PARTICIPATIVE RESEARCH WITH DIVERSE END-USER GROUPS: MULTI-LANGUAGE, MULTI-COUNTRY BLIND AND VISUALLY IMPAIRED PEOPLE

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Abstract: This paper discusses methodological issues involved in participatory multicultural research with blind, visually impaired and deafblind people. This is an important topic for researchers in international stability, as it is related to cross-cultural research to benefit end-user groups who are frequently marginalized and who are likely to otherwise be scapegoated and discriminated against. Understanding of the needs of end-users is crucial for the development of automation, control and other systems that really meet their needs. It is also particularly important that end-user research has the widest possible coverage, including disabled people and people with diverse cultural and linguistic backgrounds. The particular focus of the paper is sampling, writing and translating questionnaires and ethical research with blind and visually impaired people.

Keywords: Methodological issues, ethics, blind people, participatory research, translation issues, multi-language research.

1. INTRODUCTION

This paper discusses methodological issues in participatory multicultural research with blind, visually impaired and deafblind people. This is an important topic for researchers in international stability, as it is related to cross-cultural research to benefit end-user groups which are frequently marginalised. In addition, understanding end-users who are not engineers, including disabled end-users, is crucial for the development of automation, control, ICT and other systems that really meet their needs. However, this issue has largely been neglected in engineering (education). End-user research (on the impacts of automation, ICT or new technologies) should have the widest possible coverage, including disabled people and people with diverse cultural and linguistic backgrounds. New applications of ICT should be tested with blind and visually impaired and disabled people to ensure that they are fully accessible and usable by them. In addition to the importance of ensuring the acceptability of ICT across the widest possible population groups, modifications to ensure use by disabled people can have benefits to the non-disabled population. The potentially global uses of ICT applications give rise to a need for testing with blind, visually impaired (and other disabled) people in many different countries. This paper therefore considers the development of appropriate methodologies for carrying out multi-cultural research to develop assistive technology for blind, visually impaired and deafblind people.

The paper focuses on sampling, writing questionnaires and ethical research with blind and visually impaired people, which are discussed in Sections 3-5 respectively. The context of the discussion is a research study of travel issues for blind, visually impaired and deafblind people. This is presented in Section 2. The paper is introduced by a very brief overview of the literature in section 1.1. The use of the term ‘participant’ rather than ‘research subject’ reflects a commitment to a participatory process with the equalisation of power on both sides, though this may not always have been achieved in practice.

1.1 Brief Overview of the Literature

Multi or cross language, cultural and national research have been treated differently in different disciplines with little cross fertilisation or attempts to draw together the different approaches. The main principles of these approaches (AIATSIS 2000; Pollard, 1992, 2002; Smith 2008; Tapp et al. 1974) are relevant to both cross-cultural research and research with blind and visually impaired people and include:

• Consultation, negotiation and mutual understanding.
• Respect, recognition and involvement, including learning about the host culture, language, history and social structure; seeking frequent guidance from the host community; and avoiding oversaturating any community.
• Avoidance of harm to the host community and ensuring real benefits to both the host community and researchers.
• Engaging only in actions that are ethically acceptable both in the researchers’ and the local community.
• Open communication and respect for participants’ rights. This includes avoiding subtle coercion, considering the power differences between participants and researchers, obtaining explicit permission to observe in private settings and protecting subjects’ welfare and dignity.
• Fostering the skills and self-sufficiency of host community scientists, who should, as far as possible, contribute equally to the research collaboration.

Quantitative research generally uses representative samples, whereas there are a number of different approaches in qualitative research (Coyne 1997), including theoretical and purposeful sampling (Patton 1990). There has been some discussion in the literature (Mangen 1999) of the problems of multi-national sampling and the drawbacks of the frequently used ‘snowballing technique’. Samples in cross cultural...
research (McArt and Brown 1990) should have comparable demographic characteristics across the different groups being studied, be collected at about the same time to avoid the impacts of organisation and policy changes in the interim; and be culturally sensitive across different groups.

