User-centric Approaches in Access Services Evaluation: Profiling the End User

Anna Matamala, Pilar Orero, Sara Rovira-Esteva, Helena Casas-Tost, Luis Fernando Morales, Olga Soler-Vilageliu, Belén Agulló, Anita Fidyka, Daniel Segura, Irene Tor-Carroggio
Universitat Autònoma de Barcelona
MRA/126, 08193 Bellaterra (Barcelona)
{anna.matamala, pilar.orero, sara.rovira, helena.casas, fernando.morales, olga.soler, belen.agullo, anita.fidyka, daniel.segura, irene.tor}@uab.cat

Abstract

This article presents best practices for the design of a user-centric approach in accessibility research projects, taking two European projects as an example: ImAc (Immersive Accessibility) and EasyTV (Easing the access of Europeans with disabilities to converging media and content). Both H2020 projects aim to investigate access services such as audio description, audio subtitling, subtitling/captioning or sign language interpreting in media content. The paper explains the many and varied documentation required to comply with existing ethical issues in Europe. Designing alternative means of obtaining information will be explained, since interaction with participants had to cater for the needs of diverse users. The second part of the article presents an overview of user profiling in previous accessibility projects in the field of media accessibility, and shows good practices based on the two ongoing projects. Finally, the article presents an example of how users have been defined and how they have been involved in the initial stages of both ImAc and EasyTV, by summarizing the methodology developed for a series of focus groups with end users. The article concludes with some recommendations when involving users in accessibility research.

Keywords: media accessibility, user-centric methodologies, user profiling

1. Introduction

ImAc (Immersive Accessibility) and EasyTV (Easing the access of Europeans with disabilities to converging media and content) are two European projects funded by the European Commission in the ICT19 2016 call. These projects, which started in October 2017, research access services in media content, both in traditional and social media. Both projects aim to improve social inclusion by offering accessible media content through four access services: audio description, audio subtitling, sign language interpreting, and subtitling/captioning.

Working within the United Nations Convention on the Rights of Persons with Disabilities (CRPD) paradigm means to consult end users, following the "nothing about us without us" approach. Therefore, taking into account the access services researched, users involved in the tests and applications of both projects are mainly people with visual and hearing impairments.

In order to enhance the user experience, both projects take a user-centric approach when defining system requirements and when testing the technologies and services to be implemented (Harte et al., 2017). Adopting a user-centric approach requires that all procedures, from user selection to results dissemination, comply with ethical requirements. Ethical considerations in human research have been a major concern since the critical articles written by Pappworth (1967) on medical research. They are nowadays regulated by official guidelines that take into account not only the participant well-being (Human Subjects Protection, HSP), but also the communities where both participants and researchers belong to (Community-Engaged Research (CEnR) (Ross et al., 2010; Singleton et al., 2015).

Regarding ImAc and EasyTV, the research group TransMedia Catalonia (grupsderecerca.uab.cat/transmedia/) at Universitat Autònoma de Barcelona (UAB) is in charge of developing the methodology for user testing, due to the previous experience gained testing diverse users in European projects such as DTV4ALL (Romero-Fresco, 2015) or HBB4ALL (Orero et al., 2015). This paper aims to describe the first stages taken in both projects, the challenges found, and how they have been overcome. More specifically, the paper describes how ethical issues have been fulfilled and how alternative means of obtaining informed consent have been developed to comply with current European legislation. It also describes how user profiling has been carried out in previous projects and the approach taken in ImAc and EasyTV. Finally, an example of how users have been defined and involved during the initial stages of the projects is presented. In sum, this paper aims to describe what could be termed best practices for profiling end users in international accessibility-related projects.

1.1 The ImAc Project

ImAc (www.imac-project.eu) is a 30-month project funded by the European Commission aiming to research how access services can be integrated in immersive media, more specifically in 360º content. The aim is to move from current technology to hyper-personalised environments where end users can customise their experiences to meet their needs.

ImAc challenges existing subtitling guidelines (BBC, 2017; Díaz-Cintas and Remael, 2007) drafted for non-immersive media content, i.e. standard movies or TV content. ImAc also poses a new challenge to audio description since sound is immersive, and many audio description solutions can be delivered by object-based sound. Sign language interpreting also defies current practices and guidelines, because it becomes an immersive picture in immersive content.

