IPAR-UCD – Inclusive Participation of Users with Cognitive Disabilities in Software Development

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Abstract. This article presents a new inclusive research concept for research and development (R&D) IPAR-UCD. An adaptation for collaborative R&D with peer-researchers for cognitive accessibility is still missing. This inclusive research concept investigates and combines two methodological approaches: Inclusive Participatory Action Research, IPAR [1] and User-Centered Design, UCD. With this inclusive research and development method, a concept is presented that has already been successfully applied and further developed in the »Easy Reading« project (ER) itself, together with the target group [2, 14].

Keywords: Inclusive-Participatory · Action research and development · e-Inclusion · Accessibility · UCD · Cognitive disabilities

1 Introduction

About 15% of the world’s population lives with some form of disability, of whom 2–4% experience significant difficulties in functioning. According to the World Health Organization, almost 200 million people worldwide have cognitive disabilities or learning difficulties. Most of them need special support. According to the WHO this number will increase due to population growth, medical progress, and aging processes [4]. The accessibility of assistive technologies, AT, has made significant progress, but not to the same extent for the target group of people with cognitive disabilities. For them, accessibility is still missing.

The use of new media and digital services for people with cognitive disabilities or learning difficulties, e.g. for using, reading, and understanding internet content, is difficult. Often this excludes them from social communication and makes them depend on support or services. Enabling them to use the web and web technologies and thus to develop further is of crucial importance for the individual and is also a human right.

It is essential for society and the economy that people with intellectual and cognitive disabilities are and stay as active as possible, and participate in society [3, 16, 17]. The growing potential for flexibility and adaptation of digital technologies has to be encouraged for this target group to bridge the digital divide. Therefore, understanding the requirements of the target group is a key aspect of software development to create products that are accepted, wished, and can be used by the target group [2].
The involvement of the affected target group in the development process, in the sense of user-centred design, must be an integral part of this [5]. Despite some progress, however, there are still many development phases in which users are not involved due to cost and time constraints. In many cases, this leads to limited usability and acceptance of the developed products.

2 State of the Art

In research on cognitive accessibility, the W3C describes the challenges faced by people with learning difficulties or cognitive disabilities when using web content/technologies [7]. Nevertheless, there is hardly any inclusive participation of this target group as researchers or experts in their own affairs.

Literature reviews have shown that no methodological approaches to the practice of inclusive participatory research and user-centred design have been documented [18, 19]. Methods and tools to support communication and interaction to adequately involve the target group are missing.

Only in the social sciences are there some inclusive research approaches to be found. “Inclusive Research with People with Learning Disabilities” by Walmsley, Johnson [8], and IPAR, an Inclusive Disability Research Methodology by Ollerton [1], mark the beginning. In particular, this research deals with people with cognitive disabilities and involves them actively as co-researchers or peer-researchers.

Until now, conventional research has mostly assumed that people with cognitive disabilities are not able to make independent decisions [15]. Often creativity, methods and tools to support communication and interaction to adequately involve the target group are missing. There is also a lack of access and support for the target group in developing digital media [6, 18].

2.1 Findings for Inclusive Participatory Research and Development from the Literature

My own literature review gave the following insights for inclusive participatory research and development and the concept.

- Inclusion of the target groups as peer-researchers requires a high degree of willingness and intuition on the part of the researchers and developers.
- The necessary resources like time, material, and also the payment of the peers must be considered [18].
- The research project must have a high level of accessibility. For this, the target group needs all information in easy and understandable language about the research (the content and aims of the research, further processing of the information, and explanation about anonymity) [22].
- Peer-researchers are expected to participate voluntarily and to show interest and a certain degree of personal responsibility.
- To meet the ethical requirements for research, informed consent in plain language and/or another format is necessary and at best also confirmed in writing [21].
• Transparency and traceability require not only the complete documentation of the research process, but also that the peer-researchers are mentioned by name as co-authors and that the results are available to them in is easier to understand language [8].
• Before the development of the process starts, a formal introduction/training in research skills for people with intellectual disabilities is necessary to enable them to contribute to research [23, 24].

3 IPAR and UCD Together as a New Concept

IPAR, first practiced by Ollerton, is an inclusive approach, and an alternative to Participatory Action Research (PAR) as presented by Kemmis [26]. Inclusive Participatory Action Research, IPAR, represents an alternative, inclusive, empirical research approach.

