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## **National Evaluation of DHDS Diabetes Screening Pilot Programme**

### **Final Report**

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## FOREWORD

Diabetes can have a devastating impact on quality of life. For this reason, the UK National Screening Committee was asked, in the National Screening Framework for Diabetes: Delivery Strategy, to provide advice on targeted screening for diabetes. As part of this work, we established the Diabetes, Heart Disease and Stroke (DHDS) prevention project. Our aim was to test the practical implications and outcomes of implementing a systematic screening programme in primary care.

This evaluation of the DHDS has shown that even in the most challenging of environments and in the most unfavourable conditions, a targeted screening programme across the NHS is feasible. More importantly this evaluation, in looking at the potential implications for the future development of risk assessment, has played a crucial role in informing the UK NSC advice to the Department of Health that screening certain subgroups of the population who are at high risk of Type 2 Diabetes is feasible, but that it should be undertaken as part of broader vascular risk management programme.

In particular, I am grateful to Dr Elizabeth Goyder, Dr Jane Carlisle, Dr Sarah Wild, Dr Colin Fischbacher, Dr Julia Lawton, Dr Jean Peters and Dr Anne Lacey for all their dedicated hard work in undertaking this evaluation.



Dr Anne Mackie  
Programme Director  
UK National Screening Committee

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## **Glossary of abbreviations**

<b>2 hr BG</b>	Blood Glucose measured two hours after a glucose load
<b>BMI</b>	Body Mass Index ( $\text{kg/m}^2$ )
<b>CHD</b>	Coronary Heart Disease
<b>DHDS</b>	Diabetes, Heart Disease and Stroke
<b>DM</b>	Diabetes Mellitus
<b>FBG</b>	Fasting Blood Glucose
<b>FTE</b>	Full Time Equivalent
<b>GMS</b>	General Medical Services
<b>GP</b>	General Practitioner
<b>HCA</b>	Health Care Assistant
<b>HT</b>	Hypertension
<b>IFG</b>	Impaired Fasting Glucose
<b>IGT</b>	Impaired Glucose Tolerance
<b>IMD</b>	Index of Multiple Deprivation
<b>OGTT</b>	Oral Glucose Tolerance Test
<b>PCT</b>	Primary Care Trust
<b>PM</b>	Practice Manager
<b>PN</b>	Practice Nurse
<b>QOF</b>	Quality and Outcomes Framework
<b>RCBG</b>	Random Capillary Blood Glucose
<b>WC</b>	Waist Circumference
<b>WHO</b>	World Health Organisation

## **Executive summary**

### **Introduction**

In 2003 the UK National Screening Committee established diabetes screening pilots in 24 general practices in eight Primary Care Trusts (PCTs) across England. The PCTs selected were all inner-city teaching PCTs with relatively deprived and ethnically diverse populations. In each PCT three general practices were randomly selected as pilots from the practices that volunteered and a further three volunteer practices were selected as comparison practices. A multi-disciplinary team based in Sheffield and Edinburgh was appointed to conduct an independent evaluation of the screening pilots in 2004. The screening pilots ended in autumn 2005. This report presents the evaluation findings and discusses some of the potential implications for the future development of risk assessment and screening activity in general practice settings.

### **Methods**

The evaluation used both quantitative and qualitative methods to investigate the impact and feasibility of screening for diabetes in the pilot practices. A range of different types of information have been collected by the practice teams, the PCT facilitators and the evaluation team and analysed in order to both identify common issues for screening implementation and to explore variation between practices.

Data sources include:

- a survey of pre-DHDS diabetes screening policy and practice in 44 pilot and comparison practices and a baseline survey of DHDS pilot activity in 24 pilot practices
- reported total screening activity, workload and outcome data from 24 practices
- pre-pilot and post-pilot diabetes prevalence data from both pilot and comparison practices
- patient-level data based on screening records of 12 145 patients screened by random capillary blood glucose from 21 practices
- information on all new cases of diabetes diagnosed in practices between 2000 and 2005
- interviews with 23 staff and 45 patients from five case study practices, interviews with the eight pilot facilitators and seven focus groups conducted with staff from all pilot practices.

Findings are reported separately for each of these elements of the evaluation and some general issues of potential relevance to future policy and practice are brought together in the final section.

### **Results of the pre-DHDS survey and baseline assessment**

- **Previous screening practice:** Before the screening pilots started, there was very wide variation in reported screening practice, with about half of practices providing some level of systematic screening. Practices used a variety of criteria to identify and screen high risk

patients for diabetes. Urinalysis was used for screening by a minority of practices. There was also variation in whether diagnostic testing was done at the practice or patients attended hospital for blood tests: the majority took blood samples for fasting blood glucose tests in the practices but, if patients were thought to need oral glucose tolerance testing (OGTT), the majority sent patients to hospital.

- **Deprivation and ethnicity:** The 24 DHDS pilot practices are all based in areas with above average deprivation, based on the 2004 Index of Multiple Deprivation (IMD) ranking for the practice (based on practice postcode). Pilot practices vary widely in size and organisation (range from one to 11 GPs) and ethnicity of population (from over 90% white to over 90% non-white ethnic groups).
- **Protocol implementation:** The implementation of screening within the DHDS pilot programme also varied widely. Many practices widened the original inclusion criteria (patients aged over 40 years with a BMI over 25 kg/m<sup>2</sup> without diagnosed diabetes) and used a diverse range of invitation methods, both opportunistic and systematic. People with CHD were excluded in most practices as they were already routinely screened as an element of CHD annual reviews.
- **Protocol changes:** Major changes from the original protocol were related to the feasibility of aspects of the pilot and suggest that some of the more problematic aspects of implementing screening initially identified were: operationalising inclusion/exclusion criteria, use of clinical information systems to record screening information and integrating screening activities with other practice priorities, particularly the requirements of the new GMS contract.

## Results based on practice activity reports

- **Overall activity:** Screening was undertaken in 24 practices with a total list size of 165 828. After exclusions on the basis of diagnosed diabetes, age (usually excluding those under 40), known BMI (usually excluding those with a BMI under 25), and previous blood glucose testing (usually in the previous 2 years), a quarter of all patients (41 418) were invited for screening. Of those invited, 25 356 (61%) were reported to have been screened. In this screened population about one third had a positive screening test of whom 358 (1.4% of those screened) were reported to have been diagnosed with diabetes within the pilot programme. This means that about one in 70 of those screened was given a new diagnosis of diabetes.
- **Impact:** The additional cases diagnosed by the pilot activity represent an increase of about two new cases per thousand registered population, equivalent to three or four additional cases per GP and an increase of about 5.5% in the number of people with diabetes registered with the pilot practices.
- **Workload:** The median number of hours devoted directly to screening was 811 hours per practice (over 2 hours for each person invited for screening), two-thirds for screening and one-third for identifying eligible patients, organising invitations and arranging appointments. Most

screening activity was undertaken by health care assistants (55%), with a significant time commitment from administrative and reception staff (21%) and practice nurses (15%). GPs and practice managers also spent up to 240 hours on screening-related activities.

- **Characteristics of those attending screening appointments:** a comparison of those attending and not attending suggests that those who attend the practice infrequently are also less likely to attend in response to an invitation for screening and so opportunistic screening would reach most of the population that respond to an invitation. Those attending were older, more likely to attend for other reasons and more likely to have repeat prescriptions. This suggests that screening reached at least some of the higher risk population.

## Results based on patient level data

- **Data collection:** Half the practices used locally designed templates to collect data on screening on their own clinical information systems and half also used a paper format provided by the central DHDS team. Both methods of data collection proved difficult to operationalise, particularly where there was no effective way to link diagnostic test results to screening results. Tracking the results of diagnostic testing in those with a positive screening test proved difficult, whether paper or electronic data collection systems were used.
- **Data analyses:** Patient data was available from 21 practices and analyses are based on 12 145 patients for whom the results of a random capillary blood glucose screening test was recorded. Descriptive analyses were used to identify the characteristics of the screened population and identify the main risk factors for screening-detected diabetes.
- **Missing diagnostic tests:** Out of 3789 screened patients with a random capillary blood glucose over 6 mmol/l, 1189 (31%) did not have the results of diagnostic testing recorded on their screening record, even after updating records from practice information systems. These individuals represent a combination of patients who did not undergo diagnostic testing (for whatever reason) and those whose result was not recorded on the practice system, or recorded but not coded in a way that meant it could be subsequently identified as the result of diagnostic testing. Further investigation, in one PCT, revealed that the commonest reasons for not having a diagnostic test recorded were failure to record (despite the patient being tested), a clinical decision that further testing was inappropriate or patients not understanding that further testing was required, rather than patients actively declining diagnostic testing.
- **Access to oral glucose tolerance tests:** Of those with a diagnostic test result recorded, 776 (30%) had undergone an oral glucose tolerance test (as required for WHO diagnostic criteria for diabetes), the remaining 1824 (70%) having had only a fasting blood glucose measured.
- **Characteristics of the screened population:** A random capillary blood glucose (RCBG) result was available for about half the number of people reported to have been screened by practices. Those for which data were available were 46% men and 54% women. Five per cent

of those screened were under 40 and 6% were over 80 years old. 23% were within normal BMI limits, 47% were overweight and 30% were obese by WHO criteria. Of those with recorded ethnicity (34%), 71% were recorded as White and 16% Indian, Pakistani or Bangladeshi, 13% as other ethnic groups. Analysis of other characteristics by ethnic group suggests that the White population screened was older and had a lower mean BMI than the non-White population.

- **Prevalence of screened detected diabetes:** 31% of those screened who had results available had a positive screening test and 3% of all those with a positive screening test also had a positive diagnostic test result. This implies a positive predictive value for a random capillary blood glucose  $\geq 6.0$  mmol/l of 9%. Age, BMI and non-white ethnicity were all associated with screening-detected diabetes in this population. The prevalence of screening detected diabetes was almost twice as high in the 60 to 79 year olds (3.9%) as the 40 to 59 year olds (2.2%). It was more than twice as high in the obese population (4.7% if BMI $>30$  kg/m<sup>2</sup>) relative to the overweight population (2.2% if BMI 25-30 kg/m<sup>2</sup>). Recording of ethnicity was incomplete but, where recorded, the prevalence of screening detected diabetes was 3.2% in the White population, 3.9% in the Black population and 4.6% in the South Asian (Indian, Pakistani and Bangladeshi) population. The relatively low relative risk for the South Asian population compared to other studies may be due to the practices having previously actively screened more of their South Asian patients, as ethnicity was very widely recognised as a significant risk factor for diabetes. The largely White populations may have had a relatively high prevalence of previously undetected diabetes because they tended to be in the most socio-economically deprived areas.
- **Impact of changing screening criteria:** It is possible to draw inferences about the impact of restricting screening tests to those with higher BMI values or ages. For example, excluding the 618 under 40 year olds from screening would have resulted in 104 fewer patients requiring diagnostic tests and missed six new cases, implying the number needed to screen to detect one new case was 103 in this age group. Excluding those with a BMI under 25 would have resulted in 2588 fewer screening tests, 660 fewer patients requiring diagnostic tests and missed 43 new cases.
- **Practice level variation:** In the patient level dataset, there were large variations between practices in the proportion of those screened having a positive diagnostic test result (from 2% to 8%) but with an overall average of 3%. This is about twice as high as reported by practices, suggesting that, given the problems identified with recording of diagnostic test results, more new cases were identified than reported in the activity data. Examination of potential explanatory factors enables the identification of practices with unexpectedly high or low yields of new cases from screening that may merit further evaluation. The least deprived practices tend to have a lower yield, irrespective of ethnicity, suggesting deprivation is an independent

risk factor for undiagnosed diabetes. The practice with the highest yield had a largely white population, was in a very deprived area, used all three inclusion criteria (age, BMI and a recent blood glucose) to select patients for screening and used oral glucose tolerance tests for diagnosis. The latter three factors would be expected to be associated with a higher prevalence of screen-detected diabetes and these were apparently sufficient to over-ride the lower prevalence that might be expected to be associated with a largely White population.

### **Overall impact of the DHDS pilots**

- **Overall prevalence changes:** Overall between 2003 (pre-pilot) and 2005 (post-pilot) the prevalence of diabetes increased by 15% from 3.5% to 4.1% (an absolute increase in prevalence of 0.54%) in the pilot practices. Over the same period of time the prevalence of diabetes increased by 12% (an absolute increase in prevalence of 0.42%) in the comparison practices. This increase may partially reflect secular trends in diabetes risk, but is also likely to largely reflect an increase in case detection within primary care and increasingly complete coding of diabetes on practice information systems.
- **Impact on QOF:** The results show only small, non-significant differences between pilot and comparator practices. Overall retinal screening is the only indicator slightly better in pilot practices, whilst a number of indicators related to management of complications are (non-significantly) better in comparator practices. There is no indication that the pilot practices were able to achieve better outcomes overall as a result of participation in the screening pilot nor was there any evidence that quality of care in practices taking part in the pilot was markedly worse than among comparator practices.
- **Impact on screening policy:** Overall the survey confirms a continuing trend towards increasing screening and increasing systematic screening of patients with identified risk factors for diabetes and cardiovascular disease in both pilot and comparator practices.
- **Impact on characteristics of newly diagnosed cases:** Results suggest that most new cases (91%) are diagnosed in people with pre-existing risk factors. In terms of age, sex, BMI and degree of hyperglycaemia at diagnosis, the cases diagnosed through DHDS were very similar to the cases diagnosed in other ways.

## **Key results from qualitative case studies**

### **Identifying patients at risk**

- an updated searchable clinical database is crucial for identifying eligible patients
- staff generally viewed the criteria for screening as too restrictive and unfair to patients with other risk factors such as ethnicity or family history
- where the criteria were strictly adhered to, the justification was to limit the number of new cases to a number that the practice could reasonably cope with
- some staff had concerns that records were not always made when patients had been invited and screened opportunistically
- equity of access to screening for all patients at the practice was a major concern to staff

### **Inviting patients to be screened**

- the letters were generally not understood by patients and perceived as too long or complicated
- sending letters was costly in terms of both money and staff time
- letters sent in English achieved a better take up than letters in other languages
- some letters were returned as the patient was no longer at the recorded address
- contacting patients to remind them of an appointment was seen as useful but many patients were unwilling to provide a telephone number, especially for a mobile phone
- opportunistic invitation was popular because of the perceived high success rate with patients already attending the practice for an unrelated reason
- it was suggested that opportunistic approaches to patients from minority ethnic groups can be made when they attend for travel-related immunisation
- adapting the method of invitation to the type of patient population and ensuring it was appropriate to the practice generated more attendances
- it was felt that no single strategy will be appropriate for all patients
- patients who do not attend may not have received or understood the letter of invitation

### **Barriers to attendance for screening and diagnostic tests**

- a lack of availability during evenings and weekends was seen as limiting uptake
- practices were not always able to follow up patients with positive screening tests to ensure they were encouraged to attend for diagnostic testing
- retired people, women, and the 'worried well' were most likely to attend for screening
- patients from deprived areas were least likely to attend for screening
- times when screening was available was critical, as it meant many employed patients could not attend
- patients who believed their risk was low still attended for screening, expecting reassurance

- regularly attending patients are more likely to attend screening
- healthy employed patients who rarely attend the practice are unlikely to attend screening
- educating patients about diabetes may improve screening uptake
- some patients with positive results do not attend for a diagnostic test; a positive screening blood test did not always influence them to pursue diagnostic testing and they could rationalise this in terms of not feeling at risk or having an alternative action to take (eg losing weight)

### **Organisation of screening**

- screening created extra work and screening could displace other activity or other patients being seen
- resources were seen to be finite, and inadequate to meet demand
- a number of staff needed to be involved in identifying eligible patients, inviting patients to be screened and providing screening and diagnostic testing
- practice managers and GPs were happy to delegate screening and health promotion to HCAs who were seen to be the appropriate staff to carry out diabetes screening
- staff overall felt job satisfaction from providing preventative care and HCAs enjoyed their increased responsibility
- the efficiency of dedicated staff carrying out a repetitious task increased over time
- some GPs regarded diabetes screening as carried out more efficiently as part of a wider health check at a single appointment
- practices want to be able to record screening information on their own clinical information system, rather than paper forms or a separate database

### **Understanding of diabetes and screening**

- practice staff tended to have a very positive view of the benefits of screening
- informed consent was not identified as an important issue by staff: consent was assumed if patients attended for screening or agreed to be tested and tests were sometimes ordered without any explicit discussion or explanation
- patients tended to believe that a negative result gave them an “all clear”
- patient anxiety while awaiting results was a concern to staff
- awareness of diabetes was raised generally within pilot practices
- staff able to use appropriate minority languages are a useful resource in explaining information in patients’ own language
- communication with minority ethnic populations may be effectively enabled through working with local community organisations, rather than relying on translation of written information

- patients were generally ignorant about diabetes; knowledge of diabetes tended to be associated with having family members with the condition
- there was a widely held view that more information or education about diabetes would encourage attendance for screening

## **Implications for policy and practice**

- Diabetes and, more generally, cardiovascular risk reduction programmes have proved feasible and popular, despite a limited impact on outcomes in randomised trials. It is likely that primary care will in future have an increasing responsibility for primary prevention and early detection of diabetes and cardiovascular risk. Future cardiovascular and diabetes risk reduction programmes will be more effective if lessons are learnt from the experience of pilot programmes.

