MANAGING THE PARTICIPATION OF PEOPLE WITH DISABILITIES IN LARGE-SCALE R&D TECHNOLOGY PROJECTS: BEST PRACTICES FROM AEGIS AND CLOUD4ALL

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Abstract: People with disabilities are frequently mentioned as beneficiaries of participatory approaches during the research and development of technology since their special needs and preferences can be unveiled and channeled through participatory techniques. However, there are some challenges affecting their involvement and sustained participation in large-scale R&D technology projects. This paper discusses some strategies to overcome these potential barriers, based on the experience of the authors in two large-scale technology projects funded by the European Commission: AEGIS and CLOUD4all.

Keywords: participatory research, user involvement, people with disabilities, accessibility.
Introduction

Given the current economic situation and increased competitiveness in the field of research projects, European policies have been focusing on enhancing the research, development and innovation in technologies, products and services nearby the market. That is why the implementation of a research project increasingly resembles the development of an industrially produced product, which must ensure adequate quality factors to the success of the project developments. To design methodologies that engage the main stakeholders from the commencement of the project is essential to ensure the success of research projects focused on assistive technologies.

This is the approach adopted by two large-scale research projects focused on accessibility and assistive technologies funded by the European Commission: AEGIS (www.aegis-project.eu) and Cloud4all (www.cloud4all.info). These two projects have some similarities: 1) their approach building a new generation of accessible technologies, 2) the active participation of user organizations in the project consortiums, and 3) the involvement of several hundreds of individuals with disabilities in participatory research activities.

AEGIS (active in the period 2008-2012) was aimed to empower people with disabilities, as well as elderly and anyone else disadvantaged when using Internet services, PC or mobile phones (Korn, Bekiaris, & Gemou, 2009). To make accessibility to new ICT products open, personalized and configurable, realistic and applicable in many contexts more than 40 solutions were developed for both developers and users with disabilities in three mainstream ICT areas (desktop, mobile and rich internet applications).

Cloud4all is a four year-project running in the period 2011-2015. It was aimed to provide new ways to face accessibility by tailoring any device, any platform, minority or mainstream solution, to the user needs and preferences (Ortega-Moral, Peinado, & Vanderheiden, 2014). By the end of the project, Cloud4all will provide tools to collect and store the needs and preferences (N&Ps) of users regarding technology, which can be invoked to provide ubiquitous auto-configuration of devices, systems, and applications.
Key solutions were integrated in Cloud4all for desktop and mobile devices, as well as other public and private devices as TV sets or eKiosks.

The nature of these large-scale R&D technology projects imposes some challenges for the participatory activities that are organized in their context. First, the wider range of user needs and preferences should be represented along the project lifetime to validate their approach and outcomes. Second, research activities in these projects last for several years being necessary that users can have an overview of the project evolution and not only on the first prototypes or the final product. Therefore, the involvement of user communities should be part of a general strategy for recruiting and sustaining diversity in research.

AEGIS and Cloud4all both applied a users’ involvement plan along the whole project for actually fulfilling the needs of the users in the developments that were carried out. Although needed, the participation of users in the design and development of products can carry out some barriers due to the difficulty of finding users with the right profile, their selection in a balanced way and the economic cost of users’ time. To overcome these barriers, it is needed to follow a specific users’ involvement methodology to develop specific protocols for user management. The aim is to establish trusted relationships with communities, participants, and stakeholders, determining the profiles of users and the way to contact them, as well as the specific way to deal with them from the moment they confirm their participation until they leave the premises of the tests.

