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# Informed choice and diabetes screening in primary care: Qualitative study of patient and professional views in deprived areas of England

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ABSTRACT

*Aims:* To examine perceived need for, and provision of, information prior to participation in a diabetes screening programme in English general practices.

*Methods:* Case studies using qualitative semi-structured interviews with patients and practitioners in five participating practices.

*Results:* Participating patients generally demonstrated a lack of understanding of issues in relation to the benefits and disadvantages of diabetes screening or the implications of screening test results. Posted invitation letters provided written information but did not necessarily ensure that patients were better informed than those invited by telephone or opportunistically when attending the practice for another reason. Not all patients interviewed wanted the extent of information that would be required to enable them to give fully informed consent to screening.

*Conclusions:* The ways in which information is provided to patients requires careful consideration so that a patient has sufficient understanding to make a decision about undergoing a screening test and understands the implications of test results. There is a potential conflict between the ideal of fully informed choice and patient expectations that they can depend on professionals to make the appropriate decision on their behalf.



## 1. Introduction

A developing evidence base for the primary prevention and early treatment of diabetes has led to an increased interest in screening to facilitate pre-symptomatic diagnosis. In 2003–2005 the UK National Screening Committee established diabetes screening pilots in 24 general practices. The pilots were located in eight inner city teaching Primary Care Trusts (PCTs) across England with relatively deprived and ethnically diverse populations and where the predicted prevalence of type 2 diabetes (and the expected prevalence of undiagnosed diabetes) was relatively high. The evaluation of the screening programme has been reported elsewhere [1,2].

It is recognised that both the information provided and the way in which screening is organised influences screening participation rates [3]. There is also evidence that many people

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have mis-conceptions about the purpose of screening, accuracy of screening tests and the potential disbenefits (increased anxiety, false alarms or false reassurance) [4]. However there is limited understanding of the best way to gain fully informed consent for screening and ensure that patients understand the potential and actual significance of their screening test result [5]. Much of the research addressing individual responses to diabetes screening has used psychological survey instruments to assess screening related anxieties or quality of life measurements [6–8] Qualitative studies examining patients' experience of screening and diagnosis have found that some patients may have given little thought to the implications of a positive result prior to screening, and that emotional reactions to, and understandings of, screening results is variable [9,10].

The objective of the qualitative element of the screening programme evaluation was to examine the perceptions of staff involved in screening and patients who were invited to attend for screening. This paper focuses on patients' perceived need for information, their views on the adequacy of the information provided, and implications for informed choice in the context of participation in diabetes screening. The terms "informed consent" and "informed choice" are both used in discussion of appropriate information provision and we make no distinction between them in this paper. Both terms refer to a process in which a patient is given sufficient information to make a decision as to whether to agree to a course of action or not. The definition of "sufficient" information is generally a subjective judgement based on professional (rather than patient) judgement. When the intervention is a surgical procedure or participation in a randomised trial or research project (such as the research reported here), "explicit consent" usually involves the provision of standardised information, including information about any potential risks, and the signing of a consent form which is a legally recognised document confirming consent has been given. In everyday clinical practice, "implicit consent" is usually assumed if a patient seeks medical help or attends for a screening test and co-operates with, for example, providing a blood sample.

## 2. Methods

### 2.1. Study design

A case study design, with pilot practices as cases, was selected as the most appropriate method to generate in-depth data from the staff and patients participating in the screening programme. Semi-structured interviews allow in-depth study of complex ideas and phenomena and were used to explore the perceptions of practice teams, patients and facilitators. Topic guides were developed after discussion with the programme team and facilitators and subsequently piloted. The patient topic guide looked at their understandings, and experiences of, the entire screening process including their views about the method of invitation, reasons for attending/not attending; outcomes of invitation; and perceived benefits and costs of having undergone screening. The staff topic guide followed a similar pattern but started with the identification of patients to invite for screening and covered additionally impacts of the screening programme on the practice and practice staff.

Five case study practices were selected on the basis of geographical location, size of urban centre, and the proportion and diversity of the minority ethnic population. Methods of programme implementation and practice size were also taken into consideration, so that the case studies would represent as wide a range of practice and population characteristics as possible.

#### 2.1.1. *Staff interviews*

All staff involved with the pilot screening agreed to be interviewed. Interviews were carried out with the facilitator, the practice nurse with responsibility for diabetes (PN), the general practitioner (GP) with responsibility for diabetes, health care assistants (HCA) who carried out the screening in some practices, and the practice manager (PM). Staff were interviewed in a private room at their general practice.

#### 2.1.2. *Patient interviews*

Patients screened were selected on the basis of their test result to gain the views of patients with a range of screening outcomes. Potential interviewees were identified by practice staff, who sent out letters from the research team inviting patients for an interview with a researcher. Patients who responded provided contact information on an enclosed reply slip. They were contacted by a researcher and arrangements made for interview, usually in the patient's home. The researcher confirmed the interviewee's understanding of the research and why they were being asked to contribute and answered any questions before obtaining written consent.

All interviews were audio-taped and transcribed. Analysis was carried out using the framework method which is recognised as appropriate for applied policy research [11]. Categories and sub-categories were coded as the framework for assessing the range of issues relevant to the pilot evaluation emerged. Data within the sub-categories were analysed for agreement and variation and developed into the themes described in the results. Four members of the research team coded transcripts. Each transcript was coded by at least two researchers to strengthen consistency in coding and the identification of developing themes. There was overall agreement on the main themes and where there was differences in coding the data was discussed by the researchers and agreement reached. Ethical approval was received from the Trent Multicentre Research Ethics Committee (04/MRE04/52).

## 3. Results

Twenty-three staff and forty-nine patients were interviewed: 24 White, 23 South Asian, one Afro-Caribbean and one Algerian. Due to the screening pilots' location in deprived areas, the patients interviewed, all aged between 38 and 79 years, had relatively low levels of formal education. Some specific issues and information needs arose for ethnic minority respondents, and staff and patient perspectives on these will be reported elsewhere. Ethnic minority patients reported many issues in common with their white counterparts, and these common issues are reported in this paper.