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# Qualitative Assessment Methodology

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The Report on Qualitative Methodology provides the members of the consortium with details of the qualitative methodology to be used within the project.	

## Revision

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## Qualitative Assessment Methodology

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## 1. Introduction

In the 21st century, mediated communication is pervasive in everyday life. The ability to communicate is an important factor for success in the workplace and educational environments. People with autistic spectrum disorders (ASD) have a wide range of difficulties with comprehension of written information (Nation et al. 2006). They are often incapable of competently taking part in social environments, putting them at risk of social exclusion. Research by the UK National Autistic Society (NAS, 2004) shows that only 6% of adults with autism are in full-time paid employment, despite the fact that they would be capable of working if they received sufficient support. Adult sufferers of ASD state that they consider employment to be the biggest barrier they have to face (Barnard et. al. 2001; NAS, 2004). Social exclusion is not only a problem for adults: 21% of children with ASD have been excluded from school at some point in their lives; the most common reason stated for this is that the school was unable to cope with the child (Barnard et. al. 2001). Children with special educational needs (SEN), including many with ASD, are seven times more likely to be excluded from school than other children (NAS, 2004). It is expected that improving access to written educational material will strengthen the position of users of the FIRST technology, making them better able to participate and succeed in social settings such as education and employment.

The UK National Survey of Psychiatric Morbidity found that adults with ASD are more likely to have lower educational achievements than other people (Brugha et al. 2007). This may be due to their impaired reading comprehension. Several studies have indicated a connection between literacy and access to education, employment, culture, and communication. It has been noted that people with limited literacy skills find it difficult to cope with the rising skill demands of the information age (OECD, 2000). Thus, there is considerable evidence that autistic people with reading comprehension difficulties are at risk of exclusion from the opportunities available within the information society.

In the information society, much communication is mediated by textual information (e.g. instant messaging, Facebook, Twitter, discussion forums, email, e-books, etc.). FIRST technology aims to improve social inclusion of end users by providing a flexible and interactive reading support tool. This technology will improve access to this information by detecting and removing obstacles to reading comprehension. People with ASD typically have difficulties understanding figurative and non-literal language, semantically ambiguous words and phrases, and highly specialised/technical words. They also experience difficulties with morphologically, orthographically, and phonetically long or complex words or sentences as well as inconsistent formatting of elements of document structure. The FIRST technology will be used to provide personalised software to remove obstacles to reading comprehension for people trying to access it.

People with ASD are at risk of exclusion from the information economy due to their difficulties in reading comprehension. The development of this technology is expected to improve the quality of life of end users and intermediaries. For people with ASD, it will directly improve their ability to access written information and positively affect their perceptions of inclusion.

Within the FIRST project we aim to adapt existing LT resources to design a system which can be personalised to meet the specific needs of patients on the autistic spectrum, enabling them to acquire skills necessary for participation in work, education or training and social interaction. By improving their access to written materials, we aim to facilitate empowerment of people with ASD. The FIRST system is expected to help individuals with ASD to increase their independency by improving access to the wealth of textual information that is available in the information society.

One of the most important contributions of the FIRST project will be the opportunity to provide evidence about the impact of the Information Technology on social inclusion among people with autistic spectrum disorders (ASD). The aim of our study is to evaluate the impact of the FIRST system on personal experience of social inclusion by people with ASD and their carers. Qualitative approach will provide the methodological framework that will allow in-depth assessment of personal experiences of social inclusion. As far we are aware there has not been any previous qualitative research of social inclusion among people with ASD. In medical research, with its strong tradition in quantitative methods, qualitative approach is often criticized of lacking scientific rigour. The main objective of D7.1 is designing a robust qualitative methodology that will enable measurement of the impact of FIRST on social

inclusion. One of the most important objectives of WP7 is to develop a robust qualitative methodology applicable to clinical evaluation of the impact of IT developments on social inclusion.

## 2. Bibliographic search

We conducted extensive search of medical research databases - PubMed, Medline, PsycINFO that cover biomedical and psychological scientific publications, life sciences journals and on-line books, to systematically evaluate previous study designs concerning subjects with ASD. Qualitative research explores social and cultural phenomena in their natural settings and intends to make sense of these processes in terms of meanings people bring to them (Hallberg 2006). Although social exclusion among people with ASD appears to be a significant problem, studies of this phenomenon are scarce. Furthermore, there has been very limited use of qualitative methods in research of ASD (Neely-Barnes 2010, Davidson et al 2010, Causton-Theoharis et al 2009).

We evaluated methodological studies and reviews concerning methodological issues of qualitative research (Mays&Pope 1995; Hallberg 2006; Kuper et al. 2008). Qualitative methods concerning studies of stigma and discrimination and mental illness were also critically evaluated (Tanskanen et al. 2011; Sayal et al. 2010).