IPAR provides the framework for inclusive, participatory action research with people with cognitive disabilities. Ollerton [1] actively involves these people in research, either as co-researchers or as peer-researchers, to improve their quality of life. With Ollerton’s methods, people with cognitive disabilities were encouraged to define their needs in daily life and organize their lives themselves [15] or (re)design their things [12, 13].

To allow the target group to participate on an equal level, the creativity of the researcher is required. For IPAR Ollerton adapted and developed methods and tools from action research to meet the needs of the target group. These are simple instruments for data collection and analysis (see Part II. Concept) that are accessible (barrier-free) to people with different resources and qualifications. Peer-researchers can thus be involved in the whole research process, including the analysis/evaluation phases.

User-centred design and user experience design, UCD/UXD also include the potential users in the development process. That means: they deal with user-centred design processes, including the design of assistive technologies and accessibility. People with disabilities are also included as potential users in this research, with the exception of people with cognitive disabilities [5]. For this, there are important questions: Which type of services or support are useful and could help you? What is not useful for you and does not help you? What would you like to do? How would you improve it?

Traditional research and development for people with cognitive disabilities mainly uses methods such as proxy statements, interviews (which are very critical for this target group), and observations. These methods are not as time and cost-intensive, but often not adequate for the target group.

As you can see, IPAR [1] and UCD [9–11] have many parallels in the participation of the potential users but still have not been formally linked. Both can refer to a wide range of methods, techniques, and tools. These may be combined for inclusive research and development and adapted or simplified to the level of people with cognitive disabilities, so that the persons concerned or potential users could be involved in the development. This is worth a try and should be combined for inclusive research and development and adapted or simplified for people with cognitive disabilities.
3.1 IPAR and UCD and the Needs and Advantages of This Combination

There are several advantages with this link. IPAR-UCD and the collaboration with peer-researchers address their support needs:

- People with cognitive disabilities or people with learning difficulties are no longer the subject of research, but participate in research.
- Developers must respect them as users and develop applications that do not frustrate them.
- Peers must cooperate seriously. They have an important task in R&D.
- Recognition and acceptance enable good teamwork and trust.
- Methods are adapted and developed.
- Through an inclusive, user-centred design process software developers and designers more able to understand and to meet the needs of users with cognitive disabilities.

3.2 IPAR-UCD in Scientific Practice

When adapting this new concept, coordination between peers and developers on the one hand and quality criteria for qualitative research on the other have to be ensured.

- Adequacy of the research subject and the research process,
- Validity, reliability, and credibility of the data,
- Transparency and intersubjective traceability,
- Reflective subjectivity (principle of self-reflexivity) on the part of the researchers.

4 The »Easy Reading LAB« and IPAR-UCD

In the Project »Easy Reading«, together with the target group and with the help of the IPAR-UCD concept a software was engineered and designed as AT to support the cognitive accessibility of web content, e.g. reading texts. The finished software should be available free of charge for all those who need help on the internet.

The international development team of »Easy Reading LAB«, included scientists, as well as peer-researchers with cognitive disabilities and people with learning difficulties. They came from Austria, Sweden, and Germany, and were involved in all phases of the interdisciplinary project. A holistic approach to user-centred design was implemented and we involved the target group from the beginning as peer-researchers.

To be able to successfully design the intuitive use and take it into account during development, the needs and requirements of the users, as well as the context of the use of the tool, must be known. The first step was to investigate the difficulties of accessing, reading, and understanding web content.

The first step was to find out the user needs and requirements to develop the software and its services according to the needs (requirement analysis). During development, the peer-researchers tried out different forms of support and assistance. They told the developers what works well and what needs to be improved. The focus was not only on functionality but also on interaction design and the actual look and feel of the software.
In developing interaction design and information architecture, the physical, psychological, and emotional needs of the peer-researchers had to be taken into account. User Research and User-Centered Design, therefore, belong together. Due to the complexity, attempts were made to solve the design requirements in a multidisciplinary way, often focusing less on technical issues and more on creativity. However, the latter proved to be a particular challenge. The peer-researchers were primarily concerned with individual preferences in appearance and less with actual comprehensibility. However, standard design disciplines for product and communication design, as well as issues of ergonomics, information architecture, and usability research are important.

4.1 The New Challenges of IPAR-UCD in the Project

In the »Easy Reading« project, many decisions were made. The process clarified how cooperation should be structured. For example: what access the peer-researchers had to the current field of research? How did they define their role as researchers?

