



# Network 1000: Surveying the changing needs and lifestyles of 1000 visually impaired people — Indicative results from generative interviews

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Abstract. Network 1000 is a panel survey aimed at surveying the changing needs and circumstances of people with a visual impairment. The project is committed to participant involvement that is developing collaborative and inclusive strategies within the project; the purpose of this paper is to focus on one of those strategies namely, generative interviews. These interviews are used as part of the survey design stage to inform and drive the content of the questionnaire. The themes that were generated from these interview discussions raised a number of important themes ranging from independent living skills to issues around education and employment. Three other emergent issues were: transport particularly access to it and its geographically patchy nature; use of computers with their attendant costs and ease of use; and attitudes related either to visually impaired people's attitudes towards their own visual impairment, or society's attitudes towards people with a visual impairment. The use of generative interviews has been an integral part of the project and reinforces its underlying philosophy of participant involvement; the themes generated have already been incorporated into the first year of the study. © 2005 Elsevier B.V. All rights reserved.

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#### 1. Introduction

Network 1000 was originally conceived by Professor Mike Tobin from the University of Birmingham. The broad aim of the project is to carry out a panel survey over three years drawing on a panel of 1000 visually impaired people. This is an ambitious project and funding for it was achieved in 2003 from the Big Lottery Fund through Vision 2020 UK. The project commenced in March 2004. The longitudinal nature of the project enables the survey to move away from a snap-shot survey, such as the RNIB survey of 1991 [1] and 1998 [2], allowing the project to track and report changes over time.

The aims of the project are to recruit 1000 people from across the country to the project and to investigate their changing needs and circumstances. These observed changes can then be reported to policy-makers and service provider organizations. A further aim of the project is to develop a democratic and inclusive system of methodologies and methods that fosters participation and inclusion.

#### 2. Towards an inclusive methodology

#### 2.1. Participant involvement

One of the building blocks underpinning the concept of Network 1000 is that of collaboration: the research is founded upon a philosophy that emphasizes research with rather than on those who will be participating in the study. This form of collaboration is gaining currency with researchers and policy-makers alike as it is recognised as being a more democratic approach towards research and the decision-making process [3–6].

This approach has generally become known as 'user involvement'. Although this is a useful term in the current ideological climate the term suggests the 'use' of a particular service that in turn implies some form of evaluation of that service from the 'users' point of view. This is not the aim of this research project. Instead the team have adopted the term 'participant involvement' as a more neutral expression as it refers to those who are participating in the project rather than suggesting that a process of evaluation is taking place. Further, this term more accurately reflects the underlying philosophy of the project that is to embrace a collaborative approach to research.

#### 2.2. Participant involvement in practice—focus on generative interviews

In the spirit of collaboration a number of inclusive strategies have been built into each stage of the research project, one of these was the concept of generative interviews. The purpose of these interviews was to generate data on aspects of visually impaired people's lives that they considered to be important; the data would then be used to inform and drive the construction of the survey.

A sample of forty people with a visual impairment was created through a range of contacts and although this is a non-probability sample, it reflected a broad range of visually impaired people from a variety of backgrounds and stages in their lives. Interviews with the generative interview panel were either one-to-one interviews (carried out either by telephone or in person) or focus group discussions. The interviews were semi-structured following a diary format of "Tell me about your day/week/month and

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