Notice that the aim and scope of this paper regarding participatory design is limited to users’ management in the context of large-scale R&D technology projects. Other important issues not considered here are how to involve users and stakeholders prior to the project starts, during the ideation and planning phases, or how to adapt current participatory design methods and practices to allow people with sensory or cognitive limitations to equally contribute to research (Sainz, Turrero, González, & Madrid, 2014; Slegers, Duysburg, & Hendriks, 2015) .
This paper is structured as follows: First, an overview of participatory research approaches for users’ involvement is provided. Following, we describe our recruitment approach from user definition to call for participation. Next, we describe the participatory processes followed to sustaining participation in the long term, focusing on the management of ethical and legal issues and the dissemination of results. Lastly, we discuss the knowledge gained on both projects, and we draft some conclusions.

The value of user involvement in large-scale R&D technology projects

Technological advances in the information society are a significant opportunity for people with disabilities; for example enabling new opportunities for social participation, for accessing information, and improving the quality of life in general. However, they also imply some risks, as the possibility of being excluded from the benefits of these advances due to lack of access, ability, and (or) motivation (Gregor, Sloan, & Newell 2005; Macdonald & Clayton 2013). Despite the abundant norms and legislation for making accessible different types of technology, technological development seems to be faster than barriers removal. It is frequent that, after the introduction of each new technology, some time passes before its benefits are available to all users. The development of Digital TV in Europe can be used as an example: after the digital switchover DTV devices were not fully accessible for some years (TECH, NOVA, & CNIPA, 2011). This problem may appear recurrently if future generations of interactive or Smart TV are developed without considering the diversity of user needs and preferences. To prevent this kind of problems, the perspectives of people with disabilities should be not only considered in the commercialization stage, but also in the previous phases of technological research and development.

Participatory approaches are potentially able to contribute to minimizing exclusion and to promote access. Nowadays, these are extensively applied in the process of creating and adapting new technologies for people with
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Disabilities and other user groups with special needs (e.g., De Couvreur & Goossens, 2013; Vines, Mc纳米, Lindsay, Wallace, & McCarthy, 2014). However, although there is evidence of their effectiveness in this context, there are also some barriers and concerns that should be overcome when involving people with disabilities. For example, Holone and Herstad (2013) identified three tensions that arise in these participatory design activities: the need of time versus rapid prototyping, the role of users as active participants vs. recipients, and the use of direct communication versus the use of proxies. While it could be discussed that these tensions are present when involving people with other profiles (e.g., people with low digital literacy), it should be recognized that these are more prominent when working with persons with disabilities.

Together with technical and methodological challenges appearing when trying to apply participatory design in such R&D projects, there are also other sociological and organizational issues that could affect the liaison of users with the objectives and procedures of research. Some questions that should be answered when managing the participation of people with disabilities are: Who are the specific user profiles to be involved in research? Why should they participate actively? How will the project recruit and contact them? How could they be motivated to be involved in the long term?

The active participation of people with disabilities and their representing organizations in all areas of society is flourishing, but their implication in research projects and activities is less evident today. In this context, new perspectives appear that claim for a more active role of people with disabilities in research, as emancipatory research (Barnes, 2003) or inclusive research (Walmsley & Johnson, 2003). People with disabilities themselves recognize the need for playing a more active role as partners and consultants in research and not only as mere study subjects (Kitchin, 2000).

Participatory methods, techniques, and tools can be used to foster the active participation of people with disabilities in the different phases of a technological research project, empowering them to make their opinions heard and represented, so the resulting products and services will cover...
their needs and preferences. For example firstly, during initial phases they can participate in the exploration of barriers and problem definition, focusing the ideas towards a possible solution. Secondly, during design and development they can collaborate in identifying issues and propose alternatives. Finally, during the validation phases they can evaluate whether the product or service fulfills their requirements (Muller, 2009).

The participation of people with disabilities in research requires the engagement of researchers, designers and other project stakeholders with user communities at the long term, which rarely happen spontaneously (Vines et al. 2014). Appropriate resources should be allocated to the liaison with user organizations and the identification, recruitment and sustainment at the long term of the participants in research activities.