To work with such complex human and technical challenges, the project consortium is multidisciplinary. The partners include, on the one hand, technical experts, concerned with the development of platforms, players, user interfaces, and access services production tools, namely subtitle production tools, audio production tools, and a sign language editor. On the other hand, academic partners with a background in humanities and social sciences are involved with user experience establishing use cases and user requirements, as well as running pilots to test project results with real end users: persons with disabilities.

1.2 The EasyTV Project

EasyTV is a 30-month project funded by the European Commission aiming to offer easier access to converging media content to persons with disabilities. The project will work on different accessibility-related aspects. First of all, it will work on improving access services by focusing on two aspects: image adaptation, by presenting contrast/edge enhancement or modification, and improved content description, by developing narratives which can be adapted to different playing paces and by providing a cleaner audio. Secondly, the project will work towards improved personalisation of content experiencing and interaction. It will include the development of an "auto-personalisation-from-profile". User profiles together with context information (application, device, content) will allow for assistive technologies and automatic user interface personalisations and adaptations. EasyTV will demonstrate the ability of cloud-based hyper-personalisation to automatically turn on and configure accessibility features built into different TV operating systems, applications and embedded devices. A third area in which EasyTV will focus is the development of novel technologies to break the sign language barrier. Work will be carried out on translation in different sign languages, through a multilingual ontology that will map signs to ontology concepts and realistic sign language avatar animations. Additionally, crowdsourcing technology is going to be developed in combination to the sign language avatar animations. This will allow non-professional users to contribute with their own translations of audiovisual content to several sign languages and share the resulting avatar animations. These new technologies could significantly increase current sign language offer in the media. Finally, a last outcome of the project will be the improvement and development of voice and gesture/gaze recognition to control the TV set and TV applications.

2. Ethical Procedures

Ethics is an integral part of research and projects need to comply with existing regulations and codes of conduct. This is especially relevant when so-called vulnerable populations such as persons with disabilities are involved. According to the European textbook on ethics research, vulnerability is a very complex concept but when "the voluntariness of the subject's consent is compromised, this may similarly prevent them from choosing to give or withhold consent in a way that would protect their interests" (European Commission, 2010: 53). The same document goes on to acknowledge that the "physical (or psychological) condition of some subjects leaves them especially liable to harm, for example as a result of frailty through age, disability, or illness" (*ibid*). To cater for the needs of vulnerable populations, generally due to a disability or to age, both ImAc and EasyTV have followed some specific procedures that can be regarded as best practices when doing research on accessibility with end users: first of all, special care has been taken to write down the information and consent sheets in an easy-to-understand and non-technical way. Participation in both project tests has been and will be voluntary. End users are explicitly informed they can refuse to participate or withdraw their participation at any time without any consequences. Steps are taken to ensure that participants are not subjected to any form of coercion. Participants are also informed they can request additional information about the project results in case they are interested. Although the departing point is a written document, alternative means of communicating information and obtaining consent are always planned. For instance, when participants are blind or visually impaired or have difficulties reading, an electronic form is offered or an alternative oral version is provided and recorded. When deaf participants whose mother tongue is sign language take part in experiments, alternative signed informed consent forms are also provided. Finally, due to the international nature of both projects, the needs of participants in terms of languages is also catered for, providing translations when needed. The final aim is to protect the participants' rights and to make sure that all subjects are aware of the implications of their participation in the research. It must also be highlighted that avoiding any harm that might occur and ensuring the participant health and safety is and will be a priority throughout testing. Partners have been asked to identify any potential risks their technological developments might have for different user profiles. If any risk is identified, such as motion sickness in 360º videos, participants are warned about them through the information sheets and the consent forms. Appropriate measures are always taken to guarantee the participant safety and well-being, and participants thought to be unstable or under the influence of drugs or alcohol are not admitted to the experiments. Last but not least, a crucial element for both the ImAc and EasyTV projects is that ethical forms are approved by UAB's Ethical Committee.

3. User Profiling

User profiling is often carried out through questionnaires which gather demographic information. However, deciding on the specific questions and phrasing is not always as easy as it may seem. Before developing demographic questionnaires for ImAc and EasyTV, a systematic analysis of existing questionnaires from the field of audiovisual translation (AVT) and media accessibility in which access services are tested with persons with disabilities was carried out. Special attention was paid to the following 14 user reception studies dealing with audio description which can be considered representative of recent research in the field: Fernández-Torné and Matamala, 2015; Szarkowska, 2011; Szarkowska and Jankowska, 2012; Walczak, 2010; Romero-Fresco and Fryer, 2013; Fresno et al., 2014; Fryer and Freeman, 2012; Fryer and Freeman, 2014; Szarkowska and Wasylczyk, 2014; Udo and Fels, 2009; Walczak and Fryer 2017; Walczak and Fryer 2018; Walczak and Rubaj, 2014; Chmiel and Mazur, 2012; and three experimental PhD dissertations: Fryer, 2013; Cabeza-Cáceres, 2013; and Walczak, 2017. Information from the projects DTV4ALL, HBB4ALL, ADLAB, OpenArt, and AD-Verba was also gathered for the analysis. A summary of results is presented in the following subsections.

