

## Visual Impairment Centre for Teaching And Research

### The Network 1000 Project: Surveying the changing needs of 1000 people with visual impairment

#### Research Team

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#### Introduction

The visually impaired population is increasing in size, for example the Dept of Health report that the number of people registered as blind or partially sighted in England has increased from 58,000 in 1982 to 155,230 in 2003. Nor is it a homogeneous group, since the population varies widely in age, degree of visual impairment, age of onset of the visual impairment, gender, ethnicity, and in relation to a multiplicity of other factors that influence needs and preferences. These needs and preferences are changing as are general expectations about style and quality of life.

Traditional single 'snapshot surveys', for example at five to ten year intervals, do not bring out the dynamics of these variables, especially in relation to the changes in understanding and perception of needs as people age, learn, and respond to the demands and opportunities of their social and physical environments. Only a long-term commitment to ongoing data collection, analysis and dissemination can do this. NETWORK 1000 provides this opportunity.

NETWORK 1000 is a three-year project that was originally conceived in the 1990s by Professor Michael Tobin of the former RCEVH. Since then, the project has been developed by members of VICTAR in conjunction with Vision 2020 UK, with funding granted by the Big Lottery Fund (then known as the Community Fund) in April 2003. The project commenced in March 2004.

## **Aims**

The NETWORK 1000 project aims to generate information regarding the needs, circumstances, and opinions of people with a visual impairment in the UK. More specifically the project will:

- Develop a nation-wide panel of 1000 subjects ('NETWORK 1000'), representative in terms of age, gender, visual status, ethnic origin, and other defining characteristics of the visually impaired population.
- Collaborate with this group to generate information regarding the needs, circumstances and opinions of people with visual impairment. The project is adopting a participatory approach, whereby participants will be able to establish priorities and influence the direction of much of the research in a variety of ways.
- Create and collect three kinds of inter-related data: (a) Longitudinal demographic data (information describing participants' characteristics and personal circumstances) each year over the three year period; (b) Themes informed by the needs and priorities of the participants (in-depth information related to specific pre-determined topics); and (c) Response to requests from the steering group and other organisations for the collection of particular information.
- Focus on three themes: (a) Maintaining independence – effectiveness and uptake of services (including housing, social, health and community care); (b) Identifying information needs and provision – understanding preferred information formats and access to them, use of ICT; (c) Assessing quality of life – economic circumstances, access to leisure and recreational activities and community participation.
- Pass on information and issues raised by the network panel to service-providers to enable them to respond to the changing needs of service-users.

## **Method**

The sampling strategy is to recruit participants who are registered as visually impaired through social services departments. These departments are responsible for maintaining the visual impairment registers, twenty of which will be randomly selected to help recruit participants onto the project.

Telephone interviews will be the key method of data collection. Telephone interviews will permit rapid collection of raw data and can include use of closed and open-ended questions. In some cases it may be necessary to involve additional help to gain information from participants with learning difficulties. This might involve carers, social workers, contacts in local voluntary organisations, and visits to the homes of participants by researchers. Researchers will also require the assistance of interpreters (potentially including sign language) for communicating with some participants, and alternative methods will be adopted if the participant does not have access to a telephone. Discussion groups may be used for some data gathering if it is judged to be efficient and appropriate.

## **Timeline**

### *Year 1 Summary*

The sample will be recruited and database designed. Demographic and longitudinal survey content will be designed, piloted, collected and reported.

### *Year 2 Summary*

The sample will be modified following recommendations from Year 1. Data will be collected and reported for the first themed study. Demographic information will be collected and reported for year 2. Ad hoc surveys identified by steering group will be carried out.

### *Year 3 Summary*

The sample up-dated following recommendations from Year 2. Data will be collected and reported for the second and third themed studies. Demographic information will be collected and reported for year 3. Ad hoc surveys identified by steering group will be carried out.

## **Progress to Date**

*(This section will be updated on a regular basis.)*

### **March 2006**

We have completed our first report based upon the first 700 interviews. While this is a preliminary report, it still forms one of the largest consultations with visually impaired people ever carried out in Great Britain.

Further recruitment and interviewing has taken place over the last five months and we are just completing the full 1000 interviews. This full dataset will be analysed over the coming months and formally launched at the Vision 2020 UK conference in June 2006.

As well as analysis and report writing, in the final year of the current funded project we will be designing another interview schedule and returning to our participants to collect a second data capture. The topics covered in this will be dictated by the issues raised by participants the first time we spoke to them.

### **May 2005**

We are pleased to report that the sampling stage is now almost complete; to date, over 3500 letters inviting people to take part in the project have now been sent, to people selected from the registers of visual impairment in 18 social services departments around the UK.