A number of authors have noted the lack of attention to translation and transcription in reports of research studies, for instance (Temple and Edwards 2002; Wong and Poon, 2010) and the possible consequences for research outcomes (Birbili 2000; Temple and Young 2004). Both the process of translation and the influence of the translation on the research need to be considered (Larkin et al. 2007). In addition, translation is influenced by factors relating to the context and the translator, (Wong and Poon, 2010), leading to suggestions that translators should be involved as key informants in the research process (Temple and Young 2002). Good translation should include consideration of which issues can be meaningfully translated and the point at which the language should shift from that of the participants to that of the researchers (Temple and Edwards 2002). Language politics should be considered due to possible differences in status of different languages and their users. Where possible, (native) researchers with a combination of appropriate language and research skills, should be used. Alternatively, systematic methods to enhance linguistic and cultural sensitivity (Irvine et al. 2008) are required. The use of a single translator can increase consistency across participants (Twinn 1997), but could have implications for the translator’s working conditions and workload. Conceptual rather than word equivalence can ensure that research instruments convey similar meanings to members of different groups (Berry 1990) and avoid problems of ethnocentrism (Papadopoulos and Lees 2002). However, particular problems occur when the target language lacks an equivalent for a particular word or expression (Twinn 1997), often indicating that the concept, object or structure does not exist in that society. Attention should also be paid to regional variations (Bradby, 2002). (Slightly) different versions of questionnaires may be required for use in different regions.

Although the need for criteria for evaluating translations for use in cross-cultural research was discussed and suggestions made 40 years ago (Brislin 1970), a set of generally accepted criteria is not yet available. There are four main approaches to translation (McGorry 2000):

- One-way translation.
- Translation followed by back-translation into the original language by an independent translator. Comparison of the two versions, consultation with the translators and several iterations could be used to improve the translation.
- Translation by two or more independent translators. The final version is obtained by consensus or chosen by a third party.
- Decentering: linguistic modifications to a translation to fit a particular cultural group lead to changes in the original (Werner and Campbell 1970).

The quality of the translation also depends on the style and complexity of the original version, leading to the following recommendations (Brislin 1970; McGorry, 2000; Marin and Marin 1991; Werner and Campbell 1970): short, simple phrases and sentences; the active rather than the passive voice; avoiding metaphors, colloquial expressions, double negatives, hypothetical expressions and the subjunctive; care with verb tenses; repeating nouns rather than using pronouns.

2. THE RESEARCH STUDY: OVERVIEW

The research study, funded by the Leverhulme Trust, was carried out by the author in seven European countries and one outside Europe during two six-months periods. It investigated the mobility and travel experiences of blind and visually impaired people, the problems and barriers encountered, the need for new travel aids and more accessible environments, and their spatial knowledge and means of learning new routes (Hersh 2009ab). The reactions of the participants showed that these topics were important to them. Data was obtained from semi-structured interviews with blind, visually impaired and deafblind people as experts on their own experiences and requirements; technical visits to observe recently developed technologies and devices and these devices being developed; observation of mobility and orientation training; and interviews with trainers and teachers. The semi-structured approach used both provides enough structure to ensure that all the topics of interest are covered and has sufficient flexibility to enable exploration of issues raised by the participant and variation of the time spent on different topics. It also makes it easier for interviewees to discuss their own experiences, opinions and preferences rather than reflecting back those of the researcher. It allows questions to be tailored to the societal structures, culture and language of the particular participant. The majority of the interviews were carried out face to face, generally in the office of an organisation, with about 15% by telephone.

The interviews generally started with participants being asked to introduce themselves and to talk about their lives, activities, interests, visual impairment and the role of travel in their lives. A few respondents asked for specific questions. However, this generally provided an easy way into the interview by enabling participants to talk about things they were very familiar with and thereby produced some rapport. It also provided a context in which to situate and investigate the full range of issues of relevance to mobility and travel. Education and employment were included to obtain a better picture of participants’ background and context. The interviews were recorded and issues relating to consent are discussed in Section 5. The process used resonates with the description of pagtanong-tanong (asking questions) in the Philippines (Pe-Pua 1989). It could therefore have fairly wide cultural applicability, though the initial topic should be changed in cultures whose members do not talk about themselves.
3. SAMPLING BLIND AND OTHER DISABLED PEOPLE

An accepted procedure for surveying blind, visually impaired and other disabled people has not yet been developed. The smaller numbers and the lack of indication of disability status on readily accessible public lists make this more complicated than surveying the general population. The strategy used was based on the premise that it is both important to collectivise the travel experiences and requirements of blind, visually impaired and deafblind people and recognise individual differences. Thus, every blind, visually impaired and deafblind person is potentially a source of rich information, regardless of whether or not they travel independently. This led to a strategy based on recruiting relatively large numbers of participants who reflected the population diversity in each country to cover both ‘typical case’ and maximum variation sampling.

