
ETHICS AWARENESS AMONG STAKEHOLDERS IN A DIGITAL TECHNOLOGY RESEARCH PROJECT. EXPLORING DESIGNERS AND PARTICIPANTS' RELATIONSHIP WITH ETHICAL ISSUES AND PROCEDURES

*Fausto J. Sainz de Salces, Rhiannon Thomas
& Javier Bustamante Donas*

Abstract: In this paper we present the perceptions of those engaged in a digital research project. We explored participants' ethical knowledge, understanding and feelings about the whole process. We also tried to implement a plan in order to see if certain proactive actions will benefit the understanding of ethical issues among those stakeholders.

The investigation presented here explored the need for ethical awareness among stakeholders in technology research projects.¹ The Project

¹ The investigation presented on this paper springs from the research project AP-SIS4all and the FFI 2013-46908-R, "Ciencia, tecnología y sociedad: problemas políticos y éticos de la computación en nube como nuevo paradigma socio-técnico".

tried to overcome the existing accessibility barriers faced by people unfamiliar with ICT, people with disabilities and older people when interacting with Public Digital Terminals, such as ATMs and Ticket Vending Machines. As part of the research an investigation was conducted about the ethical issues that rose on the use of digital technologies and, more importantly, about stakeholders ethical issues awareness.

In this report the results from the field research carried out on ethical issues are presented. At the beginning of the project a need for research into ethical awareness among project stakeholders was identified. As part of the project's legal and ethical awareness and compliance, a limited research was carried out on ethical issues. The research carried out encompassed testing the validity and adequacy of the information provided on a purpose-made guide that also included more ethical awareness questions to explore.

During the testing sessions carried out in the pilot the questionnaire was presented to volunteers. Another questionnaire was presented to developers, and to the APSIS4 all project personnel. The expression of ethical concerns was also encouraged from both the staff working in the project and volunteers participating in the trials.

Results showed that the information provided on the documentation was adequate and, likewise, that both volunteers and consortium personnel were aware of volunteers' rights and personnel obligations.

Keywords: *ethics awareness, technology, research, disability, accessibility, testing, moral values.*

1. INTRODUCTION

It has been stated that it is uncontroversial to claim that technology and values are mutually important today (Albrechtslund, 2005) and that many values of technology are recognized in the academic debate just as technology is considered an important topic among related disciplines. However, although there is an undeniable feeling about this need to incorporate moral values and ethical approaches to technology development, in real practice it seems that there are not many paths to fulfil this need and certainly not a guide to do so. Apart, that is, from certain well-established procedures that fill in the basics on ethics, such as the informed consent or certain guidelines and professional codes of conduct.

An exception to this is the theory of Value Sensitive Design (Friedman, 1997) that promises to take into account human values. However the theory is unfortunately unknown in many technological development fields.

This need to advance on the ethical issues could, for example, ultimately be understood under the light of orthodox Darwinism that originally is described by T.H. Huxley in his book "Evolution of ethics" or under a more Rousseauian light. However our intention is certainly more humble: try to understand what benefits can provide a comprehensive approach to technology development from the point of view of those that directly benefit from it, leaving aside considerations of deeper understanding of human nature that include its origins and motivations, whether Freudian, or coming from Lorenz or Darwin.

We can only hope that the very fact of the research carried out among stakeholders, and test participants also, somehow has served as a first contact with ethical issues. A contact that can eventually, through slow sinking and reflection, help in bringing moral values to design, as proposed by Maders-Huit (2010). Somehow it is necessary to legitimate the funding of empirical research on ethics by giving ground and substance to values.

As a proof of the importance of ethical issues we can refer to the fact that the European Commission on his Communication on Ageing Well in the Society of Information has reasserted its views and determination about ethical issues as an important factor to e-inclusion.²

The research also explored perceptions about rights that are among those established in European Laws, and among those rights those regarding respect for private life, the right to participate on information society and also the protection of personal data (Mordini et al, 2009).

Another side effect of the investigation is the awareness that developers and stakeholders can have on the ethical issues related to development as pointed out by Jiménez (2008). In this case we agree that during the researchers formation it is important for them to take responsibility for their acts and also they must have it very clear in their minds that not everything technically possible is ethically acceptable. As Vallor (2010) pointed out we have to be extremely prudential on the development of new technologies as to be able to read the moral significance of new de-

² European Commission (2007).

velopments, with all their complexity, novelty and mutability and respond appropriately to those challenges.

The need to test technological developments during the APSIS project gave us the opportunity to check these ethical aspects during the evaluation stages. Presenting volunteers with the informed consent form is a compulsory part of the testing process; however, asking participants on their perceptions about ethical issues in a wider and more extensive way is not a common practice and provided us with deeper information on how volunteers perceive this issues. Also, investigating how the technical staff, i.e., those who developed the applications, thought and perceived ethical issues in relation with their job and also in their thoughts about volunteers, was an extra bit of information very relevant to understand how all these people involved in the project perceived ethical issues in a deeper and broader sense. As part of the efforts to understand people's awareness about ethical issues (their perceptions, attitudes and knowledge) during the process of technological development, two questionnaires were developed (see Annexes I and II) in order to explore the level of awareness among all those partners and employees involved in the project, and participants in the evaluation activities.