**Recruiting people with disabilities**

**Definition of user groups, sample composition and assignment to research activities**

First, it would be worth to notice that there is not a unique criterion for defining target populations of people with disabilities, defining the role they will play and assigning them to the most appropriate research activities. The definition of target user groups should be based on a deep knowledge of their characteristics and variability. In the special case of technological R&D, there are other variables (such as digital skills, use of assistive technologies, socioeconomic status, age, and gender) that are sources of diversity and should be also taken into account (Ashok & Jacko, 2009).

Defining user groups allows structuring the participation of people with similar needs and preferences regarding the use of technology. Frequently, user groups can be classified in different subgroups and sub-subgroups. For example, the *people with visual impairments* group can be categorized in *blind* and *low vision* subgroups, and the *low vision* subgroup could be also categorized in different groups as *colour blindness* or *loss of visual acuity* sub-subgroups.
Moreover, the number and concrete profiles involved in research activities is largely determined by the scope, objectives and technology being developed for each project. For example, if one project is focused in developing a new screen magnifier, the sample should be largely composed of users with low vision while the participation of other profiles will be reduced to profiles that could also benefit from such AT (e.g. older people or people with reading difficulties). This principle guided the recruitment in AEGIS and CLOUD4all, which final sample is described in Table 1.

### Table 1. User groups and sample composition in AEGIS and CLOUD4all.

<table>
<thead>
<tr>
<th>User groups</th>
<th>AEGIS</th>
<th>CLOUD4all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual impairments (Blind users)</td>
<td>80</td>
<td>104</td>
</tr>
<tr>
<td>Visual impairments (Low vision users)</td>
<td>72</td>
<td>111</td>
</tr>
<tr>
<td>Hearing impairments (including deaf and hard-of-hearing)</td>
<td>63</td>
<td>11</td>
</tr>
<tr>
<td>Deafblind users</td>
<td>-</td>
<td>31</td>
</tr>
<tr>
<td>Motor impairments users</td>
<td>101</td>
<td>-</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>106</td>
<td>25</td>
</tr>
<tr>
<td>Speech impairments</td>
<td>40</td>
<td>-</td>
</tr>
<tr>
<td>Complex disabilities (motor, cognitive and/or speech impairments)</td>
<td>44</td>
<td>-</td>
</tr>
<tr>
<td>Learning difficulties (users with dyslexia)</td>
<td>-</td>
<td>20</td>
</tr>
<tr>
<td>Older people</td>
<td>-</td>
<td>55</td>
</tr>
<tr>
<td>Users without disabilities</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>510</strong></td>
<td><strong>363</strong></td>
</tr>
</tbody>
</table>

As Table 1 shows, AEGIS largely focused in some profiles as motor or speech impairments that are not considered in CLOUD4all. The reason is that the
AEGIS project considers the development of different solutions specifically addressed to these profiles, as a mobile as an Augmentative and Alternative Communication (AAC) device for severe motor and/or speech impairments (Gemou & Bekiaris, 2010). On the other hand, the CLOUD4all project involved a deafblind user group that was not considered in AEGIS, to analyze its unique complex characteristics regarding the auto-configuration of ATs (Sainz et al., 2012).

Defining user groups is the first step to ensuring that the individual participants will represent the range of needs and preferences of their group of reference. The representativeness is a crucial aspect that, if it is not addressed properly, could lead to a entirely wrong product or service. Very frequently, people with disabilities are defined as having standard functional characteristics that rarely represents the wide range of existing disability conditions.

In practice, it is very tough that the sample of participants involved in the project could represent the full range of needs and preferences of a certain user group, and just a sub-sample of them will participate in participatory activities. To mitigate this problem, we adopted some strategies in AEGIS and Cloud4All:

- **Use a combination of constructed and random samples:** 50% of the participants in all research activities are actively selected to ensure that all key dimensions are represented (e.g. ensuring that blind Linux users are involved even when this circumstance is rare compared to blind Windows users), and 50% are selected by circumstance (e.g. the individuals are present at pilot sites or volunteer after seeing an online call for participation).