However caution must be applied in attempting to generalise from the pilot findings as the pilot practices were not randomly selected, or typical, general practices. They were all volunteer practices and they were all based in relatively deprived inner-city and urban areas. Unlike practices that undertake diabetes screening as part of routine practice activity, they were given additional resources to provide systematic screening and they were all supported by PCT pilot facilitators.

- The overall impact in terms of the number of new cases detected was low, probably as a result of the high level of screening activity in high risk groups (including people with coronary heart disease and other vascular disease, hypertension and other risk factors) beyond the DHDS-specific activity. Impact will have been further reduced by a lack of focus on high risk groups in some practices, a high proportion of those with a positive screening test not having diagnostic tests performed or results recorded, and a lack of access to oral glucose tolerance tests when diagnostic testing was performed.
- Despite availability of additional resources and support from PCT staff, data collection, for a number of reasons, was variable and therefore quantitative elements of the evaluation are potentially biased by restriction of analyses to a sub-set of relatively complete data, which may not be representative of all activity in pilot practices. In any future screening programme, consistent methods for data collection will be needed and a system for data audit and continuous quality improvement.
- Some major issues that are relatively straightforward in a screening research context, proved much more problematic when attempting to implement systematic screening into clinical

practice. The restriction of blood testing to those at high risk, the provision of information to patients, the collection and retrieval of clinical information and adequate follow up of those with a positive screening test all proved difficult to implement in every day practice.

- The qualitative findings related to the practical issues raised, and particularly barriers to effective screening, are important issues that any screening programme will need to address. The evaluation findings could therefore usefully inform future policy around screening and primary prevention in general practice. Some specific suggestions are outlined below.
1. **Uptake of screening:** Screening invitation letters should be as simple as possible. There may be limited value in using letters in languages other than English and the value of translated materials needs to be explored in each location. Opportunistic invitation may increase uptake and represent a more cost-effective strategy for both practices and patients. Patients who are in work may find it particularly difficult to attend within normal practice opening hours and may need appointments outside normal working hours.
  2. **Inclusion criteria for screening:** Limiting screening to those at highest risk is only likely to be feasible if risk information can be obtained without patients being invited to attend the surgery and if the criteria are understood and accepted by practice staff. The potential role of risk scores is discussed further below. Age criteria may be more feasible to use to identify risk groups than BMI, ethnicity or other criteria which are not universally recorded. Practices may wish to use their discretion to screen younger patients who have other risk factors (based on BMI, ethnicity and family history).
  3. **Understanding the purpose of screening:** The objective of diabetes screening might be better understood if the language of “risk reduction” was used so that all patients expected to be given advice about what they could do to reduce future risks, rather than the reassurance of an “all-clear” result. There is also a need to manage patient expectations to avoid increasing dissatisfaction, due to unrealistic assumptions about the nature or purpose of risk assessment.
  4. **Impact of screening:** The overall impact of screening will vary widely between practices depending on the underlying prevalence of undiagnosed diabetes and the screening strategies adopted. Both the overall impact and resource implications will depend largely on the inclusion criteria and choice of diagnostic tests. In particular, the use of oral glucose tolerance testing will increase both the impact and accuracy of testing, but has resource and organisational implications if all practices are to undertake testing.

5. **Screening personnel:** Health care assistants can be recruited and trained to offer screening and health promotion advice to people who attend for screening. Further work is needed to assess the effectiveness of health promotion/risk reduction interventions offered to individuals at increased risk by health care assistants.
6. **Audit of screening:** Many of the pilot practices found it extremely difficult to collect or report adequate information on their screening activity. Paper based systems were unpopular and ultimately proved to be unsuitable since the information collected was not accessible when patients attended the practice or when diagnostic test results arrived in the practice. Practice systems may be appropriate but consistency in recording and coding information on risk factors, screening results and diagnostic results using system templates would need to be better developed. Adequate audit and quality assurance is vital to any screening programme and practices need to be able to record screening activity in a consistent way and in a format that allows for audit of the screening process and that is consistent with existing data collection systems.

### **Key areas in which further development is required to support risk assessment**

It is recognised that cardiovascular and diabetes risk assessment activity in primary care is developing rapidly. The new GMS contract and inclusion of risk factor recording in the Quality and Outcomes Framework has already had a major impact on the routine collection of risk factor data. The experience of the DHDS pilots highlighted some key areas in which current and future development is crucial to ensuring potential benefits from risk assessment programmes is realised:

1. **Recording of risk factors:** Routine risk assessment will become increasingly feasible as general practices develop routine collection and recording (with consistent coding) of risk factors other than age, particularly BMI and ethnicity. The additional value of routinely recording other risk factors (family history, waist circumference) requires evaluation.
2. **Audit of risk factor assessment, diagnostic testing and management:** Additional risk assessment activity will need the development of structure and process for audit of both current and future activity. Ideally audit would bring together information on both ad-hoc and systematic screening activity and ensure data was collected on both to avoid duplication of activity where, for example, blood tests have already been done.
3. **Availability of behavioural interventions:** If individuals “at risk” are identified, there is a need for effective, feasible and affordable interventions that they can be offered, in particular for behavioural risk factors (smoking, diet, exercise) and particularly for people with IGT for whom there is good evidence that lifestyle change can delay progression to diabetes.

## **Section 1: Background**

### **1.1 Introduction**

The development of an evidence-base for effective primary and secondary prevention of cardiovascular disease and diabetes has led to an increasing interest in screening and risk reduction interventions in general practice. Despite the lack of randomised trial evidence for the effectiveness of screening for type 2 diabetes (Wareham & Griffin, 2001), screening in high risk populations is recommended by Diabetes UK (Diabetes UK, 2002) and the American Diabetes Association (ADA, 2004). Screening is generally favoured on the basis of evidence that treatment is effective in clinically diagnosed cases and that many people already have complications of diabetes at the time of diagnosis (Harris et al, 1992). Risk of cardiovascular disease is increased among people with previously undiagnosed diabetes compared to people with normal glucose tolerance (Wild et al, 2005). There is also evidence that those diagnosed by screening are as likely to already have complications as those diagnosed on the basis of symptoms, presumably due to co-existing vascular risk factors or more gradual progression of hyperglycaemia (Spijkerman, 2003).

### **1.2 The evidence base for diabetes screening**

There is a range of evidence from both epidemiological surveys and intervention studies that suggests that screening for diabetes in general practice is feasible and does identify previously undiagnosed cases. Screening for diabetes is already offered by many individual general practices using a very wide range of protocols. An early example of a systematic screening programme used urinalysis, posting testing materials to individuals at home and asking them to self-test (Davies et al, 1991). A number of questionnaires and risk assessment tools have been introduced that aim to identify individuals at risk who can be invited to attend for a blood test (Herman et al, 2005; Baan et al, 1999; Griffin et al, 2000; Franciosi et al, 2005). Reports of general practice based systematic testing have reported relatively low yields of new cases in relatively low risk UK populations (Lawrence et al, 2001). Interventions that have targeted high risk groups, based on age and body mass index (BMI) have achieved higher diagnosis rates (Greaves et al, 2004). Pharmacy schemes appear to screen relatively low risk populations, based on reports that only 5% of those screened are identified as at risk or referred to general practice for diagnostic tests (PJ Online, 2005). This compares with a prevalence of previously undiagnosed diabetes of approximately 13% in an epidemiological study in a deprived multi-ethnic population in Manchester (Riste 2001). Higher prevalence is found in pharmacy testing schemes when only those with known risk factors are tested (Lawal et al, 2003, Krass et al 2006).

A study of screening in France demonstrated the high proportion of those at risk who may be tested, even in the absence of any policy of systematic screening (Cogneau et al 2006). 88% of patients in this study visiting a French general practitioner had already had a fasting glucose measured, 75% in the previous year. There is very little evidence on which to assess current provision of screening for different population groups in the UK, or around which groups are most likely to take up an offer of screening. Given well documented inequalities in access to health care (Gulliford et al, 2001), it is likely that those with the highest baseline risk, as defined by ethnicity or socio-economic circumstances, are currently less likely to benefit from screening and earlier treatment, potentially leading to increasing inequalities. There is concern that undiagnosed diabetes will be particularly prevalent in the most deprived populations that are also at high risk of poorer treatment and subsequent complications (Goyder et al, 2000; Rhodes et al, 2003).

This developing evidence base and the major gaps in the evidence around the practicalities of screening led to the development of the UK NSC Diabetes, Heart Disease and Stroke (DHDS) Prevention Pilot Project.

### **1.3 The DHDS Prevention Pilot Project**

The National Screening Committee, having reviewed the evidence on screening for type 2 diabetes, set up the UK NSC Diabetes, Heart Disease and Stroke (DHDS) Prevention Pilot Project. This project was originally set up to develop diabetes screening and cardiovascular risk reduction programmes in 27 general practices in nine teaching PCTs, one in each of the nine English regions.

Each PCT had a project facilitator funded by the national pilot to support the PCT and participating practices in delivering the pilot programme. Each PCT initially identified three pilot (intervention) practices and three comparison (control) practices. The pilot practices in each participating PCT were funded to provide screening and appropriate interventions for all registered patients who fulfil the screening criteria. The comparison practices were expected to continue with their current screening practice to allow a comparison of practices with or without a DHDS-funded screening programme at the end of the pilot.

All recruited practices are in relatively deprived areas of England, many with large ethnic minority populations, where the predicted prevalence of type 2 diabetes (and the expected prevalence of undiagnosed diabetes) is relatively high (Riste et al, 2001). The pilot programme, which started preparatory work with practices in autumn 2003, was essentially designed to be a feasibility study of the identification and screening of high risk individuals in relatively high prevalence practices.

The project was co-ordinated by a central DHDS team comprising a nurse consultant, clinical epidemiologist, administrator and information scientist. This team was based at the Institute of Health Sciences in Oxford and the project team and the PCT facilitators met regularly to report progress and discuss issues arising from the pilot. There was also a multi-disciplinary Advisory Group to the DHDS pilot programme which provided a forum to discuss issues arising from the pilots. A report on the pilot evaluation was presented to the Advisory Group for discussion in May 2006.

An independent evaluation of the pilots was commissioned in 2004 and has been undertaken by a multi-disciplinary team from the Universities of Sheffield and Edinburgh. The main aim of the evaluation was to explore the issues that influence the feasibility of diabetes screening in general practice. The Sheffield team met monthly and worked closely with the DHDS team in Oxford. The full team communicated largely by email between meetings. Three meetings have taken place with Edinburgh colleagues to ensure the expertise of the full team is utilised in the evaluation process. An independent steering group for the evaluation, chaired by Professor Mike Pringle, was established to oversee the evaluation and has had five meetings, including two teleconferences.

It is important to recognise the context in which the pilots was implemented was one of rapid change and development in primary care. The general practices involved in the DHDS pilots were also actively involved in developing their information systems to meet the requirement of the new GMS contract and in particular the data collection requirement of the Quality and Outcomes Framework. Some practices changed their clinical information systems during the pilot period and other practices were re-organised or merged during the pilots and the impact on practices of these on-going changes are reflected in some of the issues described in this report.

## Section 2: Baseline assessment

### 2.1 Introduction

The aim of the first phase of the evaluation was to identify what screening activity had been undertaken in both pilot and comparator practices before the pilots started, to identify the characteristics of the pilot practices, and to identify the range of ways in which the pilot project was being implemented in the pilot practices. The results of this phase informed the selection of five practices for in-depth case studies and identified some of the issues that were subsequently explored in more depth through the case studies.

### 2.2 Pre-DHDS screening activity

To establish the extent of diabetes screening activity before the DHDS screening pilots started, all 24 pilot and 24 comparison practices were asked to complete a questionnaire about their own policy and practice (Appendix A). Four of the comparison practices dropped out without completing questionnaires. The data from the 44 remaining practices was entered onto an SPSS database for analysis.

*Overall level of case finding:* The median number of GPs per practice was 3.5 (mean 4.2) with a range from 1 to 13. They reported a mean of 21 new cases of diabetes detected in the previous year, with a range from 1 to 72, ie on average 5 new cases per GP. This suggests an overall population incidence of new cases of around 0.3% per year

*Secular trends:* 26 practices reported an increase in screening over the previous year and 11 reported it was unchanged. The most frequently cited reason for an increase was an increasing awareness of diabetes risk amongst patients and staff (13 practices), followed by a change in guidelines (seven practices) or an increase in capacity to do screening due to more trained staff being available (three practices).

*Identification of high risk groups:* 22 practices reporting systematically inviting high risk population groups for screening: 18 screening those with high risk conditions (ie CHD, hypertension). Three stated that they screened those of high risk ethnic origin.

*Re-screening:* 27 practices reported re-screening some patient groups at regular intervals: 18 screened those with high risk conditions (ie CHD, hypertension) either annually or every six months. Three screened those with IFG/IGT annually and three screened those with risk factors every 2-3 years.

*Choice of screening tests:* Most reported using a range of different screening tests (15 practices). The commonest individual tests used were urinalysis (positive if glucose present) (8 practices) and random capillary glucose (positive if over 5.5mmol/l) (11 practices).

*Choice of diagnostic tests:* A variety of diagnostic tests were also reported including fasting glucose and oral glucose tolerance tests (OGTTs). 34 practices took blood for fasting blood glucose at the practice and 25 sometimes or always referred elsewhere (to hospital phlebotomy service or walk-in centre). Fifteen did OGTTs in the practice, of which 13 did all the OGTTs required for their patients, while 23 referred elsewhere for OGTTs.

#### *Key points:*

- There was very wide variation in reported policy and practice
- About half of practices had some form of systematic screening activity.
- Practices used a variety of criteria to identify and screen high risk patients for diabetes.
- Urinalysis is still used for screening by a minority of practices.

- There was variation in whether diagnostic testing was done at the practice or patients required to travel to use hospital services: a majority did fasting blood glucose tests in the practices but a majority also sent patients to the hospital for OGTTs.