The 1st year survey has been developed and finalised, and over 100 interviews have been carried out with participants to date. The interviews are being carried out using Computer Assisted Telephone Interviewing (CATI) software, developed by [Interview Technology](#). Interviews will be ongoing throughout the spring/summer period.

In April 2005, members of the research team attended the Vision 2005 conference, to report on the findings from the exploratory stage of the project.

### **Vision 2005**

Three members of VICTAR, including Dr Graeme Douglas, Ms Sue Pavey and Dr Chris Corcoran, attended the Vision 2005 conference organised by the [RNIB](#) in London during April 4th - 7th 2005. Presentations included two posters and two oral presentations.

## **Presentations**

Dr Chris Corcoran (oral presenter), Dr. Graeme Douglas, Dr. Steve McCall, Dr. Mike McLinden, Ms. Sue Pavey, (2005). *Network 1000: surveying the changing needs and lifestyles of 1000 visually impaired people - indicative results from generative interviews.*

This presentation was based upon the [Network 1000 project](#), in particular looking at findings from the exploratory interviews carried out at an early stage of the project with a number of visually impaired people, which were used to develop the interview schedule for the telephone interviews with the panel of 1000 visually impaired people ("Network 1000").

Dr Graeme Douglas (poster presenter), Dr. Chris Corcoran, Dr. Steve McCall, Dr. Mike McLinden, Ms. Sue Pavey, (2005). *Network 1000: surveying the changing needs and circumstances of visually impaired adults in Great Britain.*

This poster presented an overview about one of VICTAR's largest and current research projects, Network 1000 project.

Dr Graeme Douglas (oral presenter), Prof. Peter Spurgeon, Ms. Sue Pavey, (2005). *An exploratory study of the impact of non-medical eye clinic support services in hospital eye clinics.*

This presentation was based upon the eye clinic support services research project.

## **Eye Clinic Non-medical Support Services**

Eye Clinic Non-medical Support Services are services situated in eye clinics which offer general support and advice such as counselling and links to low vision clinics. Such services are very important for patients, particularly at the point of diagnosis of a visual impairment. This is reflected in the recent RNIB support for the role of the 'Eye Clinic Liaison Officer'.

A second project funded by the Thomas Pocklington Trust involves investigating these non-medical services, and again, VICTAR is working in partnership with the School of Public Policy at the University of Birmingham (Professor Peter Spurgeon, Health Services Management Centre). The exploratory study aims to develop a methodology which would be appropriate to demonstrate the effectiveness of such services.

Following some initial pilot work, the research team have collected interview data from professionals associated with nine eye clinics – four with a 'high' level of support service provision, three with a 'medium' level of support service provision, and two with a 'low' level of support service provision (data collected from N=41 professionals). Additionally, semi-structured interviews were carried out with 21 service users. We are in the process of analysing this data, but it appears there are an extremely complex set of factors which influence the impact of such services.

An interim report outlining the project method was presented to the funders at the end of January 2004, followed by a draft final report which was presented to the steering committee mid-March 2004.

Sue Pavey (poster presenter), Dr Graeme Douglas, Dr Mike McLinden, Dr Steve McCall, (2005). *The delivery of a mobility and independence curriculum for children with visual impairment in mainstream schools.*

This poster was based upon two projects carried out by the Centre - an investigation into mobility and independence skills for children with visual impairment ("Steps to Independence") completed in 2002, and a later project completed in 2004 which developed the data from the earlier project into an online mobility and independence resource aimed at professionals working with visually impaired children.

### **Conference Proceedings**

Further details about the conference, including information about all of the presentations and their presenters, can be found on the [RNIB](#) website. The presentations will be published in the Vision 2005 Conference Proceedings by the [International Congress Series](#). The expected month of publication is October 2005.

### **September 2004**

The team are now in a position to make contact with the 20 Social Services Departments drawn in the sample. We are also now considering the design and content of the 1st year survey.

### **Links to Partner Organisations / Funding Bodies**

[Vision 2020 UK](#) was formed in 2001 and formally constituted as a charity in June 2002. One of its aims is to bring together all of the key players in the United Kingdom's visual impairment sector who have an international, national, or regional function in providing funds, services, information and advice, education, medical expertise and research. For this reason, Vision 2020 UK co-ordinates an unprecedented network of visually impaired people and organisations in the UK. Vision 2020 UK's co-ordinating and networking role in the UK means that it is ideally placed for facilitating the recruitment of the NETWORK 1000 sample, dissemination of findings, and validation of the value of the research.

[The Big Lottery Fund](#) (formerly the Community Fund) aims to give grants (Lottery money) to groups that help meet the needs of those at greatest disadvantage in society and that improve the quality of life in the community.