- **Replace part of the sample after each iteration:** For example, the Cloud4all project has the goal to have 50% of participants involved from the beginning and for the four years duration of the project. Being the development process structured in three consecutive pilot iterations, the other 50% of the sample can be new for each pilot phase, increasing the chance of representing different needs and preferences along the project.
• **Involvement of experts and stakeholders in participatory activities:** It is advisable to involve people that do not only represent themselves but also speak for their user group. A probed strategy is to include stakeholders (such as tutors, relatives, educators, rehabilitators and user-organizations staff) in focus groups and co-design sessions for complementing the perspectives of individual with disabilities.

At the same time that the sample composition is defined, the users should be assigned to specific research activities. These activities are of different nature (e.g. surveys, interviews, user testing, focus groups, co-design sessions, and so on), which required varying degrees of skills and active involvement. For example, the participants in surveys should represent a broad range of needs and preferences, while the participants in user testing or co-design sessions may need to have some special characteristics regarding their expertise with ATs or awareness about their needs and preferences.

Once user groups and sample composition are defined and assigned to specific research activities, it is possible to start the recruitment, which is not a straightforward process. Next section describes some practical strategies to manage the recruitment of people with disabilities and to overcome communication barriers to obtain the collaboration of certain user groups.

**Recruitment and call for participation**

The first instance in the recruitment of people with disabilities for participatory activities in large-scale R&D technology projects is the production of project documentation. Although it may seem that people with disabilities could be highly motivated to participate in research activities, this is far from reality. Especially when addressing to people with cognitive impairments, other people are mediating in the decision of the user to participate in research (such as tutors, family members, and healthcare professionals).
Time constraints, logistics and the availability of the participants should be carefully considered to foster their participation. An apparent lack of purpose of the activity could prevent users’ engagement, so the project aim and the potential benefits derived from users’ participation should be clearly communicated in advance.

Therefore, project documentation should be produced prior to initiating any contact with people with disabilities or even planning specific activities. This should include the project description and objectives, the expected outcomes and implications and the nature of the participation of people with disabilities in the project. Different formats can be used to provide project information (such as videos, websites and leaflets). When producing this documentation, as well as in subsequent communications, accessibility should be one of the main concerns (such as videos with sign language, captions and audio description, easy-to-read document versions and accessible web pages).

After the project information is produced, it can be used to support a first contact with the potential participants. The recruiter could approach the different contexts in which the user groups considered in the project can be accessed to reach collaboration:

- **Through user organizations, as project partners.** The organizations of people with disabilities usually have a close, trusted relationship with users and their relatives. Trust will greatly facilitate the recruitment process, especially when involving people that are not fully able to give their consent for participation.

- **Through user organizations, as mediators.** In the cases that the organizations cannot participate as partners, it is advisable to include them as project associates, to play an intermediary role between the researchers and people with disabilities. Otherwise, they can somewhat limit the user involvement even actively if they do not trust in the institution responsible for research (e.g. creating obstacles for communicating the project or increasing inflexibility about ethical procedures) (Vines et. al. 2014).
• **Search user databases.** It is common practice to start by searching in user databases built from previous projects. However, the use of these databases has some disadvantages. First, international data protection policies include limitations for the utilization of these databases, especially when they include data about health or disability conditions. Therefore, maintaining these databases requires additional management efforts to cope with ethics and the legal issues of data protection and privacy. Second, people that frequently participate in research activities are in risk of becoming “professional users”, acquiring response biases and being unmotivated. To mitigate this bias, it is advisable to involve participants with different previous experiences of participation in research.

• **Open call for participation.** Announcements in specialized newspapers, magazines or forums and leaflets distributed in institutions, conferences or meetings are usually effective. The dissemination through specialized online communities is encouraged here. For example, both AEGIS and Cloud4all projects have used the most visited disability portal in Spain (DISCAPNET, [www.discapnet.es](http://www.discapnet.es)) to call for potential participants.