## **2.3 Baseline evaluation of DHDS pilots**

The first phase involved a baseline survey of the pilot practices and telephone interviews with the PCT facilitators. This was supplemented by informal discussions with the Oxford-based team, the PCT facilitators and members of the Advisory Group. A face to face interview was also conducted with the PCT facilitator and Director of Public Health from the one PCT that withdrew from the pilot at an early stage.

The baseline survey was developed in collaboration with the team in Oxford and the PCT facilitators to ensure that it was clear and unambiguous and collected relevant information. A final version (Appendix B) was sent to the PCT facilitators at the end of July 2004 with instructions to complete a copy for each pilot practice, in collaboration with practice staff and return to Sheffield by the end of August 2004. Responses for all practices were provided by 10 September and collated as a series of tables describing practice characteristics and screening activity by practice. The information provided was supplemented by discussion with facilitators, information available from the Oxford team and information from diabetes audits provided by practices before screening started. The facilitator interviews were mainly conducted by telephone in August and early September 2004. Interviewees had seen and had an opportunity to comment on the proposed topic guide at an early stage in its development (Appendix C). They were asked to outline their own role, to comment on their experience of the DHDS project and to identify and comment on any training that had been provided.

### **2.3.1 Choice of participating practices**

Initially nine teaching PCTs, one in each English region, were recruited, with an intention to randomly select three intervention and three comparison practices from all interested practices in each PCT, giving a total of 27 intervention and 27 comparison practices. One PCT dropped out before any screening started, citing current pressures on general practice. This leaves eight participating PCTs with 24 intervention practices. One additional practice, set up as a new "PMS practice" by a PCT for their unregistered patients, joined the pilot, but as this was a new practice screening all patients at registration, there is no baseline data and this practice has not been included in subsequent analyses.

Originally the intention was that from the volunteer practices in each PCT, the project team would randomly select 3 comparison and 3 pilot (intervention) practices. However where there were less than 6 interested practices to select from, additional comparison practices needed to be identified after intervention practices were selected. Some of the original intervention practices dropped out and were replaced by the original comparison practices and then new comparison practices sought. It seems likely that the pilot practices were more likely to represent practices with a particular interest in diabetes screening. Limited information is available on comparison practices, but those recruited to replace others that dropped out or replaced intervention practices are likely to be less interested in diabetes screening than others. Overall three of the original practices (in two different PCTs) dropped out and were replaced by comparison practices at an early stage. One practice dropped out at a relatively late stage after having provided complete baseline data and failed to provide any final activity data.

The original criteria for practice involvement included an ethnic minority population of 15% or over. This proved difficult to apply as practices do not generally record ethnicity and two of the PCTs had largely White British populations. At least one third of practices recruited were to be single-handed to reflect the prevalence of single-handed practice but this was not possible in PCTs where single-handed practices did not volunteer, and consequently only four single-handed practices (half the number originally planned) were recruited.

### **2.3.2 Practice characteristics**

24 practices started to offer screening for type 2 diabetes to various sub-groups of their practice population when the pilot scheme started. The range of findings in the practice survey are summarised in Table 2.1. The practices were all urban practices in teaching PCTs but otherwise they varied very widely in size, staffing, facilities and population served.

Key features of specific practices identified by the baseline survey that were likely to influence screening implementation included high rates of patient turnover, heterogeneous ethnic minority populations including refugee and asylum seeker populations, and various staffing problems such as key staff leaving through retirement or resignations or posts being currently unfilled.

**Table 2.1: Summary of baseline survey responses**

	<b>Range of responses</b>
<b>Practice characteristics</b>	
Setting	City centre, high street, inner city, housing estate
Access	Patients travel by foot, car, bus, taxi
Computer availability	Available all rooms/most rooms
Recent changes?	Staff changes, location changes, building work, computer system changes
<b>Population characteristics</b>	
Ethnic groups	Indian (Punjabi, Gujarati, Bengali), Pakistani, Bangladeshi, Chinese African (Somalian, Ethiopian, Zimbabwe, DRC) Afro-Caribbean, Eastern European (Polish, Romanian) Arabic, Syrian, Kurdish, Iraqi, Iranian
Main languages	Urdu, Gujarati, Punjabi, Farsi, Somali, Kurdish, Chinese
Rate of turnover	Low (24 patients/yr) to very high (25%/yr, >1000/yr)
<b>Practice staff involved in DHDS</b>	Practice manager (always involved), GPs (at least 1 always involved), practice nurses (1 to 5 nurses involved), Health care assistants (involved in 18 out of 24 practices), clerical staff (all except one practice)
<b>Pilot activity</b>	
Who is eligible for screening?	All patients over 40yrs (6 practices), all patients with CHD or over 40 yrs (3 practices), all patients over 40 yrs without a recorded BMI<25 (11 practices), all over 30 yrs with BMI >25 (3 practices), all over 18 yrs (1 practice).
How are they invited?	Letter, phone call, poster, information on prescription, face-to-face (opportunistic)
Who does screening?	GP, practice or PCT employed nurse, Health care assistants
What diagnostic tests are available in practice or elsewhere?	Oral glucose tolerance tests done in practice (9 practices, more likely if health care assistants responsible for screening), Oral glucose tolerance tests at hospital/walk in centre (4 practices). Only fasting blood glucose done in practice (6 practices), only fasting blood glucose done at hospital/walk in centre (5 practices).
What additional tests are done?	Blood pressure (all patients, 18 practices), cholesterol/lipids (some patients, 5 practices)
What forms of advice/information are given?	Verbal, written, leaflets in patients' languages
Repeat screening?	IGT/IFG patients to be recalled annually (10 practices) No plans reported to re-screen those screen negative

### 2.3.3 Pilot implementation

There was wide variation in the ways in which the pilot was implemented. This is summarised below:

1. *Recruitment strategies:* a range of both systematic and opportunistic strategies were used to invite patients to be screened. Overall 14 practices were using a combination of systematic and opportunistic methods, five were only inviting systematically (using postal or telephone contacts) and five were only inviting patients opportunistically. Invitations could involve letters, phone calls and/or face to face invitation when individuals attend the surgery. Prompts on clinical information systems were used by some practices to identify patients eligible for screening. Individuals who fail to respond or fail to turn up for screening appointments may or may not be contacted again either by letter, phone, or face to face when they attend the surgery. Recruitment also involved use of posters or flyers in the surgery to encourage patients to make screening appointments. Invitations either gave an appointment time or invited patients to make an appointment at their convenience.
2. *Definition of eligible population:* Some practices identified the eligible denominator population at the start of the project as the population to be screened and only offered screening to patients in this group. Others added patients to the eligible denominator population as they joined the practice or reached the age of 40 and removed patients as they left the practice.
3. *Populations targeted:* A range of inclusion and exclusion criteria were used to define the “high risk” population invited for a review and screening.

#### *Inclusion criteria*

- *Age:* Most practices screened patients from the age of 40. Three practices invited patients from the age of 30. One practice chose to screen everyone over 18.
- *Family history:* Three practices also screened new patients on the basis of family history.
- *Coronary heart disease (CHD):* A few practices which were not already doing routine screening in CHD reviews, included this group in the DHDS pilot activity. However, many practices excluded this group because they were screened instead as part of their annual CHD review. Since approximately 11% of people with diabetes also have CHD (Scottish Health Statistics, 2005), excluding new diagnoses in the CHD population may reduce the yield of the screening programme by about this proportion. Similarly excluding patients with hypertension, who some practices already screened annually, may reduce the yield of a screening programme by 30%.

#### *Exclusion criteria*

- *BMI:* Patients with a recorded BMI less than 25 were not invited for a DHDS review by 14 practices. At least three practices were screening everyone who met the age criteria, regardless of BMI because they believed the BMI criteria to be inappropriate in a largely South Asian population. No criterion was applied as to how recent a recorded BMI needed to be, in order to be regarded as a valid criterion for screening eligibility.
  - *Previous blood test:* Most practices only screened those with no record of a blood glucose in the previous two years (implying a minimum screening interval of two years for those already screened). Some also used hospital laboratory records to exclude all those who could be identified as having a blood glucose recorded in secondary care in the previous two years. (usually with a result less than 6mmol/l as it was not possible to distinguish between fasting and random samples). This excluded up to 30% of otherwise eligible patients. Some were screened, despite have a blood glucose recorded, if the level recorded was above 6mmol/l.
  - *Screening “inappropriate”:* Most practices excluded the frail, terminally ill and pregnant patients.
4. *Screening protocol:* A range of different data collection protocols and interventions were offered when patients attended for screening, although all used a random capillary blood glucose as the initial screening test (Qiao et al 1995). Some patients in one PCT had a venous sample

taken at the same time as the screening capillary sample, but only if transport was available for same day delivery of the sample to the hospital laboratory. All practices used a 6 mmol/l glucometer reading as the threshold for further investigation, although there was variation as to whether those with a reading of exactly 6.0 mmol/l were offered diagnostic testing. Some did either a fasting glucose (repeated if greater than 7mmol/l) or an oral glucose tolerance test (OGTT) in the practice, others referred patients to a hospital or walk-in centre for diagnostic testing.

5. *Health promotion:* There was a difference in emphasis with some practices focusing on screening as many patients for diabetes as possible and other providing more extensive risk assessment and primary prevention advice for all patients who attended (usually 20 to 30 minute appointments). All offered some verbal or written advice to patients attending for screening. 18 practices used the screening visit as an opportunity to record current blood pressure on the practice clinical information system. The duration of appointment varied from 10 minutes to 30 minutes where specific appointments were given but the screening intervention could take a much shorter time if done opportunistically during a clinical encounter.
6. *Resource use:* a wide range of different resources in terms of both staff and facilities were used to deliver screening and subsequent diagnostic testing. 18 practices used health care assistants to implement screening, in the other six practices only GPs and practice nurses offered screening. In one PCT district nurses were issued with glucometers for screening in the community although there were no data available on how frequently they were used.
7. *Data collection:* 12 practices used the project data collection form, either as a paper form or as a Word-based electronic form and completed it mainly for patients who were invited for screening appointments. Some were recording screening information for all individuals screened, others were completing forms only for those who fell within the original DHDS protocol even if they were in fact screening patients who fell outside the DHDS protocol. 12 practices collected screening information on their practice systems, using locally developed templates. The amount of information collected varied from including most of the data items on the project data collection form to including only the BMI, if measured, and the screening test result.

## 2.4 Discussion

As the pilot developed, it diverged in a number of ways from some of the original intentions. As the pilot is a pragmatic feasibility study, most of these changes can be explained in terms of the practicalities of implementation. For example, patients with CHD or hypertension were not included if they were already being screened for diabetes within their annual assessment as was the case in some practices. The lack of consistency in the delivery of interventions reflects an underlying pragmatic approach by the practices who adapted their protocol to suit local circumstances. Understanding the reasons for these changes, and the underlying difficulties for practices, is helpful in identifying some of the critical issues for implementation of screening in primary care. Important variations can be identified in four main areas: the objectives of the pilot, recruitment of participating practices, the screening protocol (choice of population to be screened and intervention delivered) and data collection.

### 2.4.1 Overall objectives

The pilot handbook states that the purpose of the project is “to screen for diabetes and encourage healthy lifestyle changes in people aged 40 and over considered at high risk for diabetes on the basis of a prior diagnosis of cardiovascular disease and/or being overweight”. Screening was envisaged “within a programme designed to prevent diabetes and cardiovascular disease”.

Although the overall aim remained screening patients at risk for diabetes in all practices, there was variation in the extent to which this was linked to encouragement of “healthy lifestyle changes” or a primary prevention programme. Some practices used the screening visit as an opportunity to screen for other risk factors: 20 practices recorded blood pressure and some used diagnostic testing in those who screened positive as an opportunity to measure fasting lipids/cholesterol. No

practices included systematic cardiovascular risk assessment. The health promotion interventions used were mainly tailored advice and leaflets, although some practices could also refer individuals to exercise programmes. Practices that were already offering routine diabetes screening to patients with coronary heart disease (CHD) largely excluded this group from the DHDS project. A few included them, but using CHD clinic diabetes screening protocols (usually a random or fasting venous blood test).

#### **2.4.2 Issues influencing participation and non-participation in DHDS pilot programme**

Diabetes screening has major resource implications for general practice, and the health service more widely, both in terms of running a screening programme and in terms of providing clinical care to new cases identified by screening. The DHDS pilot offered practices both financial resources and practical support for the introduction of diabetes screening in high risk patients. The decision to participate in the DHDS pilot was largely based on the perceived balance of benefit and cost for practices and perceived benefit for their practice population.

There are certain key issues that appear to influence perceptions of local need and perceptions of the DHDS programme and which will affect decisions around participation. Although PCTs and practices that have decided not to participate would be expected to be both more critical of the programme as a whole and to highlight more barriers to participation, the general issues raised are remarkably similar across participating and non-participating PCTs. The issues raised related to both local circumstances and the nature of the project and are summarised below.

Two major issues related to the local context for the project: whether diabetes (and diabetes screening) were local priorities for the practices or PCT (more likely to be the case in PCTs with large ethnic minority populations) and whether practical constraints make the development of a new screening programme difficult (eg a lack of spare consulting rooms, lack of staff, mobile or non-English-speaking populations). Local relationships between the PCT facilitator and both local GPs and PCT personnel were also key to encouraging participation.

Initial perceptions of the DHDS project as a whole were crucial to participation, specifically, whether the DHDS programme was seen as practical and feasible to implement in the current general practice organisational context and whether the DHDS team was seen as offering appropriate expertise to support practice development. Some practices may have had unrealistic expectations of what the pilot programme would provide. Practices also varied in the extent to which the programme was seen as flexible in its requirements eg in terms of data collection requirements or screening protocols and this influenced the extent to which the DHDS programme data requirement was seen as compatible with general practice clinical information systems.

Practice priorities had been influenced by the recently agreed data collection requirements of the Quality and Outcomes Framework of the new GMS contract. This includes a large number of chronic disease management process and outcome measures but did not include the collection of risk factor information for individuals without a pre-existing diagnosis of chronic disease.

#### **2.4.3 Screening protocol**

The range of different definitions of “high risk” used to identify populations offered screening are discussed above. Once patients were identified as potentially “eligible” for screening they could either be systematically invited for a screening appointment by letter or telephone or opportunistically offered screening (when visiting the practice for another reason). The definition of “high risk” patients was very varied and there was considerable screening activity outside the protocol. Anecdotally, a significant amount of screening outside the protocol was offered either on the clinical judgement of the screener (often because of the presence of other risk factors such as family history or membership of an ethnic minority group) or because of the perceived or expressed patient expectation that if invited to an appointment they will be screened. Only half the practices used oral glucose tolerance testing (OGTT) as a diagnostic test, despite the availability of project funds for diagnostic testing. Where it was offered in the practice, the testing was usually done by the healthcare assistants running the screening clinics.

#### **2.4.4 Patient data collection for audit**

The pilot practices used two different methods for collecting information on screening, using either a Word template (that could be completed as a paper form or on a computer screen) or a template developed locally for their own clinical information systems.

12 practices completed a Word template, either on a computer screen or printed out as a paper form, for each individual screened according to a DHDS protocol. A few practices also used the paper form for patients with coronary heart disease if these were screened within the DHDS protocol. Data from practices using the Word template was sent to a data entry company on paper forms to be entered onto a database. The other 12 practices designed their own templates within their clinical information system or simply entered data in fields already existing on local systems so that any data collected on screening was integrated with the main practice information system. This had the advantage that the information collected for the screening programme was available when the patient attended the practice for other reasons. The 24 practices used seven different systems on which at least some of the screening data was collected (EMIS LV5.2, EMIS PCS, Exeter, SystmOne, Torex Premiere, Torex Synergy and InPS Vision). Where practices were using their own templates, MIQUEST searches were designed in collaboration with local PRIMIS teams and used to extract data on screened patients. However it was not always straightforward to identify screened individuals if there was no specific or unique way of coding, or flagging, these cases.