3.1 Sex/Gender and Age

When asking about sex/gender, in the literature under analysis there is always a choice between male/female but the option of not answering the question or selecting another option is not generally included. More recent approaches to this question come from medical and health research, where sex and gender might be of crucial importance on interpreting the experimental results. Therefore, some guidelines have been developed giving directions on how to consider gender issues at all research stages (Day et al., 2017). In ImAc and EasyTV participants will be able to select between "female/male/other/I prefer not to reply" to account for the various options users may want to choose (Zukerman, 1973). The reason to extend to four the traditional duality male/female is twofold. First, gender is not the object of study in both projects and is not expected any relevance in the participation beyond aiming for parity. Secondly, we are moving from an attributed surface-level approach towards a self-reporting or deep-level attitudinal style (Harrison et al., 1998). Since we are dealing with persons with disabilities and vulnerable groups, self-reporting is more engaging for participants since they will be able to reflect their diversity. This diversity or context may have some relevance towards attitudinal differences, which is important, since defining end user expectations is one of the objectives of the questionnaires.

In relation to age, in the investigations under analysis, it is generally asked by offering some intervals, although in some cases it can also be an open question in which a figure has to be entered. In ImAc and EasyTV we have decided to leave it as an open question, as it gives more flexibility for data analysis.

3.2 Educational Level, Occupation, and Language

Concerning the educational level, it is not always asked in the literature under analysis. When asked, the question is presented in various forms: items can be very detailed (Fernández-Torné and Matamala, 2015), a choice of three options (Szarkowska, 2011) or something in between (ADLAB project). In the current projects it has been agreed to ask about the level of finished studies, differentiating between "no studies/primary education/secondary education/ further education/university".

As for the occupation of the participants, it is not generally asked except for one study in which this was considered to be relevant. Therefore, in ImAc and EasyTV it has been decided not to ask about this.

Regarding the language participants generally use, most of the questionnaires do not refer to it. The exception are the questionnaires in DTV4ALL and the Pear Tree project. In ImAc and EasyTV, it has been considered relevant to gather information about the participants main language as this may have an impact in the reception of media content and the opinion of users on system requirements. One of the reasons for this is the fact that, for some participants, sign language (SL) is their natural way of communication. This has a direct implication in both projects. Being visual languages, SL has a special consideration in broadcast since it is considered as a video object or a picture. Specific provisions will be taken for the picture in picture (PIP) challenges arisen from offering SL services in both projects.

It must be noted that, when doing research involving deaf users, data about their native language should not be taken only as a mere demographic fact, but also as information about the participant particular needs. The reception of subtitles by deaf users might be different depending on whether the participant has prelocutive hearing impairment and their mother tongue is a sign language (McIlroy and Storbeck, 2011; Serrat-Manén, 2013). Additionally, it should be noted that just asking users about this topic will not necessarily involve that the researcher will receive the correct answer. Sign language users generally consider themselves bilingual, knowing both their SL and the oral language of their community. However, this is not always the case, as it was demonstrated in a study where some users—who considered themselves to be bilingual—made some mistakes that entailed a difference in skill between the SL and the oral language when writing answers to open-ended questions (Romero-Fresco, 2015). Due to this finding, in Miquel Iriarte (2017) the user level of written comprehension in Spanish was determined by a standardised reading proficiency test. Thus, the question on language is not straightforward when profiling users with disabilities and needs to be taken into consideration as it goes beyond demographic issues.

3.3 Disabilities

The studies under analysis show different approaches to profiling users with disabilities. How to formulate questions is very often related to the model of disability adopted (Berghs et al., 2016). The medical model tends to define "disability in terms of a biological pathology located in an individual body, which requires medical technology, medicine or rehabilitation to make a person well" (*ibid*: xix)". Yet, this model has been criticised on different grounds by activists and academics since focusing on intellectual and bodily functions this approach fails to acknowledge environmental conditioners (Marks, 1997). This approach has been shown to be beneficial to improve medical diagnosis and treatment, but it has a series of weaknesses such as the unbalanced situation between doctor/patient leading to uneven results. Doctors are the experts, whereas patients are passive and not collaborators. Doctors "fix" what is "wrong" aiming at "normality" (Edler, 2009).