## 3. Qualitative assessment methodology

### 3.1. Sampling methods

Subjects formally diagnosed with high-functioning autism and basic literacy skills and/or their carers will be included in the study. The clinicians in each collaborating centre in London, Madrid and Plovdiv will identify suitable patients formally diagnosed with high-functioning autism from their clinical records. The patients will have a formal diagnosis of high-functioning autism based on clinical assessment performed by a fully trained psychiatrist or psychologist. The diagnosis of high-functioning autism will be confirmed by a) clinician and/or b) standardized diagnostic assessment, The Autism Diagnostic Observation Schedule (ADOS-4) (Lord et al. 2002).

The ADOS-4 is considered to be a reference or 'gold standard' research assessment of early development and current behaviour on the autism spectrum (Lord et al. 2002; Brugha et al.). It provides a direct face to face assessment of current respondent behaviour consistent with a diagnosis of an autistic disorder. It consists of tests termed 'presses' that evaluate communication, reciprocal social interaction, creativity, imagination and stereotyped and restricted interests. Respondents are also asked about their knowledge and understanding of social relationships, emotions, and daily living responsibilities. Algorithms for autism spectrum disorder and for autism are incorporated in the ADOS-4 (Lord et al. 2002). Selected ADOS-4 ratings that correspond to DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organization, 1993) criteria for Pervasive Developmental Disorder (PDD) are summed to a total score for Communication and Reciprocal Social Interaction to which two thresholds may be applied for non-specific PDD (ADOS 7+) and for Autism (ADOS 10+). A threshold of 10+ on the ADOS total score is recommended for identifying cases of autism, provided it includes scores of at least 3 on the Communication domain and at least 6 on Reciprocal Social Interaction (Lord et al. 2002).

The clinicians will write letters to suitable participants to seek their permission to be contacted by the researcher. Fully-informed written consent will be obtained from those who are willing to participate in the study.

We will use purposeful sampling in order to collect information from a diverse population with a wide range of sociodemographic variables (Glaser, Barney & Strauss 1967). We take into consideration the fact that the accessibility and utility of the new technology may be influenced by sociodemographic factors such as age, sex or ethnicity. We will select diverse participants in terms of age, sex, ethnic group, educational attainment and employment history. Participants will be required to understand and speak adequate levels of English/Spanish/Bulgarian and be able to give written informed consent.

We will continue sampling until achieving saturation - the point at which no new information or themes emerge from the data. Based on evidence from previous qualitative research applying purposeful sampling methods in relation to subjects with mental and behavioural disorders or their carers (Marsden et al. 2007; Lipman et al. 2010) we envisage conducting at least 10 in-depth interviews.

### **3.2. Fieldwork**

Qualitative data will be collected from each of the collaborating centres in London, Madrid and Plovdiv. In-depth interviews will be conducted with a group of subjects diagnosed with high-functioning autism and their carers. They will be given the new software at month 24. The technology will be used for a period of 6 months, before we conduct the qualitative interviews (month 30).

We will include 10 participants in each clinical centre (sampling methods specified above). The participants will participate in a workshop where they will be trained in the use of the FIRST technology. They will then be given access to the interface developed in WP6 together with electronic documents on various topics to be accessed by end users. The carers group will be asked to improve the accessibility of these documents for end users by means of the interface. Participants will be given the new software at month 24. The technology will be used for a period of 6 months, before we conduct the qualitative interviews in month 30.

### **3.3. Data collection methods**

In each area we will start by conducting key informant interviews with service users and carers in each collaborating centre. The objective of these interviews will be to gain an overview of user inclusion in different aspects of society and help us to develop topic guides for subsequent interviews with patients and carers.

Individual in-depth interviews will then be conducted with patients and carers. Collectively these interviews will be designed to generate information from all key perspectives. General themes will be explored with specific reference to the impact of the new reading support tool to improved access to written information and promotion of social inclusion.

### **3.4. Topic guides**

Interviews will be based on a topic guide that is explored in depth. Questioning will be structured by the interviewer to ensure coverage of key themes but will also be responsive to issues which emerge from respondents' accounts. Initial drafts of topic guides will be informed by findings of the cross-sectional survey and the suggestions of the project advisory group. It will be refined as investigations become progressively more focused and theory and understanding of process develops. It will cover a range of topics including carers' perceptions of the impact of improved reading abilities on social inclusion of people with high-functioning autism, factors that facilitate and hinder successful social inclusion and impact of the new reading support tool on users' degree of social inclusion. Topic guides will be refined through progressive focusing during the course of fieldwork.

Interviews will be audio taped with the permission of respondents and professionally transcribed verbatim. Where permission is withheld or recording is not possible contemporaneous hand-written notes will be made by the interviewer. These notes will be presented as a summary of the interview and subsequently sent to each respondent to be verified as an accurate record. All groups will be tape recorded and transcribed. In each case the researcher will listen to the recordings and verify the accuracy of the transcription.

Transcripts and interview summaries will then subject to thematic hand analysis. The researchers will achieve immersion in the data by reading transcripts of all interviews and focus groups as they were generated. Analytic induction will be employed in a primary analysis whereby emerging themes will be identified and incorporated into subsequent interviews. A reflexive approach will be taken, continuously reviewing and refining the topic guide and coding framework to ensure that all areas that respondents had spoken about are covered. Data will be summarised in relation to these emergent themes with emphasis upon description of the utility of the new tool, its impact on improved access to written information and personal experience of social inclusion.