The patient data has then been collated within Connecting for Health and forwarded to the evaluation team for analysis. Despite a great deal of hard work by the DHDS team, both systems of data collection proved difficult to operationalise. In early discussions with practices, completion of a separate form was seen as the most problematic aspect of the pilot and only half of all practices chose to use the pilot data collection form. Locally developed templates appeared initially to be a practical solution but they proved difficult to extract information from, because systems do not have either consistently used fields for screening test results or the capacity to link the screening record to the results of subsequent diagnostic testing. The process of data collection was further complicated in several practices that changed their IT systems during the course of the screening pilot.

A great deal of ad-hoc screening also occurs every time an individual has their urine or blood assessed for glucose but this information is currently either not consistently recorded, or, when it is recorded, appropriately coded, making it difficult to identify tests done for screening purposes or to identify abnormal test results and to ascertain whether appropriate follow up or diagnostic testing was ever arranged. This made it difficult to establish the overall impact of the pilots in terms of overall screening activity (both systematic and ad-hoc screening).

#### **2.4.5 Summary of main issues that influenced initial feasibility of establishing screening pilots**

1. Flexibility in invitation/screening/follow-up protocols
2. Ability to use clinical information systems for identifying patients eligible for screening and for organising screening
3. Ability to use clinical information systems for recording screening activity
4. Availability of additional staff, particularly recruitment and training of health care assistants (HCAs) by the pilot programme.
5. Availability of other resources required for implementing screening – administrative staff, rooms & computers, diagnostic testing by practice or by hospital/walk in centre
6. The extent to which diabetes screening could be integrated with meeting other practice goals including the new GMS contract requirements, integration into chronic disease management systems and integration with wider health promotion activities.

## Section 3: Quantifying screening pilot activity

### 3.1 Practice activity

As discussed above, the collection of data on the screening process proved to be the most challenging aspect of the pilot screening programme. Practices provided data to their PCT facilitators on the number of patients invited for screening, the number screened and the number of new cases of diabetes detected. The wide range of different protocols means that the data from different practices are not directly comparable. Information on exclusions or on the total number of "eligible" patients was not generally collected within practices, but most practices did send at least one invitation to all eligible patients, so the number invited is approximately the number classified as "eligible". The definition of "eligible" patients varied depending on whether practices only included a cohort eligible at the start of screening or included any patient eligible during the pilots (eg new patients or patients reaching the age of 40 during the pilot). Up to a third of patients who were otherwise eligible were excluded from screening because they had a blood glucose result (usually of less than 6 mmol/l) in the previous two years either on the practice record or in hospital laboratory records. Some practices screened more patients than they invited, because they included patients screened opportunistically on attending the practice for other reasons who had not been invited and who were potentially outside the age or BMI criteria for screening.

The number of new cases of diabetes reported as a direct consequence of the screening programme is often much smaller than the total number of new cases diagnosed during the pilot activity and it is likely that practices varied in which new cases they classified as "DHDS" cases depending on local screening protocols. Figure 3.1 shows the total activity reported and Table 3.1 shows the activity reported by PCT to show the extent of variation in uptake and yield of screening across the pilot PCTs. As expected, variation between individual practices was larger, with the uptake varying from 18% to 137% (where patients not invited were still opportunistically screened) and the yield of new cases varying from 1% to 5% of those screened.

### 3.2 Workload implications

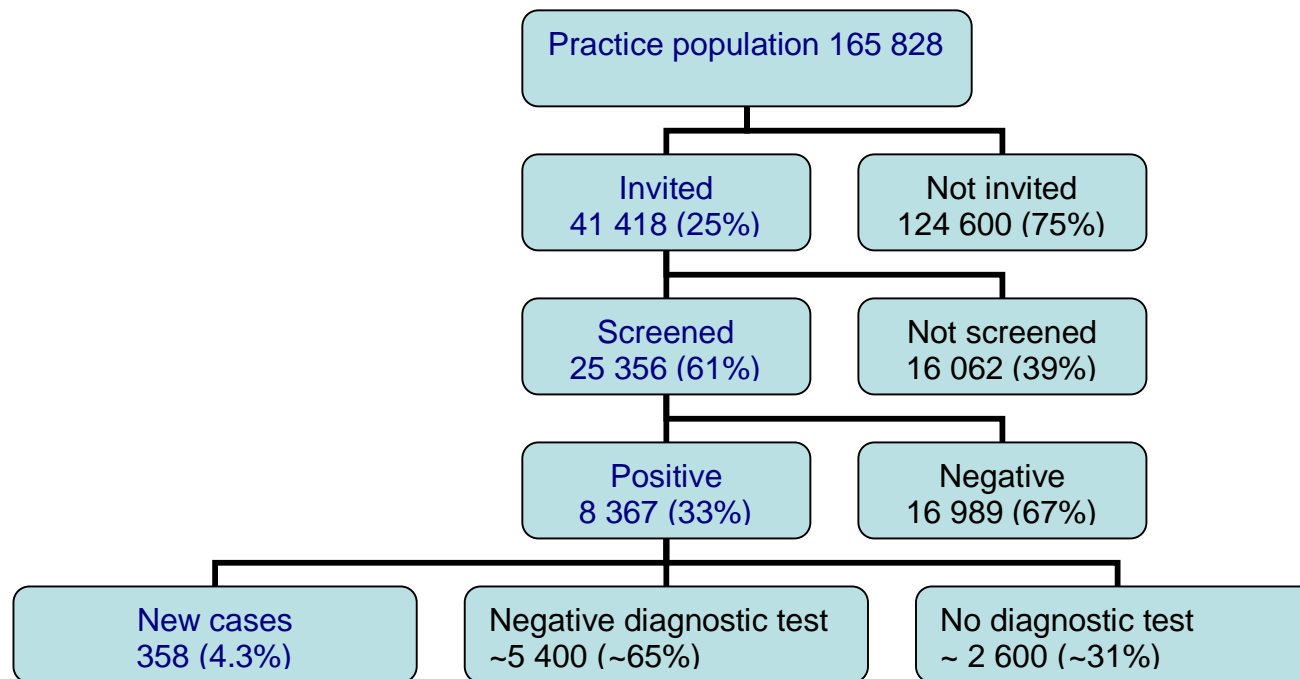
Seventeen of the pilot practices were able to provide estimates of the time spent on pilot activity. Where possible, these retrospective estimates were based on information collected by staff who recorded their hours during the pilots or information provided to PCT facilitators during the pilots.

Table 3.2 shows the time spent on different activities and the time spent by different categories of staff. As well as showing the total hours spent, this has been used to calculate activity as the number of hours of screening related activity per individual screened and the number of hours of screening related activity per individual diagnosed.

**Table 3.2: Estimated time spent on screening pilots by practice staff**

	Mean (hours)	Median (hours)	Range (hours)
<b>Staff (n=17)</b>			
GP	51 (4%)	0	0 to 100
Nurse	203 (15%)	113	0 to 1325
HCA	753 (55%)	495	0 to 2850
Practice Manager	71 (5%)	42	0 to 240
Admin/reception staff	280 (21%)	75	0 to 2175
<i>Activities (where quantified)</i>			
Offering screening (n=14)	493	317	48 to 2050
Doing screening (n=16)	979	565	178 to 3140
<b>TOTAL</b>	<b>1358 (100%)</b>	<b>811</b>	<b>244 to 4340</b>
Hours total activity per patient screened	<b>1.7</b>	<b>1.2</b>	<b>0.7 to 7.5</b>
Hours total activity per new case diagnosed	<b>124</b>	<b>81</b>	<b>24 to 723</b>

Figure 3.1: Practice screening activity - overall activity and outcomes reported by practices



**Table 3.1: Practice screening activity, uptake and new cases diagnosed by PCT based on practice reports**

Location of pilot Primary Care Trust	Total list size	Number of patients invited for screening (% of list)	Number of eligible patients screened in DHDS pilots (% of those invited, includes those invited or screened opportunistically)	Number of new cases diagnosed within DHDS pilots (% of those screened)
<b>Leicester</b>	32983	10078 (31)	3767 (37)	60 (1.59)
<b>Bradford</b>	12300	2195 (18)	1310 (60)	26 (1.98)
<b>Haringey</b> (4 practices)	10204	3569 (35)	2480 (69)	39 (1.57)
<b>Sunderland</b>	23365	4618 (20)	1988 (43)	39 (1.96)
<b>Luton</b>	32848	8605 (26)	7005 (81)	75 (1.07)
<b>Portsmouth</b>	27072	5789 (21)	6759 (117)	85 (1.26)
<b>Liverpool</b> (2 practices)	7316	1000 (14)	435 (44)	15 (3.45)
<b>Bristol</b>	22740	5564 (24)	1612 (29)	19 (1.18)
<b>TOTAL</b>	<b>165 828</b>	<b>41418 (25)</b>	<b>25 356 (61)</b>	<b>358 (1.40)</b>

These data give an overall picture of the time that practices reported as spent on implementing the screening pilots. These estimates, particularly the 11-fold variation in the number of hours of activity per patient screened (and the 30-fold variation in the number of hours of activity per new case diagnosed) illustrate how dramatically screening costs may vary from practice to practice, making it very difficult to generalise likely costs of screening across practices. Overall most hours were recorded as devoted to screening by health care assistants (HCAs). The time spent on screening-related activities by administrative and reception staff may be underestimated as, while HCAs may have been employed specifically to implement screening, other staff will have been performing screening related activities along side other aspects of practice activity (Bates et al, 2003). Resources and time required for the additional treatment of patients diagnosed by screening are not included in these estimates and may be considerable if screening results in significantly earlier detection.

The time spent on screening involved considerable administrative time (identifying and inviting eligible patients, arranging appointments, organising diagnostic tests, chasing results) as well as the time spent seeing patients to do screening or to do diagnostic tests. It is likely that this could be reduced over time as systems for identifying and flagging eligible patients become better developed. It should also be borne in mind that the data collection requirements of the pilots were greater than would be required if data collection was limited to the routine data required for audit. Ideally cost-effectiveness models need to include the considerable administrative time required to organise screening as well as the costs of the subsequent screening and diagnostic testing. The estimates here exclude the time implications of earlier treatment. The data provide no support for the existence of “economy of scale” for screening activity, ie the hours of activity per patient screened are not lower for bigger practices.

### **3.3 Audit of primary care use by screening attenders and non-attenders**

#### **3.3.1 Rationale**

Three pilot practices in one PCT with an overall uptake of screening of 44% (1988 screened of 4489 invited) undertook an audit of practice attendance in the previous year by both screening attenders and non-attenders. There is some evidence that individuals at risk of diabetes are more frequent attenders in the years prior to diagnosis (Guilliford et al 2005). The aim was to estimate the proportion of patients who, whether or not they had attended for screening in response to a postal invitation, could in principle have been screened when they attended the practice for another reason during the previous year. We were interested to know whether individuals who actively decline, or fail to respond to, a postal invitation are less likely (or more likely) to attend for other reasons than those who do attend in response to a screening invitation.

#### **3.3.2 Methods**

In each practice, for 200 attenders and 200 non-attenders selected sequentially from the alphabetical lists of patients eligible to be invited for screening, information was extracted on age, sex, ethnicity, attendance in the previous year and on presence of any current repeat prescription. In one practice, individuals could be classified on the basis of having not replied to a postal invitation (“no reply”), actively declined (“declined”) or made an appointment and then not attended (“did not attend” or “DNA”). In the other two, where all patients were sent an appointment, it was not possible to distinguish those who did not reply from those that did not attend, so all non-attenders are classified as “declined” if they replied to decline screening or as “DNA” if they neither attended or actively declined the appointment. We used chi-squared tests to identify statistically significant differences between groups based on screening status. We applied the practice-specific audit results to the total number of people invited in order to estimate how many people could theoretically have been opportunistically screened over a twelve month period.

### 3.3.3 Results

Table 3.3 shows the sampling strategy used to obtain a stratified sample on the basis of screening status. The characteristics of attenders and non-attenders for the three practices are show in Table 3.4 below. Chi-squared tests were used to identify any statistically significant differences between those screened and not screened. In all three practices those who attended or actively declined screening were older than those who did not turn up. Those who attended for screening were more likely to have been to the practice in the previous year and more likely to have a current repeat prescription than those who did not. Table 3.5 shows the numbers of those in each screening group being seen in the practice over the year prior to the screening invitation.

**Table 3.3: Response rates and audit sample of those attending and not attending screening**

	Screened	Not screened				Total
		No reply	Declined	DNA	All not screened	
<i>Practice 1</i>						
Number (%)	647 (35)	842 (46)	291 (16)	58 (3)	1191 (65)	1838
Audit sample	200	100	50	50	200	400
<i>Practice 2</i>						
Number (%)	931 (52)	-	300 (17)	567 (31)	867 (48)	1798
Audit sample	200	-	75	125	200	400
<i>Practice 3</i>						
Number (%)	410 (48)	-	138 (16)	305 (36)	443 (52)	853
Audit sample	200	-	100	100	200	400
Total						
Number (%)	1988 (44)	842 (19)	729 (16)	930 (21)	2501 (56)	4489
Total audit sample	600	100	225	275	600	1200

**Table 3.4: Characteristics of those attending and not attending screening**

	<b>Screened</b>	<b>Not screened</b>				<b>Chi<sup>2</sup></b>
	n (%)	No reply n (%)	Declined n (%)	DNA n (%)	All n (%)	p =
<b>Age: under 60 yrs</b>						
Practice 1	103 (52)	71 (71)	29 (58)	34 (68)	134 (67)	0.006
Practice 2	129 (65)	-	41 (55)	115 (92)	156 (78)	<0.001
Practice 3	135 (68)	-	69 (69)	84 (85)	153 (77)	0.005
<b>Total</b>	<b>367 (61)</b>	<b>71 (71)</b>	<b>139 (62)</b>	<b>233 (85)</b>	<b>443 (74)</b>	
<b>Sex: male</b>						
Practice 1	95 (48)	51 (51)	24 (48)	23 (46)	98 (49)	0.9
Practice 2	99 (50)	-	33 (44)	71 (57)	104 (52)	0.2
Practice 3	96 (48)	-	50(50)	57 (57)	107 (54)	0.3
<b>Total</b>	<b>290 (48)</b>	<b>51 (51)</b>	<b>107 (48)</b>	<b>151 (55)</b>	<b>309 (52)</b>	
<b>Seen in last year</b>						
Practice 1	167 (84)	61 (61)	27 54)	36 (72)	124 (62)	<0.001
Practice 2	174 (87)	-	47 (63)	95 (76)	142 (71)	<0.001
Practice 3	164 (82)	-	63 (63)	44 (44)	107 (54)	<0.001
<b>Total</b>	<b>505 (84)</b>	<b>61 (61)</b>	<b>137 (61)</b>	<b>175 (64)</b>	<b>373 (62)</b>	
<b>Repeat prescription</b>						
Practice 1	123 (62)	46 (46)	34 (68)	16 (32)	114 (57)	0.01
Practice 2	128 (64)	-	38 (51)	47 (38)	85 (43)	<0.001
Practice 3	83 (42)	-	44 (44)	30 (30)	74 (37)	0.08
<b>Total</b>	<b>334 (56)</b>	<b>46 (46)</b>	<b>116 (52)</b>	<b>111 (40)</b>	<b>273 (46)</b>	

**Table 3.5: Estimates of number seen in the practice over a year for those attending and not attending for screening**

	Screened	Not screened				Total
		<i>No reply</i>	<i>Declined</i>	<i>DNA</i>	<b>All not screened (declined OR failed to respond/attend)</b>	
Practice 1						
Number	<b>647</b>	842	291	58	<b>1191</b>	1838
% seen in a year	<b>84</b>	61	54	72		
Number seen	<b>543</b>	514	157	42	<b>713</b>	1256
Practice 2						
Number	<b>931</b>	-	300	567	<b>867</b>	1798
% seen in a year	<b>87</b>	-	63	76		
Number seen	<b>810</b>		189	431	<b>620</b>	
Practice 3						
Number	<b>410</b>	-	138	305	<b>443</b>	853
% seen in a year	<b>82</b>	-	63	44		
Number seen	<b>336</b>		87	134	<b>221</b>	557
Total						
Number	<b>1988</b>	842	729	930	<b>2501</b>	4489
<b>Number seen (%)</b>	<b>1689 (85)</b>	514 (61)	433 (59)	607 (65)	<b>1554 (62)</b>	<b>3243 (72)</b>

### 3.3.4 Discussion

This audit, conducted in one PCT with a relatively deprived, largely white, population shows that those who attended for screening or actively declined the invitation were significantly older than those who did not respond to the invitation (mean age 57.4 years versus 52.9 years). Those who attend for screening were also more likely to use primary care for other reasons than those who declined, or did not respond to, the invitation to be screened. This finding supports the views expressed by both practice staff and facilitators that those who attended for screening tended to be those who attended regularly for other reasons, rather than the infrequent attenders they rarely saw for anything.

