Funded by the Horizon 2020 Framework Programme of the European Union

D1.1

Methods and Tools for Recruitment

Easy Reading

PROJECT DOCUMENTATION SHEET	
Project Acronym	Easy Reading
Project Full Title	Easy Reading
Grant Agreement	780529
Call Identifier	H2020-ICT-2016-2017
Topic	ICT-23-2017
Funding Scheme	RIA (Research and Innovation action)
Project Duration	30 months (January 2018 – June 2020)
Project Officer	Michael Busch, European Commission Directorate-General for Communications Networks, Content and Technology, Unit &-3, L-2557 Luxembourg, +352.4301.38082
Coordinator	Universität Linz (JKU), Austria
Consortium partners	Kompetenznetzwerk (KI-I), Austria Technische Universität Dortmund (TUDO), Germany In der Gemeinde Leben gGmbH (IGL), Germany FUNKA Nu AB (FUNKA), Sweden Texthelp Ltd (TEXTHELP), United Kingdom VÄSTRA GÖTALANDS LÄNS LANDSTING (DART), Sweden GEIE ERCIM (ERCIM), France AHTENA I.C.T. Ltd (ATH), Israel
Website	www.easyreading.eu

DELIVERABLE DOCUMENTATION SHEET	
Number	D1.1
Title	Methods and Tools for Recruitment
Related WP	WP1
Related Task	Task 1.1 Recruitment
Lead Beneficiary	TU Dortmund University
Author(s)	Cordula Edler, Susanne Dirks
Contributor(s)	Ingo Bosse
Reviewers	DART
Nature	Project Deliverable
Dissemination level	Public
Due Date	2018/02/28
Submission date	2018/02/28
Status	final

QUALITY CONTROL ASSESSMENT SHEET			
Issue	Date	Comment	Author
1	2018/02/27	Clarify role and selection process of 'ombudsperson'	Sandra Derbring (DART)
	2018/02/28	Issue 1 solved	Susanne Dirks (TUDO)

ACKNOWLEDGEMENT
This document is a deliverable of the Easy Reading project, which has received funding from the European Union's Horizon 2020 Programme for Information and Communication Technologies under Grant Agreement (GA) Nb #780529.

Executive Summary

In deliverable D1.1 the first phase of WP 1 (IPAR-UCD methodology, development and application) is addressed. The aim of this report is to give an initial idea of how to establish inclusive participatory research groups. In addition to basic theoretical principles, examples of basic activities and results are given. The basic recruitment process for the peer researchers and the problems and challenges encountered during this process are described.

Table of Content

Introduction

User-centred design (UCD), and specifically inclusive design, is an approach that aims to create interfaces, artefacts, products, and services that are applicable, appropriate, and accessible to as many users as possible within the constraints of the design specification [1].

Participatory design aims to develop technologies with the close involvement of stakeholders and end-users through cycles of requirements gathering, prototype development, implementation, and evaluation [2]. To inform the design and development process, it is important to capture user information and feedback ideally at every stage, with input from everyone involved; users, designers and stakeholders.

Janice Ollerton [3] introduced the IPAR methodology adopted in the research presented here to the field of participatory research. Inclusive participatory action research (IPAR) is an inclusive disability research methodology, which combines Inclusive Research [4] and Participatory Action Research [5]. According to Ollerton IPAR is founded on an inclusive ideal. It requires research tools that are accessible to people with differing skill sets. Furthermore, the tools should support the process of including peer-researchers in the whole research process, including its evaluation.

In the context of the Easy Reading project IPAR-UCD means to research and develop software together with people with cognitive disabilities. Together with the scientific researchers, peer researchers play an active role in all stages of the research and development process. As representatives of the future users of the software to be developed, the peer researchers present themselves in the easy reading project as experts in their own right.

WP1 Objectives

As stated in the technical annex the Easy Reading Project will develop a novel infrastructure for intelligent, adaptive and personalized interfaces and affective computing for people with cognitive disabilities for managing everyday digital tasks by using original content. In order to achieve this goal, WP1 aims to adapt, use and extend the existing IPAR approaches for user-based software development.

As an open source framework, the Easy Reading framework will offer people with cognitive disabilities personalized support in coping with and working at original digital content (annotation, adaptation, translation) and facilitate independence, self-determination and self-esteem of the target user group. To date products for people with cognitive disabilities are usually designed without the target group. Following the political manifesto “Nothing about us without us”, the Easy Reading project will develop and provide an innovative method for inclusion of people with cognitive disabilities in all stages of R&D.

Tools and Methods for Recruitment of Peer Researchers

As in human resource management (HRM) recruitment is a critical component in participative research as well. It is essential to recruit peer researchers that represent the heterogeneous target group of

people with cognitive limitations in the best possible way. To do so research organizations have to implement and support a finely tuned recruitment process.