Surveys of disabled people are generally carried out through a combination of contacting organisations, using relevant email lists and research contacts, posting on websites and advertising in relevant media. All these approaches were used, as well as contacting rehabilitation centres and guide dog schools. The diverse sources of participants also countered the tendency to convenience and snowball sampling. The approach had elements of theoretical sampling. For instance, an attempt was made to contact respondents with particular characteristics, such as deafblind respondents who travel independently, to investigate the strategies they use. Several participants posted information about the research on email lists and/or sent it to personal contacts. Organisations of disabled people are very variable in their responsiveness to researchers. Small organisations are likely to be more open than larger ones and organisations involved with guide dogs to be more open than other types of organisations for blind people. Local and regional branches may be more responsive than national organisations or branches in the capital. A successful visit to one local branch can act as an enabler and facilitate visits to others. Organisations in some of the former eastern bloc countries may react positively to contacts by outside researchers.

Nearly 300 interviews were carried out, giving a good degree of variation with regards to age, gender, education, occupation, type of visual impairment, age of onset and degree of independent mobility. The sample was sufficiently diverse to include blind and visually impaired people from ethnic minority groups and people with additional impairments. Organisations of deafblind people were deliberately contacted to ensure their inclusion in the sample. Blind and visually impaired people with low levels of independent mobility, who went out rarely or only with a sighted guide, had a relatively low representation. They were mainly contacted through rehabilitation centres and their number could possibly have been increased by greater targeting of rehabilitation centres and ophthalmological medical facilities. Questionnaires were also produced.

4. MULTI-LANGUAGE RESEARCH FOR BLIND AND VISUALLY IMPAIRED PEOPLE

4.1 Language and translation issues

Although the author does not have any formal interpreting qualifications, she does have experience of both translating written materials and interpreting, though not of producing equivalent translations in several languages. Direct communication in each participant’s language facilitated contact and helped to break down barriers. It also ensured that the author learnt and used appropriate terminology for travel situations and the devices used by blind people, as well as the educational, legal, social welfare and other systems in the different countries. This might not have occurred with an interpreter. Translation can obscure important differences. For instance, one of the countries has both a neutral and pejorative term for a blind person. Participants used the pejorative version when talking about prejudice, but this may not have come over clearly in translation. Difficulties experienced by participants in discussion of their cognitive processes during travel and their (sensory) representations of space illustrate the problems in expressing highly technical and complicated concepts in clear non-technical language. This is an area where more research is required.

The original version of the questionnaire was produced in English and piloted by blind, deafblind and visually impaired colleagues in England and the USA. It included questions with different types of responses, including multiple choice questions, rating questions and questions with open responses to allow for comments. Piloting the questionnaire in the USA drew attention to linguistic issues relating to both different language usage and the differences in education system and qualifications in England and the USA. (There are further differences in Scotland.) During this process, the author started work on two further language versions and sent them to a visually impaired and a blind native speaker. They both corrected the language and used their knowledge of terminology and travel issues for blind and visually impaired people to provide feedback on the questionnaire design. This, in accordance with the principles of decentering, resulted in some changes to all versions. For instance, as a result of learning about the significant differences in the systems of education and qualifications in the different countries, a multiple choice question with specific options was replaced by a general question as to whether the participants had any educational, vocational or professional qualifications and an open question as to their main or highest qualification if any. A multiple choice question about how route information is retained in memory was replaced by an open ended question with some explanatory suggestions, as the feedback indicated that some of the suggested options were either not meaningful or not comprehensible. This is a difficult area to investigate and different individuals understood different factors.

In total, six different language versions of the questionnaire were produced. The last three versions were written after considerable development work had already taken place.
Language and stylistic corrections of these versions were obtained from native speakers who were either blind themselves or had some involvement with blind and visually impaired people. At this stage a couple of additional questions, motivated by the results of the interviews, were added to all the questionnaires. The final stage was comparison and harmonisation of the different questionnaires to ensure that any changes had been consistently incorporated and that the different versions had the same questions in the same order. To date the questionnaire has only been piloted with a small number of people and further piloting is the next stage. The approach does seem to have produced culturally and linguistically appropriate and equivalent questionnaires in a number of different languages, but was very time consuming. The involvement of the author as the only translator facilitated obtaining equivalent translations, but was a very large and difficult task for one person.

4.2 Accessibility of the questionnaires to blind and visually impaired people

The questions comprised a mixture of multiple choice, rating scale and open-ended questions. Brief instructions on how to answer the different types of questions were provided at the start of the questionnaire. Since many of the respondents would be accessing the questionnaire using screen readers and would not have a visual overview of the number of options provided for multiple choice questions, this was stated in brackets, for instance (5 options) after the question. Instructions were provided at the start of each rating scale question and asked respondents to indicate, for instance, the importance from 0 (totally important) to 5 (very important) of the factors in the question. Since these questions always included a zero effect, such as a no importance option, it seemed most natural to start the scale at 0 for zero effect, with increasing values indicating increasing effect e.g. increasing importance. Since the questionnaire was intended to complement the interviews, the majority of the questions were multiple choice or rating scale, allowing for the collection of quantitative data. However, some open ended questions providing qualitative data were also included. This allowed participants to expand on and clarify their answers and also acted as a check on respondents’ understanding of the questions.