In practice, these four channels are used at the same time to maximize the impact.

After this first contact, some expressions of interest for participation should have been collected allowing for further communications. Each research activity requires a specific call for participation, addressed to the specific participants that have been identified in previous phases and including a description of the concrete activities to be performed, the role that the people with disabilities will play in them, and the date, place and schedule of participation. Appendix 1 includes an excerpt of the call for participation used in CLOUD4all (AEGIS used a very similar template).

**Sustaining long-term participation in research**
One major issue in large-scale technology projects is the assurance of the continued availability of participants along all the project phases. It is considered wiser to keep involved the same pool of participants to the maximum possible extent, to keep track of the degree up to which their initial expectations and needs have been fulfilled by the project iteratively upgraded solutions.

**Managing ethical and legal issues**

The construction of trust between people with disabilities, researchers and designers is needed for long-term involvement. For this, a pre-requisite is to manage adequately ethical and legal issues that normally arise in any research but that are even more relevant when people with disabilities are claimed to play an active role as participants (Sainz & Bustamante, 2014).

The first thing to highlight is that recruiting users and managing participatory research with people with disabilities - especially persons with cognitive impairments - requires additional time and resources compared with those required when working with people without disabilities. On the other hand, even when the benefits of participatory approaches are clear, it is not rare that some conflicts of interest or ethical issues appear between different actors during research (between people with disabilities and researchers, between designers and researchers, between researcher and disability experts and other possible combinations) (Aldred, 2008; Sledgers, Duysburgh, & Jacobs, 2010).

Some aspects that should be considered when involving people with disabilities can be highlighted:

1. **Confidentiality, privacy and data protection.** The anonymity of participants in research projects should be guaranteed. It should be noticed that data regarding health records or the disability profile of participants has the higher protection status in several national legislations. Specific consents should be required to take and distribute pictures or videos from disabled persons. If necessary, data anonymization procedures will be applied to results and dissemination of research outcomes.
(2) **Personal safety.** Most R&D technology projects do not imply any potential physical harm, considering that the premises and equipment are complying with the accessibility and safety regulations. However, there always exist low risks of psychological discomfort or inconveniences during research activities. In the particular case of R&D projects pursuing the development of new assistive technologies, there is a chance of invoking unrealistic hopes and expectations for personal benefits in terms of access to new and better solutions, and the subsequent risk of disappointment. This should be counteracted by very explicit and adequately communicated information about the limitations of such personal benefit and also established in the explanation of the informed consent.

(3) **Informed consent.** From the legal point of view, the national and international regulations regarding the participation of users or patients in research should be considered. Consents should describe the rights of the participants and their role, the volunteering nature of participation, the aim of the activities and how the data collected will be used. It is understood that, based on the information that the participant receives from the project, he/she is aware of the data treatment. Consents should be signed by the participant and, in the case that he/she is not able to give full consent, by a proxy. Take into account that, in these cases, the assent should also be obtained from the participants. The consent forms have to be provided in accessible format so that all participants, regardless their disability, are able to read the consent information and sign it on their own.

(4) **Compensation.** Participants should receive a compensation for their time and effort during research and development activities. This compensation can be of different type and value (such as cash, gift cards, or cinema tickets), and should be fixed in advance depending on the budget available for this activity and the characteristics of the tasks to be performed by users. It should be specified to the participants that the compensation is not payment and does not depend on their performance in research activities, so their behavior and attitudes will be not biased. Additionally, compensation for transport to the facilities should be provided in case of specific profiles of users with mobility difficulties. Within this type of users, not only
physically impaired users with problems when moving, walking or taking transport are included, but also visually impaired users that can be dependent on reaching a new place because of their visual limitation for moving.