The medical model of disability is often referred to as 'the old paradigm' and stands in contrast to the social model of disability. The latter, which has at least nine different versions (Mitra, 2006), believes the medical explanation is insufficient to understand the relation between people and their environment avoiding human diversity (Edler, 2009). The social model of disability "makes a distinction between disability as the experience of oppression and disadvantage and impairment as a physical, sensory, cognitive or mental health condition" (Berghs et al., 2016: xix). If someone refers to himself or herself as a disabled person, s/he is referring to his or her identification with the experience of disablement. From critical disability approaches, as Berghs et al. (2016) explain, terms such as 'differently able' are used, and disability is viewed along a continuum of human diversity. According to this approach, disability is not the result of having a physical impairment, but the failure of society to consider individual differences (Bøttcher and Dammeyer, 2016). In other words, disability is not an attribute of the individual but a creation of the social environment requiring social change (Mitra, 2006).

The social model of disability was developed against the medical model of disability; however, within Disability Studies, the social model of disability was also under scrutiny (Degener, 2016). The UN CRPD was initially drafted as a human rights document aiming to substitute the medical model of disability for the social model of disability. Yet, according to Degener (2016), who in 2001 was a legal expert to the UN High Commissioner for Human Rights as co-author of the background study to the United Nations CRPD in 2001, the final outcome was a treaty based on the human rights model of disability. Human rights approaches, as explained by Bergh et al. (2016: xix), use "person-first definitions, such as 'persons with disabilities', establishing legal, political, cultural, social and economic rights, consistent with the normative values associated with the society within which a disabled person lives."

The International Classification of Functioning, Disability and Health (ICF), approved by the UN World Health Organization in 2001, embodies what is now called the biopsychosocial model. This is a combination of the medical and social approaches to disability (Lundälv et al., 2015). This was a response to the over-medicalisation of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the tendency of the social model to detach disablement from its biomedical origins (Imrie, 2004). It is widely used nowadays but falls short to reproduce the social and personal context.

When designing the methodology for these two projects, we took inspiration from Amartya Sen capabilities or capability approach (Mitra, 2006), which can be applied to disability too. Under Sen's approach, disability can be understood as a deprivation in terms of what he calls capabilities (understood as "practical opportunities") or functionings (understood as "actual achievements") resulting from the interaction of an individual (a) personal characteristics (age, impairment, etc.) and (b) available goods (assets, income) and (c) environment (social, economic, political, cultural) (Mitra, 2006). Disability means lacking certain capabilities/functionings due to the interaction of the above-mentioned factors. Disability depends on whether the impairment places restrictions on the individual functionings or capabilities. It is worth to retrieve the example Mitra (2016) mentions in her article: a 19-year-old boy who suffers a brain injury is considered disabled if his practical opportunity to attend university is restricted (potential disability), in contrast to an individual with a similar basket of goods, in the same environment, and with similar personal characteristics except for the impairment. In case the 19-year-old cannot finally attend college, we would be facing actual disability but in case he finally goes to university, then he would not be considered as disabled. Thus, having a health impairment does not make a person disabled.

When designing the questionnaires for the projects, special emphasis was and will be put in formulating questions that allow us to find out where the deprivation of capabilities or functionings comes from, instead of taking for granted that the problem is the health issue. For example, reading subtitles is not related to being deaf or not, but to the user reading skills, which is closely linked to education. For this reason, and away from a medical or social classification for humans, we try to get a broader overview of user capabilities/functionings through other questions. Concerning their disability, we ask them one single question: how they "define" themselves. The choice of the verb "define" was made on purpose, to respect the user self-perception. An additional question about the age when disability started has also been added. This is due to the fact that disabilities acquired since birth or at early stages in life affect in a direct way the cognitive development and communication of an individual. There are differences, for example, in the education, language acquisition process and cognitive evolution between people with prelocutive hearing impairment and people who lost hearing at a later age (D'Albis and Collard, 2013; Orfanidou et al., 2015).

3.4 Technological Abilities

Questions about technology and audio description exposure of participants were asked in most of the questionnaires under analysis. The aim of such questions was to verify whether the participants were familiar with a given technology and service, how well they knew it, and how regularly they used it. Information about participant habits regarding consumption of audiovisual content was also a regular feature of the questionnaires, by means of closed questions or multiple-choice questions.