Only about 300 out of 1988 screened (15%), would not have been seen in the practice in the previous year and the majority (56%) had a current repeat prescription suggesting a relatively high level of treated chronic illness in this population. On the other hand, of those who did not attend for screening, about 950 out of 2501 (38%) did not attend the practice for any reason over a year and so would also be less likely to be screened in an opportunistic screening programme.

Opportunistic screening, identifying eligible individuals and screening them when they attend the practice for another reason, will miss the patient group who rarely, if ever, are seen in the practice. This audit suggests that this may not be a major concern since most (85%) of those who respond to a postal invitation for screening could be screened by an opportunistic screening protocol within a year. The greater average age, more frequent attendance and higher proportion with repeat prescriptions amongst screening attenders also suggests that those that attend for diabetes screening are both older and less healthy than those that do not. This suggests it is less likely that there is a low risk healthy “worried well” population that has self-selected for screening in this relatively deprived population. Over 60% of those who do not respond to an invitation will be seen within a year, so opportunistic screening will also reach many of those who do not respond to a postal invitation, the remaining 38% being unlikely to benefit from either postal or opportunistic screening invitations. It may be that older patients are more likely to reply to an invitation because of a different view of their relationship with the practice (GP as having authority; it being important to respond to an invitation) or simply being less busy with other priorities.

### **3.4 Findings from the database of screened patients**

Patient data were only available from 21 practices in seven of the eight PCTs. Despite developing MIQUEST searches to extract information from fields related to screening, it proved difficult to obtain all the results of the random capillary blood glucose screening tests and subsequent diagnostic tests from the clinical systems used by the 24 pilot practices. The lack of an appropriate common template for recording both risk factors and screening activity created difficulties from the outset of the pilot programme. Several practices had difficulty identifying on their primary care systems the appropriate codes and fields for recording screening blood glucose results, such as a capillary blood glucose done as a screening test. Where results were recorded, the record may not include the exact nature of the test (ie whether capillary or venous sample, random or fasting or post-glucose load sample, screening test or subsequent diagnostic test). With the caveat that analyses are based on a sub-group of patients for which the DHDS protocol was followed and for which relatively complete data are available, it is possible to report on the characteristics of the screened population and the predictors of a diagnosis of diabetes in the screened cohort. Analyses are largely based on 12 145 patients without previously diagnosed diabetes for whom the results of a random capillary blood glucose screening test was recorded. 2700 patients were identified as known cases of CHD.

#### **3.4.1 Missing data items**

Initial examination of the data on screened individuals collected by practices on paper forms and extracted from clinical information systems revealed a large amount of missing data. Of particular concern, a high proportion of records with a positive screening result (capillary blood glucose of 6 mmol/l or higher) did not include any diagnostic test results. During the course of data collection, records of missing information on age, sex, and diagnostic test results were fed back to PCT facilitators to assist with improving the completeness of the data where it was thought likely that missing data items could be extracted from patient records or clinical information systems. However missing data remained a significant issue related both to data that was not routinely collected (for example: ethnicity, waist circumference) or not recorded in a format that made it easy to retrieve (particularly diagnostic test results where there was no system established to link these with the screening process). In addition, a small number of values were excluded for being outside the plausible range, although this did not have a significant impact on the overall prevalence of missing data.

Table 3.6 gives the completeness of recording of key variables in the patient dataset and the range of completeness by practice, for practices using the DHDS Word template or their clinical information system to record screening related information. This shows that the completeness of data collection varied widely between practices for most variables, with even basic demographic information (age, sex and ethnicity) missing. For most analyses the dataset is limited to individuals for whom capillary blood glucose is recorded but even this group have limited information on some major risk factors: ethnicity, waist circumference and family history.

**Table 3.6 : Completeness of patient level data collection**

Data item	Missing data from complete dataset N = 16,795 N (%)	Range by practice % missing	Missing data from dataset with RCBG recorded N= 12145 N (%)	Range by practice % missing
Age	107 (0.6)	0-100	78 (0.6)	0-100
Sex	2567 (15)	0-63	53 (0.4)	0-22
Ethnicity	6974 (42)	0-100	4114 (34)	0-100
BMI	3339 (20)	1-57	683 (6)	0.3 - 21
Waist circumference	9329 (56)	4-100	6041 (50)	0.8 -100
Family history	7810 (47)	0-100	4855 (40)	0-100
RCBG result	4650 (28)	0.1 - 60	-	-
	N = 3789			
FBG result if RCBG>6	1191 (31)	5-94	-	-
2 hr result if RCBG>6	3013 (80)	14-100		

**Missing diagnostic test results:** Out of 3789 (31%) of screened patients with a random capillary blood glucose over 6 mmol/l, 1189 (31%) did not have any results of diagnostic testing recorded on their screening record, even after updating records from practice information systems. These individuals represent a combination of patients who did not undergo diagnostic testing (for whatever reason) and those whose result was either not recorded or not coded as the result of diagnostic test. Further work is currently in progress in the Bradford practices to investigate further the underlying reasons why people do not undergo diagnostic testing after a positive screening test.

**Lack of access to OGTT testing:** Of those with a diagnostic test result recorded, 776 (30%) had undergone an oral glucose tolerance test, the other 1824 (70%) having had only one or two fasting blood glucoses measured.

### 3.4.2 Characteristics of the screened population

Table 3.7 gives the characteristics of the screened population and the prevalence of new cases of diabetes by risk factor group. Analysis of other characteristics by ethnic group identifies that the white population screened was older and less likely to be overweight or obese than the non-white population. Age, BMI and non-white ethnicity are all risk factors for screening-detected diabetes in this population.

From the data in Table 3.7, it is possible to draw inferences about the impact of restricting screening tests to those with higher BMI values or ages. For example, excluding the 618 under 40 year olds (who were screened mainly because of other risk factors) from screening would have

resulted in 104 fewer patients requiring diagnostic tests and missed six new cases. Excluding those with a BMI under 25 would have resulted in 2588 fewer screening tests, 660 fewer patients requiring diagnostic tests and missed 39 new cases.

**Table 3.7 Characteristics of screened population and prevalence of screening-detected diabetes**

	<b>No. screened (%) (n=12 145)</b>	<b>Positive screen (RCBG result &gt;6.0mmol/l) No (% of those screened)</b>	<b>Diagnostic test result recorded No (% of those with positive screen)</b>	<b>OGTT result recorded No (% of those with positive screen)</b>	<b>New cases (positive diagnostic test) No (% of those screened)</b>
<b>Sex:</b>					
Male	5589 (46)	1776 (32)	1214 (68)	376 (21)	164 (2.9)
Female	6503 (54)	2000 (31)	1376 (69)	399 (20)	167 (2.6)
Missing	53 (-)	13 (25)	8 (62)	1 (-)	3 (5.7)
			Chi <sup>2</sup> p=0.8	Chi <sup>2</sup> p=0.2	Chi <sup>2</sup> p=0.2
<b>Age:</b>					
<40 yrs	618 (5)	104 (17)	84 (81)	24 (22)	2 (0.3)
40-59 yrs	6840 (56)	1959 (29)	1379 (70)	401 (20)	150 (2.2)
60-79 yrs	3958 (33)	1414 (36)	975 (69)	312 (22)	153 (3.9)
80+ yrs	651 (5)	279 (43)	133 (48)	38 (14)	23 (3.5)
Missing	78 (1)	33 (42)	27 (82)	1 (3)	6 (7.7)
			Chi <sup>2</sup> p<0.001	Chi <sup>2</sup> p=0.22	Chi <sup>2</sup> p<0.001
<b>BMI:</b>					
<25 kg/m <sup>2</sup>	2588 ( )	660 (26)	404 (61)	151 (23)	39 (1.5)
25-30 kg/m <sup>2</sup>	5397	1652 (31)	1234 (75)	345 (21)	122 (2.2)
30+ kg/m <sup>2</sup>	3477	1282 (37)	919 (72)	276 (21)	163 (4.7)
Missing	683	195 (29)	41 (21)	4 (2)	10 (1.5)
			Chi <sup>2</sup> p=0.002	Chi <sup>2</sup> p=0.60	Chi <sup>2</sup> p<0.001
<b>Ethnicity:</b>					
White	5518	1678 (30)	1440 (86)	598 (36)	177 (3.2)
Black	990	337 (34)	286 (85)	49 (15)	39 (3.9)
South Asian	1211	511 (42)	440 (86)	100 (20)	56 (4.6)
Other	312	134 (43)	111 (83)	26 (8)	11 (3.5)
Missing	4114	1129 (27)	321 (28%)	3 (-)	51 (1.2)
			Chi <sup>2</sup> p=0.77	Chi <sup>2</sup> p<0.001	Chi <sup>2</sup> p<0.001
<b>RCBG (mmol/l)</b>					
< 6	8356 (69)	-	-	-	-
6 to 7	1962 (16)	1962 (16)	1299 (66)	423 (22)	77 (4)
>7	1827 (15)	1827 (15)	1299 (71)	353 (19)	257 (14)
			Chi <sup>2</sup> p<0.001	Chi <sup>2</sup> p=0.09	Chi <sup>2</sup> p<0.001

### 3.4.3 Variation between practices

In the patient level dataset, there were large variations between practices in the proportion of those screened having a positive diagnostic test result (from 2% to 8%). For the 18 practices for whom population ethnicity and geographical deprivation information is available, a summary of some potential explanatory variables is given in Table 3.8.

This analysis enables the identification of practices with unexpectedly high or low yields of new cases from screening that may merit further evaluation. For example the least deprived practices tend to have a lower yield of new cases as might be expected if deprivation is a risk factor for undiagnosed diabetes. The exceptions are practices 7 and 10, but both these practices have large non-white populations (47% and 99% respectively).

The practice with the highest yield (practice 1) had a white population, but was also in a very deprived area, used all three exclusion criteria to select patients for screening and used an oral glucose tolerance test (OGTT) for diagnosis. Practices with larger ethnic minority populations

tended to have higher yields and the exception, practice 13, did not use two of the exclusion criteria and did not have access to OGTTs which means that a lower risk population was receiving screening and also that people with isolated post-challenge hyperglycaemia (IPH) would not be identified by the diagnostic test of fasting glucose alone (as they would have been if an OGTT had been used). The proportion of people with diabetes with IPH is higher among the lean, elderly and women than among the overweight/obese, younger and male sub-groups.

Only nine practices used an OGTT for diagnosis, the rest using one or more fasting blood glucose only for diagnosis. Practices with health care assistants (HCAs) appear more likely to plan to use OGTTs (7/12) than practices in which only qualified nurses undertook screening (2/6). This may be because health care assistants were often specifically employed to do screening and could be trained to perform OGTTs that practice nurses might not have time to do themselves.

**Table 3.8 Practices ranked by prevalence of newly diagnosed cases in screened population and potential explanatory factors**

Practice	Population characteristics			Practice screening protocol (at baseline)					Outcomes		
	IMD 2004 decile (1= most deprived 10% of wards in England)	White % screened population	Black % screened population	Asian % screened population	Exclude if age under 40 years	Exclude if BMI <25kg/m <sup>2</sup>	Exclude if previous blood glucose result available	Use OGTT for diagnosis	HCA does screening	screen positive cases diagnosed with diabetes %	screened cases diagnosed with diabetes %
1	1	100	0	0	yes	yes	yes	yes		16	8
2	1	68	26	4	yes	yes	yes			18	6
3	1	74	11	2	yes	yes	yes	yes		16	6
4	1	69	3	26	yes			yes	yes	18	6
5	1	7	6	87	yes			yes	yes	44	6
6	1	83	6	6	yes	yes	yes	yes	yes	16	6
7	2	53	24	8		yes				13	6
8	1	70	25	2	yes	yes	yes		yes	16	5
9	1	40	41	6		yes			yes	19	5
10	3	1	2	97	yes				yes	11	5
11	1	83	4	11	yes		yes	yes	yes	13	3
12	1	100	0	0	yes		yes		yes	8	3
13	1	10	61	5		yes				8	3
14	1	99	0	1	yes	yes	yes	yes	yes	13	2
15	1	100	0	0	yes	yes	yes	yes	yes	17	2
16	2	90	4	5	yes				yes	5	2
17	5	92	2	5	yes	yes	yes			6	2
18	3	100	0	0	yes	yes	yes	yes	yes	18	2

## Section 4: Exploring the overall impact of the DHDS screening pilots

### 4.1 Introduction

Traditionally, reports on the impact of diabetes screening programmes report on the number of individuals screened and the number of new cases of diabetes diagnosed by screening. All the pilot practices provided activity reports and this overall activity is reported above (Section 3). However the numbers screened and numbers of new cases diagnosed provide only limited insight into the overall impact of the pilots. We also used a range of audits, conducted by the pilot and comparator practices, to explore the broader impact and implications of the pilots. Four audits discussed below allow direct comparisons of:

1. prevalence of diagnosed diabetes before and after the pilots in pilot and non-pilot practices
2. Quality and Outcome Framework results in pilot and non-pilot practices
3. changes in screening policy in pilot and non-pilot practices
4. characteristics of DHDS and non-DHDS newly diagnosed diabetes cases

### 4.2 Impact on prevalence: change in diabetes prevalence in pilot and comparator practices

A key aspect of the impact of screening, and one of particular concern to practices, is the impact on the overall prevalence of diabetes. The evaluation therefore examined the change in prevalence by practice and compared the change in the pilot practices with the change in the comparison practices. These figures, for PCTs with data from the same pilot and comparison practices at the start and end of the pilots are shown in Table 4.1

**Table 4.1: Absolute change in overall diabetes prevalence in pilot and comparison practices by PCT**

PCT	Pilot practices			Comparison practices		
	Pre	Post	Change	Pre	Post	Change
	DHDS	DHDS	%	DHDS	DHDS	%
<b>Bradford</b>	5.07	5.60	0.52	3.92	5.30	1.38
<b>Haringey</b>	3.40	4.27	0.87	3.14	3.40	0.26
<b>Sunderland</b>	3.46	3.80	0.34	3.43	3.79	0.36
<b>Luton</b>	3.28	3.65	0.37	3.00	3.22	0.23
<b>Portsmouth</b>	3.33	3.87	0.53	2.86	3.27	0.41
<b>Liverpool</b>	3.36	4.95	1.59	3.73	3.72	0.00
<b>TOTAL</b>	3.54	4.08	<b>0.54</b>	3.26	3.68	<b>0.42</b>

The overall increase in reported diabetes prevalence in both pilot and comparison practices suggests that most of the change in recorded prevalence is due to factors other than DHDS pilot status. The increase in prevalence is only 20% greater in the pilot practices overall (but differed

between PCTs) relative to the comparison practices and the absolute difference in the increase in prevalence is 0.1%. The other factors that may be responsible for the increasing prevalence in all practices are the introduction (during the pilots) of the new GMC contract that required complete and updated information on all patients with diabetes and a general trend towards increased screening of patients at risk including all patients with a diagnosis of coronary heart disease (CHD) or hypertension.