(5) **Ethical committees and controlling mechanisms.** It is common practice in research organizations (e.g. Universities or hospitals) to have and Ethical advisory board or committee that provides ethical guidance and controlling mechanisms for research. In our experience, the complex nature of R&D technology projects requires from specialized ethical committees. This can be formed by external experts and stakeholder with a deep understanding of both the constraints of research with people with disabilities and the particularities of a participatory approach. An additional controlling mechanism is to evaluate with users if the ethical procedures are adequately fulfilled. For example, in the CLOUD4all project an *Ethical aspects evaluation form* is delivered using an accessible document to each user participating in research activities to validate the procedures and identify potential issues (see Table 2).

<table>
<thead>
<tr>
<th>Questions (YES/NO and Open ended)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When you were volunteering, did you know about the need, on the part of the project consortium, to ensure that ethical and legal guidelines were followed?</td>
</tr>
<tr>
<td>2. Do you think existing norms and regulations regarding volunteering are generally followed?</td>
</tr>
<tr>
<td>3. Are you, as a volunteer, aware of your rights?</td>
</tr>
<tr>
<td>4. Did the informed consent form provide you all information you wanted /expected?</td>
</tr>
<tr>
<td>5. What was the main motivation for you to participate in these tests?</td>
</tr>
</tbody>
</table>
Questions (YES/NO and Open ended)

6. Did you experience any physical, psychological or social discomfort during the tests?

7. Is there any ethical issue that concerns you regarding the project?

8. Are there any ethical concerns you might have regarding the test session you have just finished?

The formal requirements of ethics are also sometimes difficult to apply in practice. For example, Munteanu, Molyneaux, and O’Donnell (2014) reported users’ difficulties in understanding informed consents, fully ensuring privacy and confidentiality, or implementing the pre-approved data collection methods. In any case, researchers should initiate a conversation and negotiation about these ethical and legal issues to build trust between the different research parties.

Dissemination of research results

Dissemination activities are a key instrument to maintain the commitment of people with disabilities. However, very frequently the results of research are just disseminated to stakeholders and experts (such as research centers, universities and standardization bodies, policy makers, industrial organizations, and service providers), through conferences or scientific papers, but this information does not really reach the end-users. Due to this, participants could be disappointed because they do not see the results of their contribution to the research activities in which they participate. It should be emphasized that the outcomes of these research projects should be transferred to the end-users and their environment.

To inform people with disabilities about the advances and outcomes of the project, different channels can be used: web portals, social networks, emails, newspapers and magazines, and special events. For example, project
website should be the main reference for reading information about project results, so its design and contents should be adequate for all users, caring for web accessibility.

Organizing special events have been also showed a successful strategy on AEGIS and Cloud4all. Two kinds of events can be identified:

- **User forums**: Collocated with project workshops and conferences, these events provide an opportunity for the end-users as well as other stakeholders and experts, to know about the different ideas and solutions and give their technical and practical feedback, suggestions and concerns about prototypes being developed. An example of this kind of events is the AEGIS user forum organized at the University of Seville (Spain) on October 2010 that involved a total of 103 individuals, 86 of which were external to the project. The focus was on providing an overview of the AEGIS project and collect feedback on specific prototypes, for which different disability-specific parallel sessions were organized to make presentations to people with similar needs and preferences (Figure 1). Full proceedings of the user forum are available (Carmona, Azpiroz, Scheuhammer, Welche, & van Isacker, 2010).

*Figure 1. User discussion at the 2nd AEGIS user forum*
Open days and Demo events: Open days are structured events lasting one or more days to present the most mature and close-to-market demonstrators. Moreover, conferences and exhibitions offer ample space to present demos during which user feedback can be gathered. Several events of this kind have been organized by CLOUD4all partners along the project duration (Figure 2).