The first questionnaire was given to those working in the project to try to understand the level of ethical awareness among project partners and also to investigate certain issues regarding their perception about volunteers' awareness. We expect that this action will somehow contribute a sense of ethical responsibility among developers, or at least to consider the effect that a person involved in a project as a developer can have on the final result and its ethical implications. We tried to make developers aware of the ethical responsibility that exists whenever technology is developed as proposed by Gram-Hansen (2009). This awareness can be inspired from the start, and not just once the technology has been developed.

Another questionnaire was passed on to volunteers during the testing (prototype evaluation) phase carried out in one of the pilot sites. This last questionnaire explored the adequacy of the ethical issues during the test, and whether partners followed of the recommendations regarding ethical guidelines.

Trust in technology is another issue that we intended to take into account, especially when developing digital systems that are inclusive in their design.

2. OBJECTIVES

The main objectives of the research about ethical issues were:

- To find out whether the previously presented guidelines were perceived as adequate
- To find out the project staff awareness about ethical issues
- To find out whether researchers and developers as project workers comply the ethical guidelines
- To explore staff perception about participants' rights, peer pressure in relation to technological advances and participant withdrawal consequence's awareness, and palliative measures
- Explore issues related to motivation and disappointment in participants

3. METHODOLOGY

In order to investigate the issues raised above, two questionnaires were prepared: one questionnaire aiming at developers and people working on the project (project staff) and another questionnaire aimed at volunteers. Staff at the consortium was presented with the questionnaire after the Ethical and legal guidelines document had been presented to them, and they had had enough time to read it.

The second questionnaire, aimed at volunteers, was presented to them after the evaluation activities had taken place. During the testing sessions participants followed standard procedures: first information about the procedure was provided to volunteers that could opt at the time to carry on with the session by signing an Informed Consent form or they could opt out and leave. Leaving aside the possible circumstances surrounding personal interest and possible peer pressure (Jansson et al. 2008), those who agreed to participate and had signed the informed consent document then performed the tasks and responded to the different questionnaires that conformed the whole testing session. Once they had finished the whole procedure they were thanked for their participation, received a gratification and were informed that if they wanted to know about the research results they would be informed about it.

Data were analysed and descriptive statistics were presented as results.

4. RESULTS

The results from the data statistical analysis gathered during the research from both questionnaires are presented in this section. Firstly, we present the analysis of the data coming from participants belonging to the institutions that make up the consortium. This information will be followed by the analysis of the data from volunteers in the pilot testing.

4.1. RESULTS FROM DEVELOPERS QUESTIONNAIRE

The results of the evaluation presented here considered the answers coming from the questionnaire (see Annex I) to each question separately and give overall information on the main issues raised during the enquiry and voiced by partners. The questions have been copied directly from the APSIS ethical awareness questionnaire. The final part of the evaluation considers the responses of the partners, and which concerns or issues were repeatedly raised in their specific answers.

There were 9 responses to this questionnaire.

Q 0- Did you know about the need to ensure ethical and legal compliance at the time of the project start?

All participants selected the yes option to this question.

Section A: General

Q 1- Are guidelines and recommendations followed?

Five people responded “yes”, two answered “no” and another two answers were missing. The reasons why some respondents answered “no” to this question were firstly that there were no guidelines due to the project being in the initial stages, and secondly because the legislation regarding data protection is inconsistent and can be contradictory.

Q 2- Do you think volunteers are aware of their rights?

Most respondents thought participants are aware of their rights (5), whilst two answered “no” and another two were missing. There was no additional information provided on reasons for selecting a particular answer.

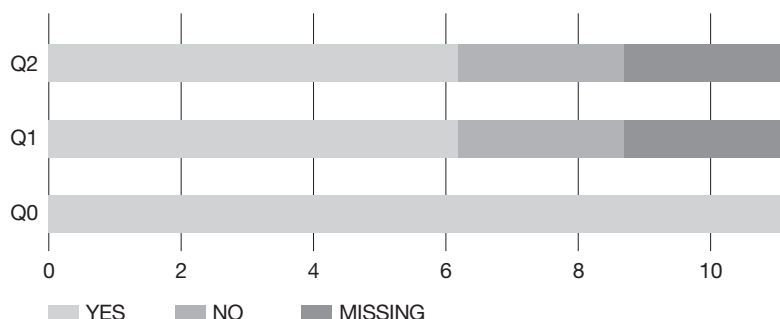


Figure 1. Answers to Questions 0, 1 and 2 from Developers Questionnaire.

Q 3- Many researchers and young people consider technological advances always an improvement in quality of life. Do elderly people think the same? Who or what had convinced them about the benefits of technology? Has it been always a naturally generated opinion or have they been forced into it?