### **4.3 Comparison of the Quality and Outcomes Framework in pilot and comparator practices**

At the outset of the screening pilots, there was some concern that increased screening activity, whilst increasing prevalence might have a detrimental effect on the ability to maintain a high quality of care for an increasing number of diagnosed cases and might detract from an overall focus on improving chronic disease management. On the other hand, several practices cited the new GP contract as a reason for getting involved in the pilot since it would provide an opportunity to call patients in and update records.

#### **4.3.1 Methods**

Pilot and comparator practices were asked to provide Quality and Outcome Framework results from 2004/05 on the specific indicators related to hypertension (BP2 – BP5) and diabetes (DM2 – DM18). Differences in the diabetes indicators would reflect any differences in the quality of management of diabetes and differences in the hypertension indicators reflect any general impact of the pilots on process and outcome indicators in the population invited for screening (since this would include a high proportion of the population on the hypertension register).

#### **4.3.2 Results**

Information was obtained from 15 pilot practices and 15 comparator practices across the eight PCTs. In order to maximise the use of the available data both an unmatched analysis (using all the results) and a matched analysis (using only results where complete data were available from both pilots and comparators within each PCT) were conducted. The results of a comparison of average scores in pilot and comparator practices is shown in Table 4.2. A matched analysis confirmed that there were no statistically significant differences in scores between the pilot and comparator practices, after matching practices within the same PCT.

#### **4.3.3 Discussion**

The results show only small, non-significant differences between pilot and comparator practices. Overall retinal screening, not usually done in practices, is the only indicator slightly better in pilot practices (DM8), whilst a number of indicators related to management of complications are (non-significantly) better in comparator practices (DM 9, DM10, DM15, DM17).

We know that prevalence was higher in pilot practices and the sheer number of patients, as well as the workload required to implement the screening pilots may make it more difficult to achieve the highest levels for these indicators. There is no indication that the pilot practices were able to achieve better outcomes as a result of participation in the screening pilot nor was there any evidence that quality of care in practices taking part in the pilot was markedly worse than among comparator practices.

**Table 4.2: Quality and Outcome Framework 2004/05: results from pilot and comparator practices**

		Number of practices contributing data		Pilot average	Comparator average	Difference
Code	Indicator	Pilot	Comparator	%	%	%
BP 2	Smoking status recorded at least once	12	12	95.39	94.29	1.10
BP 3	Smokers with smoking cessation advice or referral to specialist service	12	12	96.33	95.25	1.08
BP 4	Record of blood pressure in last 9 months.	12	11	83.74	88.36	-4.62
BP 5	Last blood pressure reading in last 9 months, 150/90 or less	12	11	63.68	66.91	-3.23
DM 2	BMI recorded in last 15 months	15	14	91.06	89.50	1.56
DM 3	Record of smoking status in last 15 months	15	14	96.44	95.36	1.08
DM 4	Smokers with smoking cessation advice or referral to specialist service	15	14	92.71	94.82	-2.11
DM 5	Record of HbA1c in last 15 months	15	14	93.57	93.00	0.57
DM 6	Last HbA1C 7.4 or less in last 15 months.	15	14	59.28	60.64	-1.36
DM 7	HbA1C 10 or less in last 15 months	15	14	86.82	87.93	-1.11
DM 8	Retinal screening in last 15 months	15	14	80.59	76.29	4.30
DM 9	Record of presence or absence of peripheral pulses in last 15 months	15	14	74.83	82.86	-8.03
DM 10	Record of neuropathy testing in last 15 months	15	14	72.66	82.57	-9.91
DM 11	Record of blood pressure in last 15 months	15	14	96.31	95.07	1.24
DM 12	Last blood pressure 145/85 or less	15	14	68.77	66.93	1.84
DM 13	Record of micro-albuminuria testing in last 15 months.	15	13	71.65	71.54	0.11
DM 14	Record of serum creatinine testing in last 15 months.	15	14	91.95	93.11	-1.15
DM 15	Proteinuria or micro-albuminuria treated with ACE inhibitors	14	12	76.66	88.17	-11.51
DM 16	Record of total cholesterol in last 15 months	15	14	92.52	91.93	0.59
DM 17	Last measured total cholesterol in the last 15 months, 5mmol/l or less	15	14	70.65	77.21	-6.57
DM 18	Influenza immunisation	15	13	83.49	85.73	-2.24

#### 4.4 Impact on screening policy: change in screening practice after pilots finished in pilot and comparator practices

**Methods:** The survey on screening policy and practice completed by practices before the pilots started in 2003 (Appendix A) was sent to all pilot and comparator practices in autumn 2005. The responses to the second survey were directly compared to responses to the first survey to ascertain if screening practices had changed in either pilot or comparator practices.

**Results:** A total of 36 practices, 18 pilot and 18 comparator, returned completed, or partially completed questionnaires. Changes in the patient groups systematically screened and changes to availability of diagnostic testing were found in both pilot and comparator practices (Table 4.3).

**Table 4.3 Changes in screening policy between 2003 and 2005**

	Pilot practices No. (%)	Comparator No. (%)	Total No. (%)
<b>Change in volume of screening</b>			
Increased	13 (76)	9 (56)	22 (67)
Unchanged	3 (18)	6 (38)	9 (27)
Decreased	1 (6)	1 (6)	2 (6)
<b>Change in groups screened</b>			
Increased	11 (61)	8 (44)	19 (53)
Unchanged	7 (39)	9 (50)	16 (44)
Decreased	0 (0)	1 (6)	1 (3)
<b>Change in proportion of diagnostic tests done in the practice</b>			
Increased	2 (11)	5 (28)	7 (19)
Unchanged	12 (67)	13 (72)	25 (69)
Decreased	4 (22)	0 (0)	4 (11)

The reported incidence of new cases increased from 3/1000 to 4/1000. Most practices reported a continuing increase in the volume of screening activity in both pilot and comparator practices. The reason given for a decrease in screening in two practices was that most eligible patients had already been screened.

One practice had stopped screening in a “well man” clinic but overall the number of groups screened systematically had increased including: patients with IGT (8 practices), coronary heart disease (6 practices), family history of diabetes (5 practices), hypertension (3 practices), overweight or obesity (3 practices), history of gestational diabetes (3 practices) and stroke (2 practices).

Access to diagnostic testing had decreased in some pilot practices who had lost staff employed on the screening pilot who had done diagnostic testing at the practice (fasting glucose in three practices, OGTTs in one practice). Six practices had increased the proportion of fasting blood tests done at the practice and one was now doing all oral glucose tolerance tests in the practice.

Overall the survey confirms a continuing trend towards increasing screening and increasing systematic screening of patients with identified risk factors for diabetes and cardiovascular disease.

**4.5 Impact on characteristics of newly diagnosed cases** : audit of recently diagnosed diabetes in pilot and comparator practices and a comparison of new cases diagnosed as a result of pilot activity and those diagnosed outside the pilot

#### **4.5.1 Background and rationale**

During the DHDS pilot programme, practices indicated that the total number of new cases detected by the systematic screening was lower than they expected, based on the expected number of cases of undiagnosed diabetes in the practice population being around 30-50% of the diagnosed prevalence (Forouhi et al, 2006). When potential explanations for this were discussed, PCT facilitators reported that several practices were diagnosing more cases outside the pilot than within the pilot. This appeared to be a consistent finding wherever information on the total number of new cases was collected and a distinction made between “DHDS” cases and cases detected by other means.

In discussion with the PCT facilitators, it was agreed that an audit of recently diagnosed cases would enable practices to quantify the proportion of cases being detected by screening or clinical presentation outside the DHDS programme and to understand why the addition of systematic screening was not having as major an impact on incidence of newly-detected diabetes as had been expected.

#### **4.5.2 Methods**

The audit proforma was developed in discussion with the PCT facilitators to ensure that the data collection would be feasible. The audit proforma collected information on age, sex, ethnicity, where testing was done, whether screening or investigation of symptoms, what blood results were at diagnosis and what treatment was given. Individual PCTs adapted the audit tool to suit local needs, for example collecting more detailed prescribing data where this was of local interest. The data collection form is attached as Appendix F. Descriptive statistics were generated for the whole dataset. Further analyses examined the characteristics of new cases by year of diagnosis to identify any secular trends in diagnostic patterns and examined whether the cases detected by the DHDS programme were significantly different from the cases detected by other means. We were particularly interested in whether there was any evidence that the systematic screening programme resulted in cases being detected earlier. Three characteristics were examined as possible proxies for earlier diagnosis: younger age at diagnosis, lower blood glucose results at diagnosis and a shorter time from diagnosis to first prescription of oral hypoglycaemic agents or insulin. These characteristics were compared to test the hypothesis that DHDS cases were diagnosed earlier than cases identified opportunistically or by other means.

#### **4.5.3 Results**

The audit was undertaken in a total of 21 practices in all eight PCTs. Data were collected in 18 pilot practices and in one PCT data were also collected from three comparator practices. Information was collected on 2051 cases of diabetes. Of these 60 were excluded because the year of diagnosis was not recorded (n=54) or prior to 2000 (n=6). Five cases were assumed to be cases of type 1 diabetes (aged under 25 and/or started on insulin at diagnosis) and excluded. These analyses are based on 1986 new cases of type 2 diabetes that were diagnosed between 2000 and 2005 and retrospectively identified from practice records. Since there were high levels of missing data for some variables, the analyses presented are limited to those variables for which relatively complete data are available. The comparison with DHDS cases is limited to a subgroup of cases aged over 40 at diagnosis since in most practices systematic screening was only offered to patients over 40.

Overall 989 out of 1927 with sex recorded (51%) were male. Recorded ethnicity was: 783/1266 (62%) White, 69 (6%) Black, 112 (9%) Indian, 211 (17%) Pakistani and 91 (7%) other ethnic groups. The mean age at diagnosis was 59.8 years (n=1954) and the mean recorded BMI 30.3 kg/m<sup>2</sup> (n=1869). 91% had at least one risk factor that might have been an indication for screening at the time of diagnosis: 1537 (77%) were recorded to be overweight (BMI greater than 25), 342

(17%) had CHD, 738 (37%) had hypertension, 48 (2%) had a history of gestational diabetes. Only 265 (13%) had symptoms recorded at the time of diagnosis. Most (1365, 77%) had been diagnosed in the GP practice, 76 (4%) in a CHD review clinic, 230 (13%) in a DHDS screening clinic and only 3 (0.2%) through pharmacy screening. 389 (22%) had been diagnosed in another recorded location, usually a hospital (either during admission or in outpatients or the emergency department).

A comparison of characteristics of cases diagnosed between 2000 and 2005 was undertaken to explore any secular trends in characteristics at diagnosis and is shown in Table 4.4. Nine practices (3 pilot from PCT 4, 3 comparison and 3 pilot from PCT 6) only completed the audit for 2003 to 2005 and these results (567 cases) are excluded from the analysis of secular trends.

**Table 4.4: Characteristics of new cases of diabetes by year of diagnosis**

	2000	2001	2002	2003	2004	2005	Total
	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)
	N=169	N=203	N=225	N=259	N=335	N=203	N=1394
Age at diagnosis	57.1 (13.0)	57.6 (13.6)	57.9 (15.0)	59.7 (14.3)	60.1 (13.5)	58.1 (14.1)	58.7 (14.0)
	N=156	N=197	N=217	N=253	N=323	N=193	N=1339
Recorded BMI	30.7 (6.6)	30.4 (5.3)	30.3 (6.7)	30.5 (6.1)	30.8 (6.2)	31.4 (7.3)	30.7 (6.4)
	N=72	N=90	N=95	N=90	N=107	N=65	N=519
<i>Test results at diagnosis</i>							
Random BG	12.4 (4.7)	12.7 (5.2)	11.9 (5.9)	12.5 (5.7)	12.6 (5.6)	13.0 (5.4)	12.5 (5.4)
	N=35	N=44	N=54	N=88	N=151	N=99	N=471
Fasting BG	9.2 (2.9)	10.5 (4.1)	9.7 (3.6)	10.4 (3.6)	8.7 (3.2)	10.3 (4.2)	9.7 (3.9)
	N=67	N=75	N=85	N=126	N=139	N=130	N=622
% symptoms (of those with a record)	18	21	27	21	23	27	23
	N=133	N=172	N=203	N=233	N=316	N=204	N=1261
% diagnosed in primary care	88	89	89	91	92	93	91

A direct comparison of cases diagnosed through DHDS and all other cases is shown in Table 4.5. The cases diagnosed through screening had a higher mean BMI. Although this difference does not reach statistical significance, it may well be a real difference since most practices did not invite patients for DHDS screening if their BMI was less than 25 and excluding cases with a BMI under 25 from the analysis abolishes the observed difference.

A comparison of cases identified as diagnosed through the DHDS pilots and matched controls (cases diagnosed in the same practice in the same year) was also undertaken, to control for local factors and any local secular trends but this showed no significant differences and so the overall comparison is shown below.

**Table 4.5 : Comparison of new cases by method of diagnosis (DHDS or other)**

	<b>DHDS cases</b>	<b>Non-DHDS cases</b>	
	Mean (sd)	Mean (sd)	t-test
	N = 223	N = 1527	
Age at diagnosis	60.2 (4.6)	60.8 (5.7)	p = 0.1
	N= 217	N= 1433	
Recorded BMI	30.8 (5.6)	30.0 (6.1)	p = 0.07
Recorded BMI (>25 only)	N = 197 31.6 (5.2)	N= 1162 31.7 (5.4)	p = 0.7
<i>Test results at diagnosis</i>	N= 107	N= 711	
Random BG	12.0 (3.0)	12.0 (3.7)	p = 1
	N= 117	N=443	
Fasting BG	9.0 (11.5)	9.6 (12.0)	p = 0.5
<i>Months between diagnosis and first prescription (patients diagnosed in 2004 only)</i>	N= 56	N=220	
Oral hypoglycaemic agents	2.6 (4.8)	3.5 (5.6)	p = 0.3
	N=1	N=10	
Insulin	6.3	4.4 (5.2)	p = 0.7
	N= 154	N= 854	
Any symptoms (of those with a record of symptoms or no symptoms)	31 (20)	181 (21)	Chi <sup>2</sup> test p = 0.8

#### 4.5.4 Discussion

This audit provides circumstantial evidence for a high level of ad-hoc screening activity in primary and secondary care. Although it is difficult from a retrospective review of clinical notes to be certain whether an individual had symptoms at the time of testing, the overall results suggest that more individuals are tested because of the presence of risk factors than are tested because of the presence of symptoms. It also highlights that there is a continuum of activity from having a relatively low threshold for diagnostic testing to ad-hoc testing of people with risk factors to systematic screening and that in fact most new cases (91%) are diagnosed in people with pre-existing risk factors.