Participant recruitment is a major challenge in many research studies. Recruitment involves a number of activities, including identifying eligible participants, adequately explaining the study to the potential participants, recruiting an adequate sample based on study goals and design, obtaining informed consent and maintaining ethical standards, and retaining participants until study completion. Findings from several studies suggest that recruitment often takes longer than anticipated, projects incur higher costs than expected, and scientists routinely overestimate the number of participants available for enrolment in their studies [6].

In addition to the above-mentioned challenges, the Easy Reading Project presents further tasks due to the special features of the intended user group. People with cognitive impairments have very heterogeneous limitations and needs and, due to their limitations, are often incapable of abstracting from problems affecting their own person.

In order to conduct inclusive participatory research together with peer researchers with cognitive impairments, a well-thought-out recruitment process is required. The following section describes the methods and tools developed as part of the Easy Reading Project in more detail.

1. Peer Researcher Groups

Who participates as a peer researcher or member of the research team, depends on the scope of the project and the special characteristics of the target group. The key question when recruiting peer researchers is that they are the representative of the intended user group and are motivated and ready to participate in the research process [4].

In contrast to the tester groups, where the teats teams consist of various smaller groups of one or two peer researchers, an already trained peer researcher and a scientific researcher, the peer researcher groups in the requirement analysis phase always include several peer researchers. Due to their specific abilities and limitations, people with cognitive impairments focus their attention on very different aspects of the materials to be evaluated. These different aspects can then be collectively assessed, evaluated and expanded in joint discussions with other peer researchers and scientific members of the team.

Peer researcher groups can include the following groups of people:

- Individuals from the target group
- Persons of an organization, such as self-help group
- Already trained peer researchers

The first issue that needs to be addressed in the recruitment process is the question of which prerequisites the peer researchers have to meet. All peer researchers should be able to develop a good understanding of the project goals and the methods to be used during the recruitment process [4]. In order to ensure this, methods that are particularly suitable for people with cognitive impairments must be applied or developed within the framework of the project.

To get a good overview of the abilities and skills of a peer researcher, the following methods can be used:

- Workshops to become familiar with the research project, the applied research tools and the team members
- Questionnaires to collect the expectations and ideas of peer researchers and to check the understanding of the project goals
- Guided interviews

2. Informed Consent

In order to be able to conduct participatory research successfully, it must be ensured that the peer researchers are able to participate voluntarily and without external pressure in the research processes. People with cognitive impairments often tend to associate themselves with the wishes of others and therefore try to do things they are not comfortable with.

Before peer researchers can be involved in research, they must be informed about the aims and conditions of their work as peer researchers by means of an informed consent. The informed consent must be structured and formulated in such a way that the peer researchers can understand it reliably, if necessary with the support of assistants and caregivers.

3. Conditions and Assistance

In addition, it is important to clarify from the beginning the conditions under which peer researchers can work on the project. What personal and financial support they can receive.

Peer researchers may require assistance for their work throughout all project phases. There may be a need to employ specially qualified research assistants for this task. Research assistants in this sense are persons who accompany and support peer researchers at work and in the tests, but are otherwise not involved in the research processes. They support the skills and experiences of peer researchers strengthening the self-confidence of peer researchers.

Unfortunately, persons with cognitive impairments, unlike the scientific researchers, are mostly not employed on the first and second labour markets. Therefore, they have to live on welfare benefits and, as a rule; additional earnings are deducted from these benefits. In order to be able to meet these varying conditions for the peer researchers, different compensation models must be developed and considered in the project.

The following compensation models are possible according to the individual requirements:

- Reimbursement of all project-related costs
- Actual or flat-rate remuneration of the time spent on project work
- Reimbursement in the form of technical equipment or project related travel allowances

4. Workshops

Different studies have shown that workshops play an important role in providing peer researchers with a comprehensive insight into the overall project and preparing them for the tasks to be accomplished [7, 8].

In the introductory workshops peer researchers are made familiar with the inclusive participatory action research and the main project ideas.

This may be followed by a question and answer session or a guided interview to make sure that the prospective peer researchers have understood their role in the process. To support understanding, all presentations and workshop related materials have to be in plain language and supported by describing images.

5. Researchers backpack for the Peer Researcher

Previous projects [3, 5] have revealed that peer researchers need support in carrying out their research tasks through suitable research resources. To keep and transport these materials efficiently, the concept of a research case or research backpack was developed.