Responses were very divided between those who believed elderly people had the same views as younger people with regards to considering all technological advancements an improvement, and those who felt the elderly had a different perspective. Those who stated elderly people did have different views wrote that the elderly are more afraid of making mistakes, and find it hard to incorporate new technologies into their everyday activities. One response was that elderly people preferred personal services, and therefore see technological advances such as self-service machines of being beneficial to the corporation or bank rather than to the end user.

Some respondents highlighted the importance of acknowledging differences between elderly people, with some being afraid of using new technologies and others embracing them. Alongside this, the issue that some young people do not embrace technological change was raised, so there should not be such a clear conceptual division between the young and the old in terms of how they regard advances in technology.

Q 4- How does the choice of technique affect both results and users participation? Is it really important?

Most responses stated the technique used was indeed very important. One answer stated the questionnaires they had used had in some cases been too long, which they felt may have influenced the outcome. An

overall opinion was that the technique must get as close to real user needs as possible if it is to be effective in identifying and rectifying obstacles currently faced by users.

Q 5- What responsibilities have participants on the co-design experience?

Honesty on the part of the participant was highlighted as being of particular importance if usability needs were to be effectively addressed. One answer was that it would be useful to have a shared work table, which clarified the responsibilities of both the participants and observers. Nearly half of the respondents did not complete this question, so some issues may not have been identified through the answers provided. Some respondents believed participants did not have responsibility as they were under no obligation to participate.

Q 6- What happened to intellectual property rights when volunteers are providing ideas and results?

The main theme here was that there should be a preliminary agreement that is signed by both participants and those conducting the research before the research begins. Participants should be fully briefed as to what their input will be used for. Exploitation of such 'good ideas' should be for mutual benefit.

Q 7- What is the correct ethical approach when a system has the ability to monitor a host of things, from motion in particular rooms to whether a person has taken his or her medicine and thus it is collecting information about a person's daily habits and condition, and then relay that in real-time to doctors or family members?

The main response related to privacy issues, and the idea that all participants should be fully aware of what their research will be used for. Ensuring responses were anonymous was another repeatedly raised issue amongst respondents, due to the idea that anonymity can minimize ethical considerations with regards to future use of the data.

Section B: Commitment

Q 8- If participants fail to attend the work session the disruption caused by their behaviour might indeed cause trouble on the research agenda, etc. with further implications. So how can this issue be addressed?

Most responses stated the number of participants recruited should be enough to overcome problems of non-attendance. Most agreed some no-shows should be expected and prepared for accordingly. Another recur-

ring comment was ensuring participants were made aware that their contribution is important for the development of the project, and that it is vitally important for the quality of the collected data for them to attend, because they could ultimately be the end-users able to benefit from the final product.

Q 9- Is it not a behaviour to be reprimanded about?

The vast majority of respondents stated this is not a behaviour for which the participant should be reprimanded, because they are volunteers and their contribution should be seen as a gift to be thankful for rather than a duty to be fulfilled. Some stated it was important to understand the reasons for not attending perhaps through a private talk with the participant, and said it was not the duty of the researcher to reprimand the participants.

Q 10- Is it appropriate to let them go “unpunished”?

Again the vast majority of responses simply stated it was not appropriate to punish those who do not show up because of the voluntary nature of the contribution. Some responses returned to the idea that it can be important to try to find out the reasons behind why the participant did not show up. One respondent stated that participants should not be punished, but stated pre-agreed rewards should not be given to those who do not complete the research.

Q 11- How can we trust the elderly to participate on the experiments and comply with their contracts?

The main concept here was that there is no particular reason why elderly people will be any less likely than other groups not to be trusted to comply with their contracts, and so trust should be based on belief in the good will of the elderly, as it is with any other group of participants. Some answers stated it should be reiterated to the elderly that their contribution is very important because they are one of the target groups towards whom the research is aimed. The presence of experts in usability and other related issues was also highlighted as being potentially helpful for the improved contribution rates of elderly participants.

Q 12- What are the moral implications of failing to attend a co-design session?

The main moral implications that were outlined related to hindrance to the development of the project, and ultimately the impact this may have on end-users. The concept that unreliable attendance can lead to unreliable results was also raised, with an explanation as to how this can lead to a defective product that can cause obstacles to use for target ben-

eficiaries. A few of the respondents, however, stated that there were no moral implications for failing to attend a co-design session.

Q 13- What can a research team do to deal with a string of continuous failings from the participants? Is it just that researchers have to predict such behaviour (participants failure to comply with research commitments) and act accordingly?

Most answers stated that an adequate number of substitutions should be available from the beginning. Many responses were that some failings should be expected, and the experience of the researcher should mean they have the ability to roughly estimate how much of the data will be inappropriate for use, an outcome for which they should be adequately prepared through the recruitment of surplus participants. The idea that individuals should feel their contribution will be a positive experience was also raised, because this will give them motivation to participate in the appropriate manner. One respondent stated that past participants could tutor new participants, which has the potential to create cohesion and complicity amongst the participants. The idea that motivation can be provided through economic incentive was also suggested.

Q 14- What happens to the participants when the project is finished and the technology is taken away from them? What should researchers do to ensure participants are not disappointed, frustrated or unhappy at the end of the project?

