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First report of the most urgent risks and Risk Plan





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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 8.3 deals with the third task of WP 8 (Ethics, Safety, Privacy, Security – Privacy, safety, ethics risk management). The aim of this deliverable is to perform a thorough risk assessment with focus on privacy, safety and ethics, to determine risks and potential issues that will need to be handled during the project.

The risk assessment is divided into two main categories, risks related to the technology and risks related to the research carried out with peer researchers and participants. For each section, potential risks and their assessments are listed in tables. The risks in those two sections are closely linked to issues raised in the deliverables D8.2 (Development and enforcement of different manuals about safety, privacy and ethics for using in the project) and D8.4 (Safety, Privacy and Ethical Considerations Document).



Table of contents

- Executive Summary 6
- 1. Introduction..... 8
- 2. Risk assessment..... 9
- 3. Technology related risks..... 10
 - Usability..... 10
 - Stability..... 11
 - Transparency..... 12
 - Privacy and data collection..... 12
 - Autonomy..... 13
 - Accessibility..... 13
- 4. Project and research related risks..... 14
 - Recruitment and information to participants..... 14
 - Testing with participants..... 15
 - Participants' comfort..... 16
 - Privacy and data protection..... 17
 - Stability..... 17
 - Accessibility..... 18
 - Advisory expertise..... 18
 - Ethical regulations..... 19
- References..... 20



1. Introduction

In Easy Reading, the goal is to develop and design a number of interface overlays that can be used for personalizing a user's experience of a website. Overlays allows users to work with the original content on the website instead of needing specially adjusted websites. Easy Reading aims to help the user succeed in using the web, no matter how they want to access it.

Easy Reading develops services and researches best practices together with peer researchers that have own experiences of cognitive impairments. This approach is to ensure that the users are in the center of the development in all phases and that services are really entailed to their needs. The project will also gather views and opinions from several additional participants during the course of the test phases. This means that there will be many people to test the technical solutions and data will be collected in a number of ways.

The question of ethics always has to be present in a project where users are heavily involved in the process, and particularly in a project where the technology has the ability to capture so much information and draw conclusions from it. This data has to be managed in a careful and secure way and take the privacy and security aspects into consideration.

This deliverable is a first version of a risk assessment of questions in the project concerning ethics, privacy and security. It strives to identify risks that can occur, their likelihood and impact and propose solutions if they occur. It is meant to be used by partners as a helpful aid when developing and researching together with our participants. This document will be revised and updated during the project as the technical services take form and more specific risks and their assessment can be added.



2. Risk assessment

To assess the risks, we have used a matrix with two four-graded scales. The first one assesses how likely it is that the risk occurs. The second one tells us how serious the impact is, if it does occur. The matrix then gives us a score for each combination, which is seen within each cell. Those scores can be labeled in five steps from very low to very high.

In each table in this deliverable, the risk score is calculated and presented for each risk that has assessments for likelihood and impact. The colors make it easy to quickly assess the level of the risks.

The matrix is pictured below.

		Impact			
		How severe would the impact be if risk event occurred?			
		1 Insignificant	2 Minor	3 Significant	4 Major
Likelihood	4 Likely	Medium 4	High 8	Very high 12	Very high 16
What is the chance of the risk occurring?	3 Moderate	Low 3	Medium 6	High 9	Very high 12
	2 Unlikely	Very low 2	Low 4	Medium 6	High 8
	1 Rare	Very low 1	Very low 2	Low 3	Medium 4



3. Technology related risks

In all projects where technical development is included, there will be multiple risks involved. Concerns regarding the development, technical barriers and limitations, time frames and other issues connected to the development process are not included here. This report instead concerns the ethical issues that may arise when people use the system.

We have collected possible risks, divided into subcategories such as usability, reliability and privacy. In the final version of this document, each risk will be rated by its likelihood to occur, its impact if the risk does occur and a possible solution to solve it. In this stage of the project, the services are yet to be tested by users which means that some risks are difficult to predict. Thus in this first version of the report, we have estimated the ratings for a only number of risks, but remaining risks and solutions will be rated as the services take form.

The Easy Reading framework does not have any limitations to how many different interfaces it can incorporate since it is component based. The risks are therefore intentionally written somewhat generic, so that they will be able to apply to several different systems or overlays. Over time, some risks may be updated to apply to specific solutions.