The following list was compiled together with the peer researchers and contains all items considered relevant for the research tasks:

- iPad and user manual
- Writing materials and templates (see below)
- Team calendar (paper based and/or digital)
- Information and documents illustrating the main project goals in plain language
- Jointly adopted rules for conducting research
- Jointly adopted rules for communication

6. Communication rules

In order to enable smooth and effective communication between all team members, different communication channels are established. Participatory research projects involving people with cognitive impairments must ensure that team members who are unable to read and write can also participate without loss of information and communicate on an equal footing.

The following channels have proven useful for project communication:

- WhatsApp
- Email
- Skype

As WhatsApp seems one of the preferred communication channels for people with cognitive impairments, the following rules for communication via WhatsApp were specified:

- Send only voice messages on WhatsApp
- Send only messages with a maximum length of 1 Minute
- Send messages only during the week from Monday till Friday between 9 am and 5 pm

7. Templates for Research

Within the scope of the project described here, the following templates were developed and considered useful by the peer researchers.

- Project diary (template for records from peer researchers and supporters that may lead to deepening and continuing observations or form for photo diaries) [9]
- Data-Presentation (templates for different presentation forms of the data for the other peer researchers for analysis, e.g. in form of maps for card sorting)
- Result documentation (Various forms of presentation in lectures, reports or texts)

8. Further questions to be clarified in Participative Research Projects

Participant constellations with peer researchers always depend on the project and the participants. There are various possibilities to conduct participative research with the target group of users with cognitive impairments. The following three examples of research group layouts have been proven as useful in other research projects:

- One single research group containing peer researchers, scientists, developers and designers
- Focus Groups: Peer Researchers as discussion-group
- Peer researchers and developers / designers / supporters work in tandems or small groups

An ombudsman should be appointed as a central contact person for all team members in order to resolve conflicts and support them in resolving general and interpersonal problems. The selection of an appropriate person and the definition of the Ombudsman's specific tasks will be developed in the context of the work undertaken in WP8.

Conclusions

This report outlines the initial activities of the development of tools and methods for the recruitment of peer researchers has gone through.
It shows the need for flexibility the organisers have to have to adapt to the participants needs. Furthermore, the report shows the process of giving the participants control over the project from a

state where the scientific researchers lead the session to a state where the peer researchers are able to work autonomously or only with a little assistance on the project.
However, there were some situations where the peer researchers felt that the process was imposed on them rather than they had a chance to participate actively in the process. Not all participants shared this view, but it was an important impulse to further optimize the processes. Because of the resulting discussions significant changes to the practices were made, e.g. with regard to the communication rules or procedures and in identifying research activities.

The first two months of establishing the peer researcher groups in Linz (Austria) and Düsseldorf (Germany) have clearly provided many challenges for all involved team members, but the ongoing commitment of all peer researchers demonstrates not only their enjoyment of the project but also the importance of the overall aims of the project to them.

References

[1] S. Keates and P. Clarkson, "Countering design exclusion: bridging the gap between usability and accessibility", Universal Access in the Information Society, vol. 2, no. 3, pp. 215-225, 2003.

[2] V. Sharma, R. Simpson, E. LoPresti, C. Mostowy, J. Olson, J. Puhlman, S. Hayashi, R. Cooper, E. Konarski and B. Kerley, "Participatory design in the development of the wheelchair convoy system", Journal of NeuroEngineering and Rehabilitation, vol. 5, no. 1, p. 1, 2008.

[3] J.M. Ollerton, “IPAR, an inclusive disability methodology with accessible analytical tools”, International Practise Development Journal, 2, 3, 2012.

[4] J. Walmsley and K. Johnson, “Inclusive research with People with Learning Disabilities”, London: Jessica Kingsley, 2003.

[5] S. Kemmis, “A Self-Reflective Practitioner and a New Definition of Critical Participatory Action Research”, in Rethinking Educational Practice Through Reflexive Inquiry, N. Mockler and J. Sachs, Eds, New York: Springer, 2011, pp. 11- 29.

[6] US Department of Health and Human Services, “Participant Recruitment Research”, Internet: https://healthit.ahrq.gov/ahrq-funded-projects/ emerging-lessons /participant-recruitment-research, [Feb. 26, 2018].

[7] M. Nind, R. Chapman and J. Seale, J., “The conundrum of training and capacity building for people with learning disabilities doing research”, Journal of Applied Research in Intellectual Disabilities, DOI:10.1111/jar.12213, 2015.

[8] H. Moser, “Instrumentenkoffer für die Praxisforschung: Eine Einführung“, 6. Auflage, Freiburg i.B.: Lambertus, 2014.

[9] J. Fullana, M. Palisera, and E. Catala, “Evaluating a Research Training Programme for People with Intellectual Disabilities Participating in Inclusive Research: The Views of Participants”, Journal of Applied Research in Intellectual Disabilities, 30, 684-695, 2017.

Appendix 1: Presentation of Introduction Workshop