The responses stated that participants should be fully aware of the time limits upon their use of the product from the beginning to try and reduce disappointment later on; no expectations should be raised by the researcher. Some answers also discussed the possibility of keeping participants informed of the progress of the research, and said those involved should be praised for their contribution, so that they feel it is valued. It was also stated that participants should have the right to contact the researchers about the progress of the project if they so wish. One response stated it could be helpful to let the participant know the product may be available to them in the future, and that their contribution has been important for the development of the product that can potentially benefit many people.

Q 15- What happened to people and their wishes and hopes when the development of the project got stagnant or finished and the technological services that were promised or experienced and used are taken away from them?

Most of the answers given reiterated what was said in question 14. There was a general consensus that no promises should be made to respondents, and the situation with regards to access to equipment and technology should be made very clear from the outset. It was also stated that participants should be reassured that their contribution was very important and they should be made to feel proud to have participated.

Section C: Ethical issues information documentation

Q 16- Do you think the documentation provided is relevant to the project?

Generally, people gave a positive response to this question. Seven out of nine responses considered the documentation relevant to the project. The respondent who answered “no” stated there was no information regarding ethics included in the document. One of the questionnaires was not completed so this has been counted as missing data.

Q 17- Do the contents of the document fit the project?

Again the responses to this question were generally positive (6 affirmative, 1 negative and 2 missing). The same respondent answered no to this question as question 18 because they stated no information on ethical issues was provided.

Q 18- Were the document objectives clearly stated at the beginning of the document?

The response to this question was more mixed (4 positive, 4 negative and 1 missing). The main feedback related to the need for clearer objectives because it can be hard to understand exactly what the expectations were with regards to implementing ethical guidelines to a specific research.

Q19- Was the content easy to relate to?

Most responses were affirmative (6) whilst there was a missing answer. The negative comments (2) here related to the issue that it is sometimes hard to understand what is needed. This is generally the feedback given for those answering no to any of these questions, so it raises the issue that greater clarity may be needed regarding ethical implications for research and how exactly ethical guidelines should be adhered to, particularly when the legislation is inconsistent.

Q 20- Was it easy to understand?

Again the majority of responses were positive (6 positive, 2 negative and one missing), but issues of clarity were again raised.

Q 21- Indicate on the following scale, the level to which you feel the objectives have been achieved (where 1 = 10% and 10 = 100%).

Average score for this question was 7.7 with the lowest score at 5 and the highest at 10.

No additional feedback was included from any of the respondents. Three respondents did not answer this question.

Q 22- What could have been done or what do you feel you needed that could have facilitated information acquisition on the ethical area?

One respondent stated they did not understand this question. Generally, respondents felt nothing was needed, but some stated a list of documents on the subject along with information on how to access such documents could have been helpful. Again, not all questionnaires were completed so some issues may not have been highlighted.

Q 23- Were there any inconveniences to following the ethical procedures? If you found some obstacles to following ethical guidelines, which were they?

The issues raised were that 3rd party consent was sometimes needed which could cause complications. It was, however, clarified by some respondents that experienced experts were involved in the process to prevent or overcome obstacles to the greatest extent possible. Most respondents reported no obstacles or inconveniences.

Section D: Participants experiences

In order to measure how respondents feel about the effort to make colleagues aware of the ethical issues a Likert scale was used, where 1 was the value assigned to represent a very easy task and 5 represented a task perceived as very difficult. The question was worded as: "Q 24- Making colleagues aware of the ethical issues compliance need was:"

The lowest score was 2, the highest score was 3 and the average and to mounted 2.5.

Again no additional feedback was given for this question aside from the numerical rating. Three partners did not complete this question.

Q 25- Did volunteers realize about the ethical implications of their participation on the research?

Most respondents (5) stated that once ethical issues had been explained, they understood the implications of their involvement. Nearly half of respondents (3), however, did not answer this question.

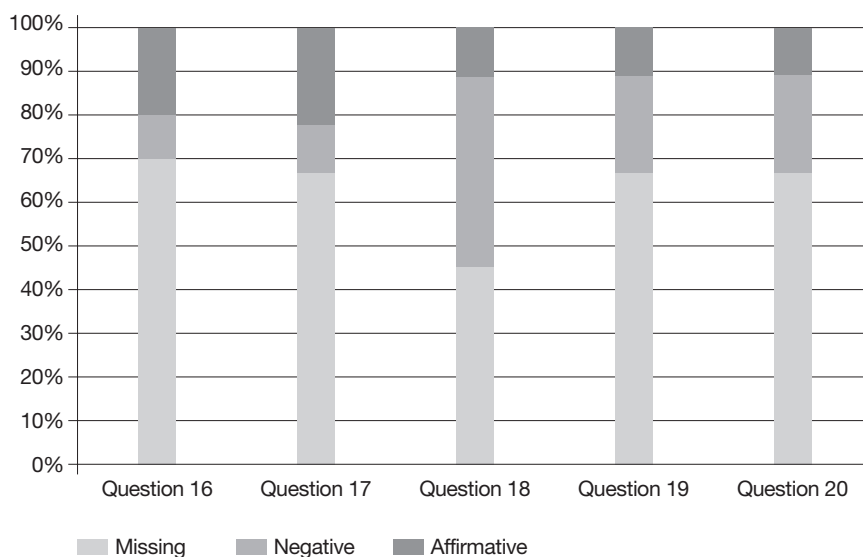


Figure 2. Answers to questions 16 to 20. Developers Questionnaire

Q 26- Did volunteers realize the possible ethical implications of the product development and use consequences?