Since the data have been collected retrospectively from patient notes, the data set represents an incomplete cohort of all cases diagnosed between 2000 and 2005. Some will have left the practice since diagnosis or died and therefore excluded and in two PCTs data were not collected for cases diagnosed before 2003. However it seems unlikely that the characteristics of these individuals at diagnosis would be so different from those still alive and registered with the practices to make these patients unrepresentative of most recently diagnosed patients. Another issue will be that, retrospective data collection inevitably means that the dataset will be incomplete and there was significant missing data in some fields so the validity of findings is limited by the assumption that cases for which information was available are representative of all cases.

This analysis offers no support for the hypothesis that there have been significant changes in the characteristics of newly diagnosed cases in the past six years or that cases detected through the DHDS programme were significantly different from patients diagnosed in other ways.

## **Section 5: Findings from the case study interviews and focus groups**

### **5.1 Introduction**

The overall aim of the qualitative element of the evaluation was to gain an in-depth understanding of the issues that influenced both the feasibility and impact of screening in the pilot practices. The baseline data from practices highlighted the potential to explore the reasons behind the diversity in approaches to recruitment, screening and diagnostic testing in the pilot practices. The case studies consisted of qualitative semi-structured interviews with a range of staff and patients involved in the pilot screening for diabetes. This enabled in-depth study of complex phenomena and captured the day to day experiences of benefits and difficulties of carrying out screening in general practice.

While there is a relatively large literature on patient attitudes and experience of cancer screening, few studies have examined patient views towards being screened for diabetes, which may be perceived by both patients and professionals to be a less serious or less life-threatening condition. Relatively small qualitative studies have explored staff attitudes to screening (Whitford et al, 2003). Most of the research addressing individual responses to screening has used psychological survey instruments to assess screening related anxieties (Adriaanse et al, 2002; Adriaanse et al 2003; Adriaanse et al 2006; Farmer et al, 2003) or quality of life measurement (Edelman et al, 2002). Studies that have examined the impact of a diagnosis of diabetes identify a range of issues that may arise in a screened population if tests are positive (Beeney, 1996; Peel et al 2004).

In our case studies, major themes were identified relating to the different stages in the process of identifying eligible patients, inviting them to be screened, delivering screening and subsequent follow up. The findings from the staff and facilitator interviews, patient interviews and focus groups were initially analysed separately. Having identified many common themes emerging across this range of informants, the results have been integrated and summarised in this section.

### **5.2 Methods**

The qualitative element of the evaluation used semi-structured interviews to explore the perceptions of practice teams, patients and PCT facilitators in five pilot practices. We selected case study sites on the basis of geographical location, size of urban centre, and the proportion of people of minority ethnic origin, as well as the diversity of the minority ethnic population, so that the cases would represent as wide a range of characteristics as possible. We also took into account the methods of programme implementation, and the size of the practice.

*Staff interviews:* Interviews in each case study area were carried out with the facilitator, the practice nurse with responsibility for diabetes (PN), the GP with responsibility for diabetes, the team member who carried out the screening with patients, the practice manager (PM) and, in some cases, the GP lead for diabetes with the PCT. In case study practices the screening was carried out by a health care assistant (HCA) or a PCT-employed practice nurse (PN).

*Staff focus groups:* In order to gain the maximum benefit from the experiences of staff involved in setting up, implementing and carrying out screening in all the pilot practices focus groups were held at the Wrap-up Conference for the project in February 2006. These groups were facilitated by members of the research team and a project facilitator who had attended advisory group meetings. Groups consisted of staff of similar occupations, as groups are likely to talk more freely within professional peer groups and it would be easier for them to compare experiences with colleagues who had a similar role in the pilots (Krueger 1994). All PCT facilitators were interviewed during the pilot implementation and were not included in the focus groups.

*Patient interviews:* The majority of patients in four of the five practices were from minority ethnic groups, mainly South Asian (Indian and Pakistani), but including some from the Middle East. Patients screened were selected on the basis of their test result (negative, false positive, and true positive ie those patients newly diagnosed at screening as having diabetes). Patients who had not attended for screening, or who had screened positive but had not attended for the diagnostic test,

were seen as an important group to interview so that their reasons for non-attendance could be explored. By the very nature of non-attendance, access to these patients was more difficult and the uptake of an invitation to take part in an interview was lower.

Potential interviewees (according to screening status) were identified by practice staff, and sent a letter offering a £10 voucher as compensation for taking the time to talk to the researcher. Patients who contacted the researcher provided contact information on the enclosed reply slip. They were then contacted by the researcher and arrangements made for an interview, usually in the patient's own home. Because language and culture are key to understanding perceptions, additional interviews with Gujarati patients in two of the case study practices were conducted by a Gujarati speaking interviewer. All interviews were audiotaped and transcribed for analysis using the framework method which is regarded as the appropriate approach for applied policy research (Silverman, 2001; Ritchie & Spencer, 2002). The topic guides, developed after discussion with the DHDS team and facilitators and subsequently piloted, are included as Appendices.

### 5.3 Results

Overall a total of 23 staff were interviewed, ranging between four and five in individual case studies. All eight PCT facilitators were also interviewed. The facilitators were responsible for supporting the screening pilots in the participating practices and, although their level of day-to-day involvement varied, they all had an overview of how the pilots had operated in the different practices within their PCT and had been involved in addressing the problems and barriers to successful implementation as they arose. Most, but not all, of the facilitators had clinical backgrounds (nursing or medicine). Seven focus groups were undertaken with GPs, practice nurses, health care assistants and administrative staff. The focus groups were held at the DHDS "Wrap-up Conference" so participants could contribute from the perspective of their experience of seeing how the project had developed over the life of DHDS. Each group consisted of between six and nine people of, as far as possible, similar roles although there was some overlap in order to be able to accommodate all participants. There were two groups of health care assistants, (Gp 1, Gp 2), two groups of practice nurses (Gp 3, Gp 7), two groups of GPs, (Gp 5, Gp 6), and one of practice managers (Gp 4).

A total of 45 patients were interviewed. All non-white patients were South Asian except for one Afro-Caribbean and one Algerian patient (both female). Tables 5.1, 5.2 and 5.3 give the profiles of the case study practices, staff and patients who were interviewed.

**Table 5.1 : Characteristics of case study practices**

Case study	GPs (fte)	Estimated ethnicity of patients:			Screened population identified by	Invitation method
		White(%)	Asian(%)	other(%)		
1	1	50	35	15	age only	opportunistic+letter
2	10	<1	98	<1	age+BMI+family history	opportunistic+letter poster/leaflets
3	2.5	50	2	48	age+BMI	opportunistic+letter
4	3.5	1	98	1	age	opportunistic+letter+grapevine
5	3	98	2	0	age+BMI+no test in previous 2 yrs	opportunistic+letter+telephone+leaflet/poster

**Table 5.2 : Number and roles of staff interviewed for case studies**

Case study	GPs	Practice nurse	Practice manager	Health care assistant	Administrator/IT	Total
1	1	1	1	1	-	4
2	2	1	1	1	-	5
3	1	2	1	-	1	5
4	1	1	1	1	-	4
5	2	1	1	1	-	5
Total	7	6	5	4	1	23

**Table 5.3 : Number and characteristics of patients interviewed for case studies**

	Non-attenders	screen -ve	screen +ve dna diagnostic	screen +ve diagnosed normal	diagnosed IFG/IGT	diagnosed diabetes	Total
white male	2	2	1	1	3	3	12
white female	-	3	1	3	1	3	11
non-white male	6	2	1	1	-	2	12
non-white female	3	1	1	1	2	2	10
Total	11	8	4	6	6	10	45

### 5.3.1 Staff and facilitator results (interviews and focus groups)

Main themes were identified from the interviews as:

- identification of eligible patients
- the relative success of a range of invitation methods
- the importance of appropriate IT systems
- response rates to the invitation
- perceptions of screening
- organisational issues
- health care assistants
- pilot specific issues
- outcomes of screening pilots
- ethnic minority issues
- ethical issues
- staff perceptions of patient views

#### Identification of eligible patients

Several practices used age as the only criterion to identify the eligible population initially because BMI was not usually recorded, so often patients were invited and then excluded if their BMI fell below the 25 cut off point. One practice recorded BMI as new patients registered. Focus groups explained that occasionally a patient recorded a high blood sugar level when their BMI was low, and they might then be put in as a DHDS screening after the event. Facilitators reported that practices had found it useful to identify non-eligible patients by trawling the blood sugar levels taken in the previous two years, at hospital as well as the practice, and excluding these patients.

The case study practices evolved different ways of extracting the eligible population from their records. Some called in patients in alphabetical order, others started with the oldest patients.

### **Importance of IT**

There was general agreement that staff with IT expertise were needed to carry out searches and send out letters. The overall view was that it was better for one person to take responsibility for calling in and following up patients to ensure the record was accurately maintained. Computerised practices found it easy to identify eligible patients by excluding, for example, those with a random blood glucose or an OGTT in the previous two years, and patients on the CHD register, and emphasized the importance of entering data in a systematic way

*we used the same read codes and coding for everybody.. phlebotomists use the same codes so we didn't have a problem (Focus group 2)*

. The importance of good IT systems was recognised as a major requirement for identifying a particular group of patients. A sound system was considered to be essential and practices where the database was found not to be searchable experienced difficulties which appeared to be a function of poor IT facilities

*I'd definitely get more IT support more than anything else because that is the most useful. The searches, keeping the systems right, making sure the data goes on. The read codes weren't on, weren't developed at the beginning.. one thing, it's not an exact science, any of it (Facilitator 7)*

Some practices which had experienced problems changed the way they coded blood sugars as a result of DHDS. While some practices were able to identify and follow up patients who did not attend for the diagnostic test, for others this was seen as too difficult or too labour intensive to be feasible

*..we had 4 or 5 different things to look for.. had to try and exclude those or find out what their results were. It was just a nightmare and we ended up trawling through some of them physically instead of going through computer records (Focus group 2)*

*I don't know if it was our system but we had quite a job with the exclusions.. suddenly realized we had about four different codes for blood sugars (Focus group 4)*

The facilitators tended to see implementing the pilots as part of a learning process.

### **Methods of invitation**

Case study practices used a range of ways to invite patients for screening. Common practices included sending letters of invitation personally addressed to eligible patients; asking patients opportunistically when they attended the practice for another reason; and calling patients by phone. In addition, some practices explained the pilot screening on their electronic messaging system in the waiting room, displayed posters in the waiting room, or announced the start of the pilots in the local newspaper. There was no consensus across case studies as to which method generated the greatest response.

Facilitators described how patients who were not expected to attend or people believed to be at work who might be unable to attend were telephoned rather than sent an appointment in the post. Smaller practices tended to know their population better so used invitation methods which the staff saw as appropriate to individuals, especially telephone calls. Some facilitators were unsure of actual invitation processes, and based their information on *'from what I've been led to believe'*. (Facilitator 1)

One case where the patient's BMI was less than 25 meant a finger prick test was not administered. He was diagnosed two months later with intermittent claudication and seen in the CHD clinic by a nurse who carried out a routine random glucose test and found his blood sugar to be high. The patient was consequently diagnosed as being diabetic. This was reported as a cautionary tale of a patient who had been seen for DHDS but did not meet the criteria and so was not invited for a glucometer test.

## Letters

Letters were sent out in batches of various numbers, with some practices trying to regulate the flow so that they would receive a manageable number of patients for the designated staff to screen within a reasonable time scale. Sending out 500 letters at a time was perceived to be unmanageable in terms of receptionists taking telephone enquiries for appointments as well as staff to carry out screening, especially where it was only available to patients on one day each week. Letters generally asked patients to make an appointment as it was found that giving patients a set time to attend for screening often resulted in clinic time being wasted when patients did not attend.

Several staff perceived letters to be the most successful method for inviting patients and experienced very good take up, one employing two extra staff to send 4500 letters.

*we tried to sell it in our letters 'We're one of only 27 practices in the country to be able to offer this screening'.. we're a small practice, about 2500 patients and we only used letters and it worked a treat.. being small you kind of rely on the patients knowing if the doctor calls them in, they know to come in and they did.. (Focus group 2)*

A letter seen as successful because it yielded a good return consisted of an appointment box (or offered an alternative if the patient contacted the practice) in the middle of the page saying when the appointment was

*which is quite good because it focuses the eye on what you're actually wanting the patient to read. (Facilitator 2)*

One practice sent two letters, one giving an appointment with date and time, and the other giving information about screening. This was seen to overcome the problem of patients being put off by having to read a dense letter, while providing the essential information about attending the practice. Letters from a GP were seen as more successful and

*had quite a positive effect in that it was signed by a doctor and they felt like it was a personal invite; [but there are] those who don't want to come no matter how hard you try.. (Focus group 6)*

Others described letters as an expensive way of inviting patients because of the cost of stamps, stationery, and the staff time required, compounded by the number of letters returned undelivered. Many ghost patients were identified as a result of trying to make contact by letter. Letters were seen by many staff in the study to be unsuccessful because they were often poorly understood, or misunderstood, by patients. The difference in literacy levels of the eligible patients meant that some practices found a letter successful while others did not. Several facilitators thought the letter from the NSC was too long and too complex, and so "*dumbed it down*". All facilitators agreed that the letter needs to be very simple and had adapted it.

*I think my experience in other things is that people find it very confusing and too much information means they just screw it up and bin it and think 'Oh, I can't get my head around that' (Facilitator 4)*

*our letter was complicated - I don't want to read that never mind some of the patients - and boring about the Department of Health.. people who are not very well educated they just put it in the bin (Focus group 2)*

Practices in areas of high deprivation, or with a large non-English ethnic population, tended to find that letters were not properly understood, and personal contact was helpful so that staff could explain the pilot screening to patients in the appropriate language. Facilitators considered that the population at large do not want much information, but simply want to know

*'Am I at risk? Have I got the disease? And what can I do about it?'* they don't want lots of words (Facilitator 4)

Others had experiences of patients who were unable to read the letter

*they get the letter and they don't know what it is and they throw it away* (Focus group 7)

*I think half the time they don't understand whatever is written on the paper because they don't recognise that "my appointment was on the 20<sup>th</sup>", they turn up today when they get the letter. Their education is not.. I think they didn't just read it, or didn't get their daughter to read it...* (PN 1)

Some practices included a slip and stamped addressed envelope in the letter to be returned if people were not going for screening giving reasons why but few were returned. Letters sent out shortly prior to Christmas had a very poor response. Some staff had found that although older patients had not always understood the letter they still came in

*because they thought they were going to get something basically* (Focus group 3)

Staff felt some patients had been deterred by letters which described DHDS as a 2 year pilot as some patients thought they would have to attend the practice over a 2 year period. The format of the letter was seen to be crucial

*It depends on what the letter says [it must be] brief and to the point* (Focus group 2)

It was suggested that making explicit what would happen at the screening appointment could improve uptake, especially when patients were worried about undressing. It might be helpful to explain in a letter that

*'You will not need to undress' or 'will not be examined'* (Facilitator 5)

#### *Telephone calls*

Smaller practices often recruited patients by telephone because they produced a better response than letters. However this was not the case where the patients were not well known to the practice, where there was a high population turnover, or where mobile telephones were common and numbers changed frequently. Patients could be unwilling to provide the practice with a number for a mobile phone. It became apparent that a substantial proportion of younger patients did not have a landline. Large practices found it impossible to phone all the eligible patients and relied on letters.