The challenge in the »Easy Reading« project was to identify their ideas on research and development in concrete terms and to include further proposals on the inclusive research agenda during the development process. The stepwise, often iterative procedure requires more time and personnel support than in standard research projects. It was also a challenge to develop inclusive attitudes, procedures, and methods so that the peer-researchers were perceived as fully-fledged members of the research team and that cross-border and cross-language cooperation was able to function.

5 Development and Improvement of the IPAR-UCD Concept

The method used here is “Design-Based Research” (DBR) [12, 13]. Development and further development of the proposed IPAR-UCD concept was based on this quality approach. This means: iterative designing and redesigning by those who are involved.

A preliminary concept was set up based on numerous experiences with the target group, and digital media as well as on the scientific background of media education research. After recruitment of peers and a workshop at the beginning of the »Easy Reading-LAB«, three groups started their work as peer-researchers in different places. The peer researchers were given an iPad as a personal tool, which they could use mainly for communication (e-mail, skype and observation). Most of the time they worked in their group with support, or in tandem (peer-researcher and assistant). The work with the developers took place on-site but also virtually. Focus groups were installed for discussion. Diaries and notes were used. New suggestions were developed again until everyone was satisfied with the result and could work with it.

For the IPAR-UCD methodology, individual steps of the research process, as well as the research instruments, were selected and tested together with the different participants and their individual skills. For this purpose, a mix of methods was used in order to give equal attention to each peer-researcher and to promote the empowerment and responsibility of the other co-researchers.
The working materials and research methods had to be simple and understandable. The research concept as well as all materials for the peer-researchers and methods for inclusive-participative design were selected and adapted, for instance:

- **Collaborative Method** - participatory group process for planning, implementation, and evaluation;
- **Focus Group** - Moderated group discussion with the peer-researchers;
- **Card Sorting** - Development of requirements and information architecture;
- **Scenarios** - Detailed description of a possible defined situation;
- **Visual Storytelling, Photo and Video Elicitation** - Visualization of interactions, scenarios and visions;
- **Cognitive Walk Through** - Plan and realize action steps;
- **Thinking Aloud Test** - Pronouncing your thoughts during testing

The quality criteria for the collection, analysis and interpretation of data have been clearly and comprehensibly defined and applied. The results and analyses of the qualitative data and their conclusions have been presented as far as possible in accessible form.

6 Experience with IPAR and UCD and Advantages of This Approach

This combination of IPAR and UCD as a first inclusive, design-based research concept enables the participation of people with cognitive disabilities as peer-researchers throughout the development process and support user-centred R&D.

The experiences in the research lab »Easy Reading« showed, at the beginning of a project, a workshop with all team members is essential. It is important to become familiar with the tasks, instruments, methods, inclusive work, and also to set a concrete timetable. Peer-researchers working in a group (focus group) or team was preferred in the »Easy Reading« project. For example, the peer-researchers carried out the adapted Cognitive Walkthrough in tandems. This gave them security, and it did not affect the result. Also, we noticed that methods that work from the beginning with visualization are more suitable than text-based or strongly language-oriented methods. In many cases, text-based methods need additional explanations and/or visualizations. Therefore, in a new research project, IPAR-UCD should first be adapted and refined together with the target group.

It has been shown that adequate attention and creativity on the part of researchers and developers and the adaptation and (further) development of usability methods and tools lead to inclusive participation of potential users as peer-researchers in user-centred R&D processes.
7 Conclusion

IPAR-UCD as a concept for inclusive research and development was used in the »Easy Reading« project for the first time. Further, it was modified in collaboration with the peer-researchers of the project. The »Easy Reading-LAB« demonstrates that people with cognitive disabilities can very well be involved as peer-researchers in the development of interactive digital media and services from the first design phase onwards. The research for »Easy Reading« should be done together with them.

For new applications, adapted methodology and tools are now available. They can be used in these contexts. This ensures that people with cognitive disabilities can participate in a research and development process that affects them, and that development can match their needs [1, 6, 14].

Different perspectives on inclusive-participatory research with people with cognitive disabilities have shown that this research approach IPAR-UCD also is also based on German law and on the precepts of UN-CRPD and as such feasible, normative, and ethically justifiable for research and development. Therefore IPAR-UCD can be referred to an alternative methodological approach for inclusive research and development (R&D) and human-computer interaction (HCI). In future, IPAR-UCD could fill a gap as a new qualitative research method in inclusive research.

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