A thematic framework grounded in the data will emerge during the course of the study. A two level coding framework will be used at this stage to code all transcripts. The first level will incorporate thematic descriptive codes and the second, subcategories of the first level codes and conceptual codes, which will be identified through the analytical process naturally occurring in the formal coding of transcripts. In the full final analysis this thematic framework will be used to code transcripts, which will be re-read and indexed to indicate the presence of key themes.

The main aims of analysis will interrogate this thematic framework to identify different users' experiences of their social inclusion and their perception of stigma and discrimination. We will also set out to construct a typology of factors promoting and hindering social inclusion and explore how the use of the new tool contributes to different users' experiences. Under each theme we will retain verbatim quotes for use in the reporting of findings but will employ these only where they illustrate a point with particular clarity.

#### **4. Statistical methods**

Qualitative data from the survey and in-depth interviews will be transcribed and downloaded for analysis using the *NUD\*IST Vivo* computer package (Scolari/Sage). Qualitative data collected in Madrid and Plovdiv will be translated from Spanish/Bulgarian into English. All data will be analysed in the UK (LNFT). A draft coding frame will be devised based on the preliminary analysis of data to identify users' experiences of social inclusion. Triangulation of data sources on each site will ensure that researchers are fully aware of differing views, interests and perspectives of the participants and that valid inferences are made during data analysis. The relationship between the users experience and perception of social inclusion will be examined at each centre and differences between participants' opinions at different sites will be explored.

#### **5. Training**

Researchers involved in qualitative research will receive formal training provided by Prof Mike Crawford, Department of Psychological Medicine, Imperial College London. A workshop for clinical partners involved in the clinical evaluation (WP7) will be organised during the first annual project meeting that will take place in Alicante, 20-21<sup>st</sup> September 2012. The purpose of the workshop is to ensure that all researchers involved in WP7 use a consistent approach of qualitative interviewing across study centres.

#### **6. Expected impact**

Achievement of this objective is expected to further understanding of the contribution that LT can make to perceptions of inclusion by people with ASD and their carers.

## REFERENCES

- Barnard, J. (2001) *Ignored or ineligible? The reality for adults with autism spectrum disorders*. NAS: London.
- Brugha T, McManus S, Meltzer H, Smith J, Scotch FJ, Purdon S et al. (2007) Autism spectrum disorders in adults living in households throughout England. *Report from the Adult Psychiatric Morbidity Survey 2007*. The NHS Information Centre for Health and Social Care. London.
- Causton-Theoharis J, Ashby C, Cosier M. Islands of loneliness: exploring social interaction through the autobiographies of individuals with autism. *Intellect Dev Dis* 2009;47:84-96.
- Davidson J. 'It cuts both ways': a relational approach to access and accommodation for autism. *Soc Sci Med* 2010;70(2):305-12.
- Glaser, Barney G & Strauss, Anselm L., 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago, Aldine Publishing Company
- Kuper A, Lingard L, Levison L. Critically appraising qualitative research. *BMJ* 2008; 337:687-689.
- Lipman E, Kenny M, Jack S, Cameron R, Secord M, Byrne C. (2010) Understanding how education/support groups help lone mothers. *BMC*,4:4-10.
- Lord, C., Rutter, M., DiLavore, P. C., & Risi, S. (2001). *Autism Diagnostic Observation Schedule*. Los Angeles: Western Psychological Services.
- Marsden P, Karagianni E, and Morgan J. (2007) Spirituality and clinical care in eating disorders: a qualitative study. *International Journal of Eating Disorders*, 40(1):7-12.
- Hallberg L. (2006). The core category of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Wellbeing*. 2006;1:141-148.
- Mays N, Pope C. (1995). Rigour and qualitative research. *BMJ* 1995; 311:109-112.
- NAS (2004). A Place in Society: The Importance of Planning for Life for People with Autistic Spectrum Disorders; <http://www.autism.org.uk/about-autism/autism-library/magazines-articles-and-reports/reports/our-reports/a-place-in-society.aspx>
- Nation, K., Clarke, P., Wright, B., and Williams, C. Patterns of reading ability in children with autism-spectrum disorder. *Journal of Autism & Developmental Disorders* 2006;36:911-919.
- Neely-Barnes SL, Graff JC, Roberts RJ, Hall HR, Hankins JS. "It's Our Job": A Qualitative Study of Family Responses to ableism. *Intellect Dev Disabil*. 2010;48:245-58.
- OECD (2000) *Literacy in the Information Age: Final Report of the International Adult Literacy Survey*. OECD. Paris, France.
- Sayal K, Tischler V, Coope C, Robotham S, Ashworth M, Day C, Tylee A, Simonoff E. Parental help-seeking in primary care for child and adolescent mental health concerns: qualitative study. *Br J Psychiatry*. 2010;197:476-81.
- Tanskanen S, Morant N, Hinton M, Lloyd-Evans B, Crosby M, Killaspy H, Raine R, Pilling S, Johnson S. Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study. *BMC Psychiatry*. 2011;11:157.