One respondent stated they were not in a position to answer this question, and perhaps this would be better analysed by an ethical expert. Again, there was quite a large amount of missing data (3 missing).

Five responses indicated that they had a positive perception on volunteers' awareness in product development.

Q 27- Did volunteers comment on any ethical aspect during the time involved in the research?

None of the respondents stated that participants asked questions relating to ethics during their involvement in the research. One respondent stated they were not in a position to say.

4.2. SPECIFIC ISSUES RAISED BY EACH PARTNER

The evaluation so far has focused on overall subjects and responses for each of the questions included in the APSIS ethical awareness questionnaire completed by each of the partners. This section has an inverse focus,

so partners were questioned about their main concern. The following information includes those concerns voiced by the consortium partners.

The main concern raised through the answers to the questionnaire by our first partner related to a desire for slightly more clarity on exactly what is expected with regards to adherence to ethical guidelines, with clearer outlines of objectives highlighted as being of potential use. The importance of informed consent, including issues relating to intellectual property rights, was a recurring consideration in the answers they gave.

The concerns raised by another company were how guidelines should be implemented at the very early stages prior to participant research. This partner stated that it is important to ensure participants feel their contribution is valuable to the outcomes of the project, and they should be made to feel pleased with their contribution.

A recurring issue raised in the answers of another partner was that of sample size, i.e. there should be a surplus of participants to counteract the potential problems which are likely to be faced at some point during the research, such as no-shows, unpredictable participant behaviour and participants dropping out once the research has started. It seems to be emphasised that issues to do with problems in attendance or behaviour are the responsibility of the researcher to correct, rather than the participant to oblige. The concept that the research should try to maintain a user-centred focus to the greatest possible extent is also discussed several times in the answers given.

One concern raised by another partner related to the idea that no promises in terms of availability and development of equipment from the research should be made to the participants in order to reduce the possibility of disappointment. Overall, this partner did not raise many concerns regarding ethical issues.

One partner again raised the issue that the recruitment process should take into account no-shows and drop outs, which should be prepared for through an estimation of the percentage of data collected from participants, which will be inappropriate to use. It is also highlighted that ethical considerations can be minimised if the data are anonymous. Privacy seems to be a specific concern of this partner. This came as no surprise as according to Rachels (1975) if we are able to control the relationship that we have with other people, in a real situation, we must also have control over who has access to us, both physically and digitally.

Another partner raised concern about some of the difficulties faced when considering the application of ethical guidelines to research because

the legislation concerning data protection is inconsistent and can be contradictory. They also stated that improvements can be made in the comfort and efficiency with which some groups, such as the elderly and those with physical impairments, are able to use the technologies under development through making information on how the users can benefit from what is currently available more widespread. This partner also suggested that 'special interest groups' formed by those who are highlighted as least likely to participate in the research could help improve compliance, and could make the experience of these participants more positive. Repeatedly informing recruited participants of the importance of their role was another important element for Höft and Wessel in order to ensure participation rates are as high as possible, thus producing better quality data.

The importance of ensuring participants are fully aware of what exactly the data collected from them will be used for, and why their contribution is valuable: this seems to be an issue raised by most of the partners. This is both to try and ensure high rates of participation, and to help counteract a sense of disappointment, which may arise at the end of the research once the technology is no longer available. Candidate screening is also suggested by this partner as an option to try and ensure high rates of participation (although this could compromise the quality of the data through selection bias). Again the importance of recruiting surplus participants was raised.

The issue of privacy is highlighted as being of utmost importance both when collecting and storing the data. They also make the point that whilst participants should be fully informed of the ethical implications of their contribution, it is important not to instil fear. It is stated that it is important to prepare for no-shows, because this can be hard for some participants to avoid, and can be unpredictable so it is important to have a back-up plan to protect data quality.

Another partner stressed the importance of contributions being voluntary, with each contribution considered to be a 'gift to be thanked rather than a duty to fulfil'. This means that not attending sessions should not be reprimanded because it is not the participants' 'duty' to complete the tasks. It is the responsibility of the researchers to rectify problems that may arise as a result of a lack of participant contribution. Personalised data that will be used for any reason should only be used with the permission of the participant. The importance of anonymising data is also raised as a method to minimise ethical considerations.

