimes the words are also difficult to understand</li> </ul> <p>In the <b>Project Easy Reading</b> peer researchers and developers research how to help people to a better understanding of the internet.</p>	



<p><b>Your cooperation</b></p> <p>In the project, you will  try different ways of using the Internet  answering questions about what is easy and difficult  and what you think is good or bad</p> <p>Participation in this project is voluntary.</p>	
<p><b>Your personal data</b></p> <p>People who want to take part in this project  allow the use and collection of personal data.</p> <p>For example:</p> <ul style="list-style-type: none"> <li>- name, sex, age</li> <li>- questions about using the computer</li> </ul> <p>Sometimes we would like to take photos and videotape when we  discuss and test different things.  We might want to show the photos and the films when we present  the project.  You can choose if you want to be photographed or videotaped.  You can still participate in the project even if you don't want it.</p> <p>Each participant is allowed to revoke this permission at any time.  You are allowed to get to know,  which of your data within the project are saved or being used.</p> <p>You are allowed to delete or put them right.  In doing so you have no disadvantages.  You can finish your participation in the project at any time. Nothing  will happen if you do this.</p>	



## The informed consent

### Agreement:

**I agree to participate  
in the Research Project Easy Reading.**

**I provide my data,**

**Including pictures of me**



☐ yes ☐ no

**Including videos of me**



☐ yes ☐ no

.....  
(place, date)

.....  
(signature)

.....  
(if necessary signature legal representative)