In the ImAc and EasyTV projects, it was decided to ask what technological devices participants use on a daily basis, giving the possibility of selecting more than one (the options being television/PC/laptop/mobile phone/tablet). In the ImAc project, they were also asked whether they have any device to access virtual reality content. It was also considered relevant for the current projects to ask about their preferred device for watching online video content. All these elements help us construct a more thorough profile of the users and their capabilities/functionings, to use Mitra's terminology.

4. Involving Users: Focus Groups in ImAc and EasyTV

In ImAc the implementation of access services in immersive media will be tested, whereas EasyTV will focus on testing user interaction on improved and customisable media access services. What is especially challenging in both projects is that access services will not be developed after the technology is fully implemented but will be discussed during and after the development, prior to implementation. At the beginning of the projects, input from a reduced number of users has been sought through focus groups, whilst pilots will aim to carry out experiments with bigger samples at a later stage.

The first step in the focus group preparation was to identify the various stages in the workflow. Four main stages were identified: content management, content production, content delivery, and presentation. The second step was to identify the users who would be interacting with access services at those different stages, and two main categories were identified: on the one hand, professional users (those who will be producing the access services) and, on the other, home users (those who will be consuming accessible media content). The third step was to identify user scenarios linked to various technological components in the different stages. The last step was to derive a list of specific questions related to the technological components to be developed. These questions were used as a guide during focus group development.

A common methodology was developed for the focus groups of both projects. Regarding ImAc, focus groups dealt with audio description and audio subtitling in the UK and Catalonia and on subtitling and sign language in

Germany and Catalonia. In EasyTV, focus groups dealt with technologies related to avatars, crowdsourcing, audio narratives, image magnification, speech recognition, gesture-gaze and sign language translation, distributed among their developers from Italy, Greece and Spain.

It was agreed that focus groups would include between 6 and 12 participants in ImAc and EasyTV, where both professional and home users with technical expertise would be involved. A balance in terms of age and gender was sought.

A specific feature of all focus groups was the final agreement in the form of a series of conclusions approved by all participants. These conclusions referred to end users wishes, expectations, needs, and recommendations in relation to the creation or consumption of access services. The logistics for being able to deliver such written conclusions on the spot included, in the case of ImAc, a team composed by: a facilitator to manage the focus group, one note-taker to take general notes, and a second note-taker to structure the results of the focus group in the form of conclusions. This was possible through sharing and editing live a common e-document. Similarly, the focus groups from EasyTV included two facilitators: one who dealt with group members and kept the discussion on track, and a second taking notes and drafting the final jointly approved conclusions.

Focus groups proved a useful tool to identify user needs and had an impact when developing user requirements. During focus groups users came up with innovative solutions and put forward challenges that academic and technological partners had not considered. The aim of this paper is not to present the results of such focus group but to highlight the usefulness and the lessons learnt when involving persons with disabilities.

5. Conclusions

This paper has presented the user-centric methodology adopted at the initial stages of two on-going European projects. Special emphasis has been put on the key issues to be taken into account when involving end users from the so-called vulnerable populations in accessibility-related research.

First of all, investigations on users with disabilities should not be developed without end users' involvement. In this regard, recruitment through user associations proves to be useful to guarantee a wider reach.

Secondly, ethical requirements should be fulfilled taken into account the needs of diverse participants in terms of communication. An informed consent cannot be considered valid if the end user cannot fully access and understand it.

Thirdly, when asking about disability, researchers should be aware of the different approaches to the concept of disability, and the consequences of their choices when phrasing the questions about disability. Moreover, they should be aware that sometimes factors beyond the specific disability may have a higher impact on the capabilities of the users. It is recommended to pilot the questionnaires with end users representative and agree on the phrasing of specific questions with them, as it was done in the projects presented in this paper.

Regarding focus groups, it was very useful to have one facilitator, one note-taker and another note-taker that summarised the conclusions of the focus groups. These conclusions were approved by participants at the end of the session, and if requested, they were also shared with them via email. This was valued by focus group participants, who had an immediate feedback on their contribution.

The room arrangement in a U-shaped form also proved to be a good practice in the case of deaf and hard-of-hearing participants, because it allowed to clearly see other persons speaking (and therefore read their lips) or see the sign language interpreter.

Although our research is limited in scope because it only deals with persons with visual or hearing impairments and because it is still at an initial stage, we hope it can contribute to define best practices in profiling end users in user-centric research projects with persons with disabilities, a field in which more extensive research is needed.

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