4.3. INTERIM CONCLUSIONS

The affirmative reply to the first question implies generic awareness about legal and ethical issues from staff working on the project. Also it is important to notice the reality regarding the difficulty perceived by users on data protection and privacy in relation to legislation. Technology's fast development poses an enormous challenge in this aspect, where sometimes legislation is contradictory or developers have to be guided by legislation coming from other technological areas that needs to be adapted *ad hoc* and might not fulfil all social, personal and commercial requirements.

It is relevant also to notice the perception about the benefits of technological advances among not so young people.

It is important to notice that regarding the perceived responsibility of users in the case of co-design respondents understood the freedom inherent to volunteers in the testing and co-design activities. Respondents were also aware of the rights and procedures to guarantee privacy and freedom to volunteers; this also applies to the issues related to the commitment volunteers can have regarding the research, where solutions were also hinted.

It seems that the guide provided to the consortium on ethical issues was regarded as satisfactory, both in content and relevance, and it was also an easy task to relate to and understand the documentation. However, perhaps the inclusion of a list of documents and how to access them could have been helpful.

Interesting ideas appeared, ideas that had not been innovative show certain social compromise: one response was that elderly people preferred personal service, and therefore technological advances such as self-service machines are seen as being beneficial to the corporation or bank rather than to the end user. Contingency measures were perceived as necessary and palliative procedures.

Honesty is an important attitude when collaborating in research, especially relevant in the information provided to participants. Ideas were also presented on how to manage volunteers' participation in the trials and their collaboration. Ideas on how to encourage and promote participation were raised too.

General perception of the elderly as a group is no different from other segments of the population, being equally trustworthy.

Most respondents thought that the documentation provided is relevant to the project, that it is adequate to the project, that it was also easy to

understand and relate to, but exactly what the expectations were with regard to implementing ethical guidelines was not perceived as clear. This idea was repeatedly voiced.

Also most respondents seemed to be aware of their ethical implication in the research process.

4.4. RESULTS FROM VOLUNTEERS QUESTIONNAIRE

This section summarises the responses of the project participants' ethical awareness questionnaire and corresponds to the results of the Spanish partners only, as this was the only respondent to provide completed data sets at the time of writing. A total of 30 completed participant questionnaires were analysed; the results were collated and are presented in this report. Questions are presented in the same manner as the original ethical awareness questionnaire. The majority of the questions were closed, that is, participants were given the option of answering either 'yes' or 'no'. Where the response was supplemented by additional qualitative feedback, this is presented and discussed in the main body of this report.

The first part of this report presents respondent demographic information with the second part presenting the answers to Questions 1 to 9 that were completed before the tests. The report ends with a summary of the responses to Question 10, which was completed after testing had taken place.

Respondent Demographics and Profile

Gender: 53% (n=16) of the respondents were female; 47% (n=14) were male.

Age: All but one respondent were aged 30 or above with the range being 28 – 73 years old and the mean age being 48.3. A breakdown of each age group is presented in Table 4 below.

Table 1. Respondents' age distribution

Age Range (Years)	20-29	30 - 39	40 - 49	50 - 59	60 - 69	70 - 79
Number of Respondents (%)	1 (3.3%)	9 (30%)	8 (27%)	4 (13%)	3 (10%)	5 (17%)

Profile: The respondents indicated that they experienced a range of disability categories, as presented in Table 5. Please note that a distinction was made between deaf and hard of hearing to match respondents' answers.

Table 2. Profile of Respondents

Profile	Cog- nitive	Low Vision	Blind	Deaf	Hard of Hearing	Motor	Others
Number of Respondents (%)	4 (13%)	4 (13%)	4 (13%)	4 (13%)	4 (13%)	4 (13%)	6 (20%)

Section A: Completed Prior to User Tests

Q1. With the explanation you received about the project and the test that you are about to participate, and after reading the informed consent, would you have been clear about your rights as a participant?

Everybody (n=30) answered 'Yes' to this question.

Q2. Did you know about these rights?

Almost three-quarters or 73% (n=22), of respondents answered 'Yes' to this question, while 27% (n=8) of respondents answered 'No' to this question.

Q3. Do you know your responsibilities as a participant in the test to be performed?

Almost all, or 97% (n=29) of respondents, answered 'Yes' to this question, with 3% (n=1) of respondents answering 'No'.

Q4. Do you believe you have been adequately informed of your responsibilities?

All respondents answered 'Yes' to this question.

Q5. Regarding the informed consent form that you signed, did it include all the information you expected /wanted?

All respondents answered 'Yes' to this question.

Q6. Is there an ethical issue that concerns you regarding the project?

Only 7% (n=2) of respondents answered 'Yes' to this question, while the vast majority, 93% (n=28) of respondents answered 'No'.

Q7. Have you previously participated in similar tests or other research projects?

One third, or 33% (n=10) of respondents answered 'Yes' to this question, with the other two-thirds, or 66% (n=20), answering 'No'.