4.3 Issues relating to analysis of the questionnaires

Any significant difference in responses across, for instance, countries or gender could indicate either a real difference in respondents’ experiences and/or opinions or differences in response strategy across countries, gender (or other factors). National, cultural, gender and other differences in response strategy for the particular sample can be investigated by examining the use of options by the different groups of participants. This includes differences in willingness to use extreme values or the use of higher values for the same degree of satisfaction. Literature on different national tendencies in rating scales should be used with caution, since it may not be valid for the particular participants in the particular context. Trends in the results will be investigated when the questionnaire is analysed to determine whether differences are ‘real’ or due to differences in response strategy.

5. ETHICAL ISSUES: INFORMATION AND INFORMED CONSENT

Ethical good practice (BPS, 2009) requires all research participants to be given full information about the research, including any associated benefits and risks, to give informed consent and to be able to withdraw at any point. This raises a number of problems in the case of blind, visually impaired and deafblind people who are contacted through third parties. Where organisations provided lists of potential participants with their phone numbers, they could be contacted, given (additional) information about the research and consent discussed in advance. However, many of the interviews were organised by organisations in their offices, where the author frequently spoke to participants for the first time. While this had the advantage of reducing the author’s workload, it made her dependent on the organisations providing full information about the research to the participants. She did check what information participants had received and whether they required any further information or had any questions for her. However, the commitment of time and effort in travelling to the office of an organisation, made it unlikely that participants would withdraw from participation at that point without answering any questions. This can make the right to withdraw at any point a theoretical rather than a real one. Some of the interviews were organised by one of the research participants. This allowed potential participants to discuss the research, ask questions and obtain answers from the perspective of a participant rather than a researcher.

The research topic of travel issues was clearly of great concern to the participants and positive changes could make a great difference to their lives. The importance of this topic generated considerable good will in the communities of blind, visually impaired and deafblind people and encouraged participation. However, this made it particularly important to be extremely careful in stating the research aims and to avoid giving rise to false expectations. While this was easier when the author was able to speak to participants in advance, misunderstandings still occurred. For instance, the author discovered after a few interviews in a rehabilitation centre that some participants mistakenly thought that she was a medical doctor and able to facilitate their access to treatment. The author unfortunately had to disabuse them and explain that she was not in a position to do this. These particular participants were in the process of losing their sight and desperate for a ‘cure’ and other participants at this rehabilitation centre who had been blind for longer did not have this misunderstanding. However, this does raise the issue of avoiding misconceptions, particularly when potential participants may be searching for ‘cures’. In subsequent research at another rehabilitation centre, the author explicitly asked for potential participants to be informed that she was not a medical doctor and could in no way affect their treatment, and the problem did not occur. However, the second rehabilitation centre was part of a hospital, which
provided state of the art treatment facilities for a variety of eye conditions.

Some of the deafblind participants were very isolated and lacked sufficient contacts with other people and opportunities to go out and/or participate in interesting or, indeed, any activities. The issue of isolation and the need for more volunteers to take her out arose in an interview with a contact signer with a close relative interpreting. What does informed consent and the right to withdraw at any time mean in this context? The deafblind participant clearly benefited from a new communication partner and something new happening to her, which she could presumably talk about later to her relative and the next time she met other people. She was even excited by the fact that the author communicated with her in a very rudimentary way using her rather limited knowledge of (contact) sign languages. She would therefore have been ‘willing’ to continue the interview for hours, though she might have preferred other topics of conversation. In addition, the research did not involve her in any inconvenience and could lead to significant long term benefits to deafblind people, including her. However her relative eventually became tired and may have found interpreting stressful. There has been little attention to the needs of interpreters, particularly unpaid family members and friends, in guidelines for ethical research practice, but they should be taken into account. This gives rise to the question of what is ethically best when the needs of the deafblind participant and the family member interpreter are in conflict.

It is also unlikely that blind and visually impaired participants will indicate explicitly to researchers when they become tired, feel they have responded sufficiently or otherwise wish to withdraw. This puts a certain onus on researchers to be aware of any signals participants give that they have had enough. Researchers should ask participants at the start how much time they have available and subsequently check whether or not they wish to continue.