Usability

Since the goal of Easy Reading is to improve simplicity and flexibility of any webpage, it is of course of outmost importance that our solutions and interfaces are easy to use for our target users. In this section we summarize risks concerning the interfaces and the overall interaction with the design of the system. Hopefully, those risks may be of use to developers during the project phase and, if discovered by the peer researchers and test participants, may easily be solved before a release.

Risks	Likelihood	Impact	Risk score	Proposed solution
Products do not follow universal design sufficiently				
Manuals/helps are not easy to read	2	3	Medium 6	Add manual in accessible format (images, easy-to-read text, speech output)
Overlay is not customizable for users	2	2	Low 4	Work with users to add customization options
Information on screen is not easily understood or meaningful to the user	1	3	Low 3	Enhance information with image, text and speech support
Systems do not provide sufficient help to the user to understand the content	2	3	Medium 6	
Systems have not enough tolerance for error				
System error messages are not clear				Improve messages so that they relate to the problem



				and inform of possible solutions
Systems require too much physical effort	1	3	Low 3	Look over the navigation and design and make sure they are compatible with alternative access methods
Interface components are not large/visible/positioned widely enough	2	3	Medium 6	Make sure users can customize their preferences to re-arrange components' size and position
Systems are not easy enough to learn				
Tasks in systems require too many steps for the user	1	2	Very low 2	Try to minimize the number of steps required for each task
Within a system, the user interface is inconsistent	1	2	Very low 2	
System is not beneficial enough to make the users actually want to use it	1	4	Medium 4	This depends a lot on the user experience, so the solution is to make sure the system is stable and easy to use
System is not accessible for different access methods	1	3	Low 3	Make sure alternatives to mouse and keyboard work for navigation of the system
System does not provide enough accessible and various output formats (images, text, video)	2	3	Medium 6	Have a wide range of alternative systems and options to customize
The user's needs are not in the center of the system	2	3	Medium 6	Involve peer researchers and test users and iterate solutions according to their opinions
Systems are supported equally for all languages intended	4	2	High 8	Try to implement back-end solutions or compensatory functionality for languages with less support

Stability

This section covers risks concerning the stability of our systems. Any technology can fail and it's important to have solutions ready for those cases. The system of Easy Reading also includes parts that track user behavior and try to draw conclusions from those observations. That we have solutions in place if observations, and system behavior depending on them, go wrong is also essential.



Risks	Likelihood	Impact	Risk score	Proposed solution
Systems fail or crash too often				
Systems are too unpredictable in behavior or respond too poorly to user's intention	2	4	High 8	
The reasoning part of the system stores/predicts/assesses participants' needs incorrectly	2	3	Medium 6	It has to be easy to turn off unwanted functionality that is proposed
The profiles created reflect the participant's needs incorrectly or "insensitively"				
The back-end system to adapt profiles manually fails to override automatic settings				

Transparency

Something that contributes greatly to the understanding and acceptance of a system for a user is to get information about what is happening in the system and why. Risks regarding these issues are collected here.

Risks	Likelihood	Impact	Risk score	Proposed solution
System's limitations and weaknesses are not transparent to users	2	3	Medium 6	Provide clear and accessible information about what the system can do, how, when and why
System's handling of data is not transparent to users	3	1	Low 3	
Features of the system are not transparent for the user	1	3	Low 3	

Privacy and data collection

Risks in this section are closely related to the data privacy laws that are regulated in the EU. In all systems that collect data, there are risks that data is stored and accessed in ways it shouldn't be and these risks need to be addressed.

Risks	Likelihood	Impact	Risk score	Proposed solution
Unnecessary data was collected by the system	1	2	Very low 2	All data collection and treatment must follow European regulation.
Data is stored for an unnecessarily long time in the system				



Data is not stored securely enough by the system				If a risk occurs, this will be reported to a data protection officer who will handle this accordingly.
A third party had access to data without consent				
Data from tracking and browser history is used inappropriately or not protected				
The user cannot control the level of privacy when using the system				

Autonomy

The Easy Reading tools are designed to give users autonomy in performing tasks they may not be able to today, for example reading the content of a website without help. Therefore, we must strive to make our own tools possible to use independently. This sections mentions risks that may occur if we don't think of this carefully enough.