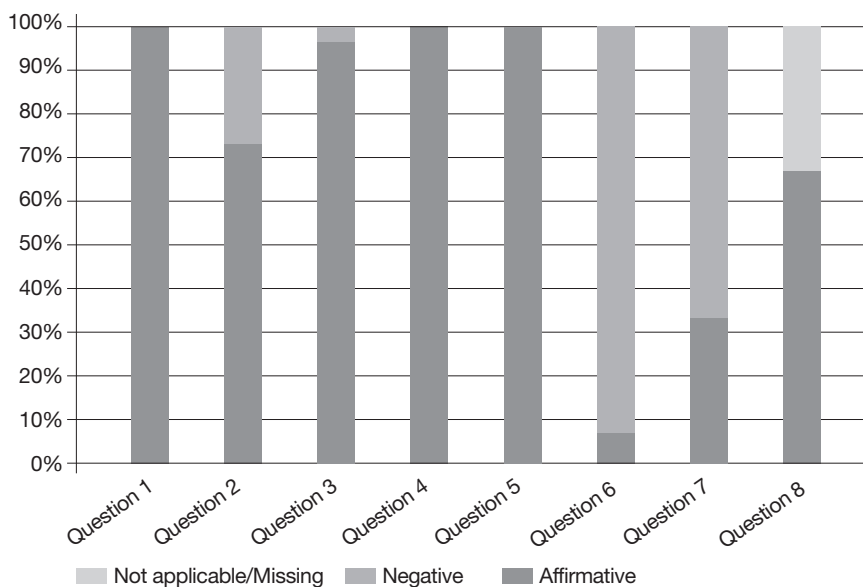


Figure 3. Participant's questionnaire. Answers to Question 1 to 8.

Q8. In case of involvement in other tests, do you think you were properly informed of your rights and responsibilities?

Two-thirds of participants, or 66% ($n=20$), answered 'Yes' to this question. The other 10 respondents did not enter a response. We therefore assume this question was not applicable to them.

Q9. There is a general idea that technological advances involve improving the quality of life for people, and especially people with disabilities and the elderly.

a) Participants were asked to subjectively rate their agreement with this statement on a 1-7 Likert scale; 1 being strongly disagree, 7 being strongly agree.

The majority of participants (73%; $n=22$) indicated that they strongly agreed with the statement, with no participant providing a stronger than neutral response in disagreement.

Responses ranged from 4-7, with the mean response being 6.4 and the mode value being 7.

b) Why do you think that people with disabilities and the elderly rely on the beneficial effect of technological advances? You think it's a personal opinion or is something generated by media or by researchers and technologists?

Table 3. Respondents' Agreement Level

	1	2	3	4	5	6	7
Response	Strongly Disagree	Mo- derately Disagree	Slightly Disagree	Neither Agree Nor Disagree	Slightly Agree	Mo- derately Agree	Strongly Agree
Number (%)	0 (0%)	0 (0%)	0 (0%)	3 (10%)	1 (3%)	4 (13%)	22 (73%)

All but two respondents supplemented their agreement (or otherwise) with a free-text subjective response. The majority of those who responded felt that a reliance on the beneficial effect of technology was down to an individual's personal opinion. One respondent felt that not all technology necessarily leads to advances and another one felt that some advances could be harmful to people with disabilities. Despite this, the majority were very clear in their opinion that technology has the potential to provide significant benefits to older people and people with disabilities.

Respondents overwhelmingly indicated that technology could be of great use to people with disabilities as it can make performing everyday tasks easier. Some felt that all technological advances had the potential to improve the lives of people with disabilities as it can match users' specific needs. Generally, respondents felt technology can improve accessibility by enhancing mobility, communication and access to information, thus improving quality of life for individuals and helping them learn.

One respondent articulated what they perceived to be clear benefits of technology as follows:

"Technological advances allow for alternative communication systems, mobility and enhance the autonomy in daily-life activities."

Another one added:

"User opinions are important. In the future it will be possible to improve and make life easier for people with disabilities, making technology easier to learn and use."

Another respondent felt that while technology could aid people with disabilities, it was still not being used to its full potential and some developments still need to be implemented:

"Technology is useful, but there are still some advances that are not being implemented, like automatic language translation."

Some respondents pointed to a potential psychological barrier to uptake of technology, particularly among the elderly, meaning some users would

still have difficulties and this was often down to the individual mind-set of the user.

This is highlighted by one respondent who commented as follows:

“It depends of the individual. Some people with disabilities trust in technology, others don’t”. This comment highlights the importance of trust and understanding we have about technology. In broad terms, as pointed by Turilli (2007) we need to understand what does it mean to us that devices behave in accordance with the ethical principles endorsed by our society, specially nowadays with the widespread diffusion of highly developed devices and applications.

Section B: Completed Post Testing

Q10. Is there any ethical issue that concerns you regarding the test you just finished?

All respondents answered ‘No’ to this question.

4.5. INTERIM CONCLUSIONS VOLUNTEERS' QUESTIONNAIRE

It can be seen from the answers to the document that respondents feel that the information presented to volunteers was adequate regarding ethical issues in APSIS4all testing sessions. This points at a good instantiation of the recommendation made by Magnusson and Hanson (2003) regarding the ethical principles relevant to research technology and development projects, “Namely, respect for human dignity, worth and fundamental rights, autonomy and privacy, confidentiality, informed consent, non-maleficence, justice, beneficence, and veracity or truth-telling”.