The indication of consent is generally based on the signature of a written form. This procedure will be inaccessible to many blind and visually impaired people. While a large print version would be suitable for some visually impaired participants and a Braille version for some blind participants, not all participants read either Braille or large print. It is also useful to have one procedure for everyone to avoid the need for questions about accessibility issues, including the size of large print, before the start of the interview and consent has been obtained. Reading aloud by the researcher or another person also seems unsatisfactory. While deliberate misrepresentation is unlikely, it seems important that the research participant has direct access to the information on the form. Therefore an oral procedure was used for providing information and asking for consent. In the case of (contact) signing deafblind participants, this was translated into (contact) sign language by an interpreter.

Consent to tape the interviews was also explicitly asked for and participants were informed that the only people who would listen to the recordings would be the researcher and the transcriber. However, since consent for transcription was obtained after consent for participation in the interviews and the author did not wish to annoy the participants by repeatedly asking for consent, the granting of consent was not recorded. This process is not totally satisfactory and the author is considering how to improve it. In one of the organisations, a written consent form completed by the author or a member of staff was additionally used due to organisational requirements. However, the inability of most of the participants to read it, made its usefulness questionable. Therefore, the use of oral consent with print disabled participants is preferable, but a process for recording this consent is required.

While the literature, for instance (Rubin and Rubin, 1995) states that recording interviews may make participants self-conscious or uncomfortable, the author very rarely found this to be the case. Indeed, most of the respondents seemed to have a very relaxed attitude to being recorded and to be almost surprised at being asked for permission. It is possible, but this would require further investigation, that this relaxed attitude is a consequence of the fact that blind and visually impaired people frequently use audio material. Only one blind or visually impaired person and one mobility instructor refused permission and notes were taken of these interviews.

6. CONCLUSIONS

This paper has discussed some of the methodological issues involved in participatory multicultural research with blind, visually impaired and deafblind people. This is an important topic for researchers in international stability, as it is related to cross-cultural research to benefit end-users from groups which are frequently marginalised. Understanding of the needs of end-users is crucial for the development of automation, control and other systems that really meet their needs. It is also particularly important that end-user research has the widest possible coverage, including disabled people and people with diverse cultural and linguistic backgrounds.

The paper therefore examined the question of developing appropriate methodologies for carrying out multi-cultural research to develop assistive technology for blind, visually impaired and deafblind people. The particular focus was issues relating to sampling, writing questionnaires and ethical research. The discussion was presented in the context of a research study of travel issues for blind, visually impaired and deafblind people.

Research with blind and visually impaired people in different countries has two cross-cultural dimensions: the different countries and blindness/visual impairment. Although blind and visually impaired people do not have their own culture in the same way as the Deaf Community, many of the participants showed community identification, for instance through the use of ‘we’ language. There has been some discussion in the literature of research with disabled people, particularly deaf people (Pollard 1992, 2002), where there are also issues of the use of a distinct (sign) language and fluency in the second/foreign national language, and multi or cross
cultural and language research separately. However, to my knowledge there has been no discussion of the combination. The principles of good practice and ethical research developed to date for cross- and multi-cultural research are relevant to both cross-cultural dimensions, but further research will be required on the development of principles which cover the two cross-cultural-dimensions.

The research process also highlighted the importance, recognised in the literature, of the research topic being of value to the participants as well as the researchers. Particular issues in cross and multi-cultural research with blind and visually impaired people relate to good practice in sampling and ethical issues, including the provision of information, informed consent and the right to withdraw. Sampling was complicated by the need to ensure that all participants were either blind or visually impaired, possibly with additional impairments, and to obtain samples which are in some sense ‘comparable’ in the different countries surveyed. The approach used was based on the assumption that every blind or visually impaired person is a potential source of rich data on the topics of interest, and the use of diverse sources of contacts with blind and visually impaired people. Thus rather than strict comparability across countries, the aim was samples which represented the full diversity of the blind and visually impaired communities in each country. The approach used was reasonably successful at doing this, but there would have been benefits in tabulation of respondent data as the research progressed to determine whether particular efforts at the recruitment of certain groups of respondents were required. The approach also allowed an element of theoretical sampling in order to further investigate or try to corroborate particular theories.

Acknowledgements: I would like to thank the Leverhulme Trust for the award of a Research Fellowship which supported this work, the many blind, visually impaired and deafblind people who gave of their time and expertise and the colleagues and organisations who provided me with support. I would also like to thank Dr Larry Stapleton and Prof Mike Johnson for their very helpful comments and suggestions.

REFERENCES


Hersh MA (2009a). Designing assistive technology to support independent travel for blind and visually impaired people, tutorial session, CVII '09, Wroclaw.