Risks	Likelihood	Impact	Risk score	Proposed solution
System cannot be turned on and off at any time				Make sure the toolbar can be closed and opened easily by the user when the system is active - and easy to log out completely
User can not choose when to use or not use the system's features (e.g. turn off tracking)				
User cannot use system autonomously	1	3	Low 3	Depends on the cause

Accessibility

When thinking about our services, we need to strive towards including everyone that wants to use them. Obstacles for using them might be for example physical ability and the fact that some preferences of users might not be available. Risks of this nature are listed below.

Risks	Likelihood	Impact	Risk score	Proposed solution
Systems do not include all users' functionality or preferences	4	2	High 8	Strive to fit as many as possible
Insufficient back-end functionality to provide own alternative conversions				



4. Project and research related risks

In all projects where users are involved, the project management needs to be aware of and carefully consider the ethical issues that may arise. This is particularly true in a project like Easy Reading, where not only end-users are concerned but also peer researchers and test participants, who are closely involved in the different project stages.

We have collected possible risks that may arise during the project's different processes. The risks are divided into subcategories such as participants' comfort, data collection and stability. The risks are rated by their likelihood and impact and have a proposed solution. Most of these risks have been fairly assessed already at this stage of the report, but revision may always occur during the project time if needed.

In addition to being divided by subcategory, the risks in this section are also grouped by type of user. Certain risks apply to all users, whether they are end-users, test participants or peer researchers. Other risks are more tied to the nature of the peer researchers' or the test participants' tasks.

Recruitment and information to participants

The pilot testing is a big part of the project. It also involves many steps and all of them have to do with user interaction in some way. In the process of recruiting and giving sufficient information, there are ethical considerations to be made. In this section we summarize risks concerning recruitment and interaction with users before the testing.

Risks	Likelihood	Impact	Risk score	Proposed solution
Information on pilot procedure is not clear to participants	2	1	Very low 2	Strive to be as clear as possible. Understanding of procedure may also come over time.
Participant expects different outcomes from pilot procedure	3	1	Low 3	Be clear from the start about the possibilities with participation
Participants are not sufficiently made aware of how services function or their weaknesses				Be sure to inform clearly about limitations
Participants are not sufficiently informed of the Ombudsman or other contact persons and their role	2	3	Medium 6	Make this a task in the routine presentation for participants
Recruitment process excludes certain users	1	2	Very low 2	
Recruitment process did not allow room for participant to say no	2	3	Medium 6	Important to be respectful and pay attention to what signals prospective users send and make sure to ask



				explicitly and give time to think about it
Difficulty finding a high enough number of relevant participants	3	2	Medium 6	Spread information and recruit at many different venues and find many ways to find participants
Informed consent is not understood by participant	2	4	High 8	Make sure that the consent is thoroughly explained in a way that the participant can understand

Testing with participants

As the participants enter the testing phase, there is much to think about regarding their participation. There need to be plans in place for unexpected events, possibilities to facilitate access and balance the interaction with participants against the reality of software development. In this section we have listed risks that may occur during this phase and proposed solutions where we already can see them.

Risks	Likelihood	Impact	Risk score	Proposed solution
Participants withdraw from participation mid-testing	1	1	Very low 1	Make sure there are enough participants so that a few withdrawals do not affect the outcome
Difficulty finding time to test with participants	2	3	Medium 6	Make sure that technology is ready for test early and distributed to pilot sites for preparation in time
Span or setup of testing goes differently than expected	1	1	Very low 1	Researchers responsible for testing are flexible for changes
Participants cannot use the systems due to lack of suitable tools	1	3	Low 3	Make sure to know in advance any needs for adaptations or alternative access and adapt the test situation accordingly
Participants' opinions are not taken into consideration during testing	1	4	Medium 4	
Materials are not presented in an accessible way (e.g. with pictures, easy text)	2	3	Medium 6	Researchers prepare materials beforehand in accessible formats
Requirement list does not take into account all users' needs	2	2	Low 4	



Participants' views and validations are not taken into account in the software development process	2	2	Low 4	Researchers are responsible for conveying all opinions from participants and developers do their best to incorporate them
Peer researchers don't feel equal to the rest of the research team	2	3	Medium 6	Researchers must treat and respect the peer researchers in accordance with IPAR-UCD
Peer researchers' opinions are not taken into consideration	1	3	Low 3	
IPAR-UCD methodology does not suit peer researchers	1	2	Very low 2	Researchers must be open to change and adapt the methodology to the user's benefits
The regulation regarding compensation for participation is not followed by pilot sites	2	4	High 8	Researcher are careful to tell peer researchers the conditions for participation before they consent

Participants' comfort

When testing together with participants and peer researchers, there are a number of situations that can arise and that we as researchers need to try to be prepared for beforehand. In this section we have listed risks concerning the participants' comfort in the testing situations and proposed possible solutions.