Figure 2. CLOUD4all Open Days at ILUNION in Madrid

Conclusions

In this paper, some issues have been considered for the involvement of people with disabilities in large-scale R&D technology projects, using the AEGIS and the CLOUD4all projects as examples of best practice. From a perspective related to inclusive research, it addresses how to foster the liaison between project partners and people with disabilities and their user organizations, and how to maintain this participation over time. These issues frequently impact the quality of the collaboration users in research, affecting the practice of researchers and designers in participatory activities indirectly.
User organizations are key actors to guide project objectives, facilitate recruitment of participants and transfer the project results to society. They can also support researchers in the management of the complexity of ethical and legal issues, which are intrinsic to disability research, but that can impose a burden for technology researchers. Therefore, some efforts should be difficult allocated not only to involve individual participants but also to foster a deeper liaison with user organizations.

People with disabilities can and should participate in all the phases of an R&D technology project: ideation and planning, collection of requirements, design and development of technology, and pilots and validation. However, it is hard to sustain their participation if trust is not build between them and other actors in research. The paper has discussed two aspects that have been shown useful in our projects: caring of ethical and legal issues and creating a dissemination strategy addressed not only to researchers and funding bodies but also to people with disabilities and their user organizations.

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References


Appendix 1. CLOUD4all project call for participation

Dear participant,

Thank you for considering taking part in the evaluation activities of Cloud4all research project (Contract Number: 289016) which aims to develop a complete new concept in accessibility, by replacing adaptation of individual products and services for a person with automatic-personalization of any mainstream product or service. This new concept uses cloud technologies to activate and augment any natural (built-in) accessibility the product or service has, based on a profile of the user’s needs. The evaluation will happen under the direction of [supervisor name, name of test site]. This study is being held in the context of the [iteration order] evaluation round of Cloud4all project. In this round of evaluations we aim to test some of our technological outcomes with you, expecting to get your valuable feedback and investigate to which extent they meet your needs. Your feedback will be very valuable in improving our solutions. I have enclosed some information about the project to help you decide whether to participate in this part of the study.

Participation involves

If you agree to take part you will be asked to sign the consent form at the bottom of this information sheet.

Interviews, questionnaires completion and testing prototypes will take place at a time which is convenient for you at your place of work e.g. school or offices or at a convenient centre or at [name of the supervisor centre]. The session will last approximately 2 hours.

If you think you would be willing to become involved, arrangements will be made to contact you to discuss the possibility of your being observed using the prototypes and asked for your views on them. This can be conducted through focus group interviews or individually.
What will happen with the information collected in this activity

With your permission, some interviews and tests may be digitally recorded. These will then be transcribed and the recording deleted. If you are observed using the devices, field notes will also be taken. At no time will your name be used in any subsequent report, shared or made public in anyway.

All transcriptions, field notes, responses to questionnaires and session logs will be treated confidentially. These will be allocated a unique test ID to retain anonymity and stored electronically on a private computer with security measures. You will have the right to access, review and/or ask for the deletion of these data from our databases. In any case, these data will be destroyed in October 2016 (i.e. one year after the completion of the project).

Risks

It is entirely at your own discretion whether you participate in this project. There are no risks involved and all data will be treated confidentially. This data will be destroyed one year after the completion of the project.

If, after having taken part you subsequently change your mind, you are still free to withdraw from the project up to three weeks after the day of your participation and any data you have submitted will also be destroyed if requested, without any need to give a reason.

You also preserve any right to withdraw from the tests at any moment if you wish so, without further justification.

Benefits of the research

The final report will summarize the findings from a range of different perspectives and will be available to you upon your request. Additional information on the progress of the Cloud4all project can be accessed at the project Website www.cloud4all.info.
It may also be shared with the wider research community to help others with an interest in accessible solutions. All names will remain anonymous in any publication.

Contact details

If you have any questions or require further details of if you consider that this study has harmed you in any way, please contact me at the following address:

(To be filled by the supervisor)

Name (in capitals):

Expertise:

Post Address:

E-mail:

Telephone:

Fax:

This project and its testing activities fully comply with local Data Protection Laws and the Cloud4all specific Ethics Policy, approved by its Ethical Advisory Board.

On behalf of the Cloud4all Consortium, thank you.