There were no ethical concerns regarding the test performed by the volunteers, thus the information provided in the informed consent and during the testing session must have been adequate which confirms the previous compliance from evaluators to the guide.

All participants feel they were adequately informed about their responsibilities and they thought the informed consent included all the expected information. However, it could be argued that participants expressed no opposition to the informed consent because they did not understand it. In this sense as participants didn’t have any pathology that limited their understanding we have to understand these answers as the

result of a well-presented document with clear information about participants rights on the test (Löfman, 2004).

Most volunteers agreed with the idea that technological developments aid people with disabilities and the elderly, although there were critical comments about this view too.

5. CONCLUSIONS

Although it is not possible to demonstrate the improvement in ethical awareness from the informal information gathered at the beginning of the project, a clear advance on this awareness was accomplished through the development of the guidelines. In general the main conclusions from the study were:

- The guide presented on Ethical and legal issues was adequate and fulfilled its objectives, however including detailed information on resources can be a good step to improve the documentation. Clarification on how to proceed with regards to implementing ethical guidelines might be necessary in certain cases.
- The majority of volunteers and project workers are aware of test participants' rights, thus participants rights are known by all interested parties.
- Participants' perception on ethical issues matched that of developers' perceptions of participants' awareness.
- There was difference between both groups regarding the variety of views on technological development and its effects on elderly people and people with disabilities, which confirms the divergent views on the matter.

Although the area of ethics in technology is not familiar to the majority of APSIS4all personnel, the documentation provided during the first months of the project regarding ethical and legal issues seems to have helped this group to stay in touch with these issues. Awareness from partners and volunteers on ethical issues seems to have been accomplished. It is our hope that by reflecting upon the ethical questions asked to developers they realise how technology should not be considered neutral but it has moral and sometimes political impacts on people's lives (Manders-Huits, 2010).

The authors hope that this paper will further dialogue and debate, especially concerning the ethical aspects of designing technology for those less favoured, taking into account new paradigms such as cloud computing and robotics in a fast changing world where technology seems to reach far ahead of moral values.

BIBLIOGRAPHY

- Albrechtslund, A. (2007) Ethics and technology design. *Ethics and information technology*, 2007 9:63-72.
- Friedman, B. (1997) Human Values and the Design of Computer Technology. CSLI Publications & Cambridge University Press, Stanford, California & Cambridge, New York.
- Gomez Pin, V. (2008) Filosofía. Interrogaciones que a todos conciernen. Espasa Calpe. Madrid.
- Gram-Hansen, S. (2009). Towards an Approach to Ethics and HCI Development Based on Løgstrup's Ideas. Human-Computer Interaction – INTERACT 2009. T. Gross, J. Gulliksen, P. Kotzé et al., Springer Berlin Heidelberg, **5726**: 200-203.
- European Commission (2007). Ageing well in the information society: action plan on information and communication technologies and ageing, an i2010 initiative. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee of the Regions. COM (2007). Brussels, 14 June 2007.
- Jansson, M., Mörtberg, C. And Mirijamdotter, A. (2008) Participation in e-Home Healthcare @North Calotte. Proceedings NordiCHI 2008, October 20-22. 192-200.
- Jiménez Garrote, J. L. (2008) Aspectos éticos a tener en cuenta en la investigación psicofarmacológica. *Bioética*, Enero-Abril, 18-21.
- Löfman, P., Pelkonen, M, and Pietilä, A-M. (2004) Ethical issues in participatory action research. *Scandinavian Journal of Caring Sciences*, 2004; 18, 333-340.
- Magnusson, L. And Hanson, E. J. (2003) Ethical issues arising from a research, technology and development Project to support frail older people and their family carers at home. *Health and Social Care in the Community* 2003, 11 (5), 431-439.
- Manders-Huit, N. (2010) What values in design? The challenge of incorporating moral values into design. *Sci Eng Ethics*. DOI 10.1007/s11948-010-9198-2. Springer.

- Mordini, E., Wright, D., Wadhwa, K., De Hert, P., Mantovani, E., Threstrup, J., Van Steendam, G., D'Amico, A. and Vater, I. (2009) Senior citizens and the ethics of e-inclusion. *Ethics Information Technology*, 11, 203-220.
- Rachels, J. (1975) Why privacy is important. *Philosophy and Public Affairs*, Vol. 4, N. 4, 323-333.
- Turilli, M. (2007) Ethical protocols design. *Ethics and Information Technology*, 2007, 9: 49-62.
- Vallor, V. (2010) Social networking technology and ten virtues. *Ethics and Information Technology* 12, 157-170.

Fausto J. Sainz de Salces
Brighton University
faustosainzsalces@gmail.com

Rhiannon Thomas
Sydney University
rct20@rocketmail.com

Javier Bustamante Donas
Universidad Complutense de Madrid
jbustama@telefonica.net

This paper was received July 23rd 2016, and was approved on November 15th 2016.