Risks	Likelihood	Impact	Risk score	Proposed solution
Participants is stressed or frustrated in the test situation	2	3	Medium 6	Researchers are well prepared in the test situation and can offer something else to try
Participants don't feel valued	1	4	Medium 4	
Testing environment cannot be suited to participants' needs	1	2	Very low 2	Researchers responsible for testing are flexible for changes
Testing situation intrudes too much on the participants' lives	1	1	Very low 1	Participants must be informed of their rights to evoke consent
Participants do not receive enough support during the project	2	3	Medium 6	
Participants are not allowed to leave a test situation	1	2	Very low 2	Researchers must make sure that support persons do not pressure participants



Privacy and data protection

Risks in this section are closely related to the data privacy laws that are regulated in the EU. In this section the risks do not concern the data collection within the systems but rather the data we collect and treat when we recruit, meet and ask for feedback from our participants. All of this data must be treated according to regulations.

Risks	Likelihood	Impact	Risk score	Proposed solution
Unnecessary data is collected from participants	2	2	Low 4	Researchers must think through what data is absolutely necessary
Participant data is not stored safely	2	4	High 8	Pilots sites are responsible for keeping data stored securely in accordance with regulations
Participant data is kept too long	2	2	Low 4	
Participant data is not deleted when requested	2	4	High 8	Researchers must comply with such request immediately
Unauthorized staff has access to participant data	2	4	High 8	Pilots sites are responsible for keeping data stored securely in accordance with regulations
Data is collected without permission or consent	1	4	Medium 4	Researchers must make sure that no participant is photographed or filmed without consent, by anyone
Data is published without consent	1	4	Medium 4	Researchers must make sure that all data that is published in any format has consent
Sensitive data is collected				If data that is considered sensitive according to GDPR regulations needs to be collected, we will ask for explicit consent
Data is not given to participant when requested	2	4	High 8	Researchers must comply with such request immediately

Stability

Risks in this section go hand in hand with the corresponding technology risks. It is therefore important for developers to test thoroughly beforehand and for researchers to be prepared in case something goes wrong.



Risks	Likelihood	Impact	Risk score	Proposed solution
Systems are not tested sufficiently before released to the participants	2	3	Medium 6	Developers must make sure that the systems are ready for testing and researchers must be prepared and know the system well before users test it
Insufficient access to technical support during testing sessions	2	2	Low 4	Developers must be available for questions when the testings are underway

Accessibility

Naturally, we want everyone willing to test our services and participate in the pilot testing as long as they belong to the target group. But there are risks that some users may get excluded in a recruitment or testing situation. Below, some of those risks are stated.

Risks	Likelihood	Impact	Risk score	Proposed solution
Participation is restricted due to economic reasons				Researchers responsible for testing are flexible and try to coordinate testing so that it suits the participant
Participation is restricted due to physical limitations				
Participation is restricted due to communicative limitations				

Advisory expertise

Easy Reading has an external advisory committee with experts in various fields relevant to the project. This is a huge advantage in the process that could be of tremendous help should a situation arise. However, it is also important that the committee really represents our target group and that's why we have listed a few risks concerning this.

Risks	Likelihood	Impact	Risk score	Proposed solution
Advisory committee does not fairly represent the target group				
Advisory committee does not have sufficient expertise in all needed fields				



Ethical regulations

Since there are three different countries responsible for testing services together with participants, consideration needs to be taken to the countries' national regulations regarding ethics and human research. Below are some risks that may occur during the project that each pilot site would have to handle.

Risks	Likelihood	Impact	Risk score	Proposed solution
Pilot sites do not follow their set research and ethics guidelines	1	3	Low 3	
Pilot sites do not have a Data Protection Officer to contact about data processing	1	2	Very low 2	
Pilots sites do not have an Ombudsman	2	2	Low 4	Each pilot site needs to make sure there is an Ombudsman for participants to contact
Ombudsman is not suitable for the task	1	3	Low 3	Each pilot site needs to follow the guidelines on the Ombudsman selection in D8.2



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