One facilitator and her practice staff expected that at least 20% of their population would be illiterate which indicated phone calls rather than contact by letter, except where phone numbers were inaccurate. Incorrect phone numbers and a lack of spoken English gave variable success with telephone contact. The usefulness of telephoning was thus dependent on the transience and characteristics of the population

*trouble with telephone calls is most of our patients have got mobile phones.. issues about confidentiality if they change phones and you ring them and it's somebody else on the phone* (Focus group 4)

Staff in some practices found that telephone calls useful as a follow up to a letter and, especially, for reminding patients the day before to attend for their screening appointment. Telephone calls were generally described as successful where the patient population was fairly stable and staff knew most patients by name. One practice found it effective to telephone patients because they could explain in the amount of detail the patient wanted about the pilot or, by their response, realized that a patient was unlikely to attend.

#### *Opportunistic invitations*

Opportunistic invitations were seen by many staff to be highly successful and uptake increased if the facilities were available to screen patients at the time of the invitation. General agreement that opportunistic screening is successful was based on the experience that no patient had declined to be screened when they had been approached face to face by a member of the practice staff. By its nature however this type of invitation was only possible with patients who attended the practice for another reason. Efforts were made to ensure that staff with patient contact, from receptionists to GPs, were aware of which patients were eligible for diabetes screening. This was often flagged on the patient's notes, so that any member of staff calling up the record would be able to see immediately who should be offered a screening test. Some practices 'screen-messaged' GPs to remind them about inviting eligible patients. All staff who discussed this topic agreed that patients were most likely to attend for screening if asked by their GP

*..patients tend to have a higher appreciation of the seniority of the doctor. My feeling is that those patients that come in opportunistically, "so you fit into this age group, and you ought to have this test done", are probably the ones that are more likely to attend (GP 1)*

*I think the recruiting really needs to be done opportunistically and I think everybody needs to do it, it's just the awareness that we need to have within the practice that all over 40's need to be screened and book them for the DHDS screening. The next bit of recruitment is really by opening the letter and I think that's probably the next most effective way of doing it. There's gotta be those two approaches (GP 2)*

*managed to see half the patients but it would have been better if the doctors had invited them (Focus group1)*

Receptionists were successful in inviting patients. However, while some practices updated their lists as patients attended, others found difficulty in keeping receptionists up to date with which patients had been screened. Opportunistic invitations were described as not possible for practices with large lists, which led to some people being screened who did not meet the criteria because

*once they've made the appointment you can't turn round and say 'No, you can't have this done' can you? People are very keen to come and have a check (Focus group 4)*

Staff from several case study practices explained that new patients registering who fell within the inclusion criteria would be opportunistically asked by a HCA to attend for screening, after explaining about the pilot. The influenza vaccination clinic in one practice was highly successful for recruiting patients when screening was carried out at the same visit. Patients attending hypertension or smear clinics were also often invited opportunistically. Some staff however expressed concern that patients invited and screened opportunistically might not always have been recorded as having been screened. It was generally perceived that a combination of activity was most effective but in some areas people were seen to have chaotic lifestyles and staff felt there was no benefit in sending appointments because patients were unlikely come. This population was most easily invited opportunistically

*and they've done very well.. managed to catch I think about 55 to 60% of their people, have done very well doing what's right for their population (Facilitator 6)*

#### *Other*

One practice had used a patient satisfaction form to aid recruitment which also helped with quality points for the practice.

*Each doctor needs to have something like 80% questionnaires returned so it generates a lot of paperwork but it's been a good recruitment method (Facilitator 8)*

Some staff would try to minimise the intervention for frail patients and

*tick the extra box on the lab form for the patient to be screened in that way.. if you've got a frail person who you don't want to pull back for an extra appointment (Facilitator 2)*

One method seen to generate a good response was to print the invitation on repeat prescriptions, and to offer a general health check which was provided even if the patient was not eligible for DHDS. It was however generally recognized that no single strategy would be appropriate for all patients.

#### *Key points*

- letters were generally not understood by patients and perceived as too long or complicated
- letters were costly in terms of both money and staff time.
- some letters were returned as the patient was no longer at the recorded address
- many patients were unwilling to provide a telephone number, especially for a mobile phone
- contacting patients by phone to remind them of an appointment was seen as useful
- opportunistic invitation was popular because of the perceived high success rate with patients already attending the practice for an unrelated reason
- some staff had concerns that records were not always updated when patients had been invited and screened opportunistically
- adapting the method of invitation to the type of patient population generated most attendances

#### **Response rates and reasons for non-attendance**

GPs and practice nurses who had previous experience of offering interventions to patients said, in general, that the uptake of diabetes screening had been better than they would have expected. It was suggested that the high profile of diabetes in the media had prompted patients to attend. Invitations which were sent directly from their own practice, rather than from a third party, and which were not presented as invitations to participate in research, were also seen to increase uptake.

Screening was available at some practices from Monday to Friday, and up to 6 pm on some evenings. However, no practice offered screening after 6 pm or on a Saturday. One practice offered only Mondays, while some were restricted to either mornings only or afternoons only on two or three specified days weekly. Staff believed that this may have prevented patients in full time employment from attending for screening. Staff in one practice were surprised that patients aged 40 to 50 came during the working day. Their explanation was that screening was being sold to patients as a check up which included heart disease and stroke screening, as indicated on the early letters. It was felt that patients were keen to be screened because of anxiety about heart disease, and uptake would have been lower if they had known that it was for diabetes only.

Screening regardless of eligibility was described as easier than sending patients away disappointed. It was perceived that, overall, patients were more concerned about heart disease than diabetes and very few failed to attend the CHD clinic. Men were seen as less likely than women to attend.

*it's men.. they are the hard ones to get through the door for appointments especially when you're getting down to the 40 to 50 age group.. people of working age (Facilitator 2)*

*men are not so easy to capture because they are not being invited for anything routinely, and possibly tend to be less likely to go and seek advice (Facilitator 3)*

Many people in work were likely to find the times when screening was offered did not fit with their work commitments, especially as this was limited in some practices to one half day per week.

*I think if you're working you're not going to take time off work just for a check up.. if you were poorly you might do it (Focus group 2)*

The group who were seen to worry most about becoming ill were those whose employment involved driving because it could affect their insurance

*And if they are bus drivers or lorry drivers or something like that they just may not want to know* (Facilitator 3)

Checking cholesterol at the same time proved a useful incentive, and was expected by many patients because of the pilot title. Offering a cholesterol test with a fasting blood sugar was effective at encouraging patients to attend for a diagnostic test

*they didn't have to go to the hospital it was all done at the surgery, it was quite good.* (Focus group 4)

A number of patients in all practices never attended any appointments, not just DHDS. It was suggested that providing information on the full cost of their treatment to patients would encourage them to appreciate the importance of keeping appointments.

Patients with a positive result did not always attend for a diagnostic test, and in some practices when a patient had a reading higher than ten but could not attend for an OGTT they were offered two random or two fasting tests as an alternative. It was felt that the inconvenience of waiting for the OGTT test to be completed may have deterred some patients from attending for a diagnostic test after having a positive screening result. At one practice ten patients at a time had to wait for two hours for the OGTT, and the practice nurse felt it would have been more acceptable if some distraction, such as television, were provided. Group members described patients being

*excited about the finger prick test but if I said they had to come for an OGTT test most of them told me they wouldn't come..* (Focus group 2)

despite its importance being explained to them. Staff said it was easier if phlebotomy was available at the practice, although several patients were also deterred because of the long wait.

*they say 'Oh we'll do it another time.' The nearest place, you have to queue for about an hour in the waiting room to get seen [at blood clinic]* (Focus group 2)

#### *Patient characteristics*

Some of the staff who were interviewed identified no difference in response rate in relation to age, gender, or ethnicity. Others, however, perceived retired people, women, and middle class patients as most likely to attend for screening. Staff described the 'worried well' who already attended the practice regularly for clinics and check ups as presenting for screening. They were pleased to have an extra health check but, staff felt, as they were already health conscious, these patients were unlikely to be at greatest risk of diabetes.

*Some patients attend for everything and are regularly at the practice for health checks* (PN 2)

Patients who regularly visited the practice and attended whenever anything was offered were contrasted with another group who did not visit the practice for several years.

*some are here for any kind of screening, but they tend to be the ones who are already coming for something else, they come for everything and anything. But we have an awful lot of people who'll not come for cervical screening, breast screening, blood pressure management. They'll not attend no matter what we do, the working class culture; others experience chaotic lifestyles..* (PN 3)

Facilitators mentioned patients who have needle phobia and so do not return to have venous blood taken. People with chaotic lifestyles were likely to have other priorities for their time

*and I suspect that screening for diabetes is quite low down on their list..* (Facilitator 5)

By the nature of those who did not attend, it was not possible to ask them why, but patients from areas of greatest deprivation, and those in work, were seen as groups who were less likely than retired people to attend for screening.

Housebound patients and people in residential care were unlikely to attend, although some practices had arranged for a member of their team to screen patients who were housebound or in care homes. None of the practices had, at the time of the interviews, screened patients in residential care. Some staff found an appreciation of the constraints on the practice led to increased uptake of the services offered.

*I was most impressed with the.. not the voluntary uptake, but the people that came up and said, yeah I want to be part of that, instead of us asking. (HCA 1)*

#### *Key points*

- a lack of availability during evenings and weekends was seen as limiting uptake especially for patients in employment
- practices were not always able to follow up patients with positive screening tests to encourage them to attend for diagnostic testing
- retired people, women, and the 'worried well' were most likely to attend for screening
- patients from deprived areas were least likely to attend for screening

### **Perceptions of screening**

#### *Implications of screening*

Some staff could be confused about the implications of screening. All HCAs were keen on the benefits of screening and tended to the view that discovering a patient with diabetes in the pre-symptomatic stage would prevent further problems. HCAs suggested that changes to diet and increased exercise would have a major effect on future health, and impede the advance of diabetes, so that complications were unlikely to develop.

Patient understanding of the implications of screening was more limited, and many were reported to believe that a negative screening result gave them an "all clear" so they could maintain their current lifestyle without any adverse effects. This is a potentially important example of "false reassurance".

#### *Screening-identified IGT/IFG*

Staff saw the care of patients with impaired glucose tolerance (IGT) as a shared responsibility between the patient and the healthcare professionals. Patients with impaired fasting glucose (IFG) in one practice were informed that they needed an annual oral glucose tolerance test, and were advised to contact the practice to arrange for the test. This contrasts with GP attitudes to IGT as reported by Wylie et al (2002). Lifestyle advice was provided, and if they were thought to be at high risk patients were given the appropriate dietary advice but

*it wouldn't be hugely different from what we would be advising anybody else (GP 4)*

At another practice impaired glucose tolerance was treated because

*..usually it precedes diabetes anyway. The way the GP manages it is that they all come to the diabetic clinic. We check the impaired glucose annually, then we go through lifestyle and diet because most, I would say the vast majority of them, within a couple of years, do turn into diabetics. (PN 1)*

#### *Alternatives to general practice diabetes screening*

GPs believed that any patients at risk of diabetes would be tested for blood sugar level as part of their ongoing care, especially if they were already being seen in, for example, a cardiovascular clinic

*..symptoms, screening when patients come in for other problems, so there are other ways that the diabetics have been identified other than the DHDS. (GP 5).*

Additionally, the provision of diabetic screening by local retail outlets such as Lloyds pharmacies was mentioned.

## **Organisational issues**

GPs did not see screening separately for diabetes as a viable option. The time taken to invite patients, make an appointment, and carry out the screening would, they suggested, be much more efficiently organised as part of a general health check, where one patient visit would enable a range of checks to be made. Diabetes screening was, however, seen to be important and to embody major benefits for patients. It was described as ideally being a part of the health checks carried out at clinics for CHD and hypertension. There was a view that screening was most efficiently carried out by the practice executing the brief and maintaining control to suit the individual practice.

### *Staff and roles*

The screening pilots were set up variously by the facilitator, the practice manager and the lead GP for diabetes in the PCT in each practice. They would then delegate tasks involved in DHDS. The practice manager was often responsible for identifying eligible patients by computer search initially, before passing on this task to an administration clerk. Usually a HCA would carry out the screening, fill in the template, and provide health advice, although sometimes a practice nurse was brought in from the PCT. Screening was generally carried out more quickly and more systematically where staff were taken on specifically to carry out DHDS screening

*we've actually recruited our healthcare assistants specifically because of DHDS because we were very keen to get on board with it, so we recruited two healthcare assistants and had them trained in phlebotomy.. (PM 1)*

Generally it was found to be more efficient for a dedicated administrator to identify and invite patients while a health care assistant carried out the screening. The clerk and the HCA comprised a complementary team in one practice, working well together while each became more expert and therefore faster at carrying out their own tasks.

*it is much better.. if I'd realised how much more useful I would have done that earlier, splitting it into two [admin and screening] (Facilitator 1)*

*I've worked a lot with health care assistants and it depends on your health care assistant. So we made the job spec, you know, reasonable, exactly what we wanted, and we knew we should get the right candidate (PN 1)*

One of the study practices had not wanted administrative support at the outset, expecting to be able to rely on opportunistic invitations and phone calls. However, ongoing updating of records required dedicated administration input. All staff who expressed an opinion thought it unnecessary for a qualified nurse to carry out the screening and health promotion with patients. One practice nurse explained the difficulty of working in general practice, where they bore sole responsibility for many tasks, compared with working in a hospital with other staff, where any unfinished task would be completed by another staff member

*but here you're on your own, we've got our paperwork to do, we've got our patients to see, set clinics, time seems to be going so quick. (PN 4)*

The importance of communication within the primary care team was stressed, so that everyone who worked in the practice was aware of a project

*all staff like to be aware, they don't like it if they don't know, they don't like to feel silly when people ring up and say 'I've had this letter, what's it all about?' if they don't know (Facilitator 8)*

However, attempts to include all staff were not always successful

*we've tried to include [GP] in a lot of the discussions but he doesn't seem to understand the mechanics of the project. If the GPs would remind patients of the importance of coming for the screening that might help to get the non-responders (Facilitator 7)*

A lack of IT knowledge in the person executing the pilot was seen as major problem and several staff emphasized the importance of read codes for searches to trace patient outcomes. Staff found it was easier to keep track of patients who had a diagnostic test at the practice rather than those who went to the hospital. Organising appointments in such a way that efficiency was maximised was recognized, sometimes belatedly, as important

*We ran clinics three times a week and there were some days when absolutely nobody turned up at all (Focus group 4)*

GPs explained how enthusiasm was created from the top

*the more interest you develop, give them support, the more keen they are to do the job.. it's team work and encouraging people to get involved (Focus group 5)*

Greater cooperation between practices was seen by some staff as a missed opportunity when practices could have worked together and shared templates and health care assistants  
[but] *everybody kept themselves to themselves (Focus group 3)*

### **Health care assistants**

HCA's were seen by practice managers and most facilitators as the most appropriate level of staff to carry out screening although in some practices their role was restricted to the glucometer test while in others they would provide lifestyle advice. By the time of the focus groups GPs also felt that HCA's were the appropriate level of staff to carry out screening. Using an HCA released a practice nurse to carry out tasks more appropriate to her training, which in turn released a GP to carry out higher order duties. All staff in one practice attended the facilitator meetings which was seen to aid the personal development of the HCA. However, HCA's were not immediately seen by everyone to be appropriate to screen patients

*they were quite reluctant to have their health care assistant.. sort of encroaching on their space.. practice nurses wanted to do the education side of it because didn't think [health care assistant] would be qualified enough (Focus group 2)*

Facilitators or a practice nurse would usually arrange for training to enable a HCA to carry out screening and health promotion, but in one practice

*I just got thrown into it and I didn't know anything about diabetes.. I don't know what I'll be doing, I'm frightened to death (Focus group 2)*

Generally the lead GP made the decision to employ HCA's (rather than D grade nurses favoured by the facilitator in one PCT). Some practices had arranged for HCA's to carry out OGTT which was seen as likely to encourage patients to attend for a diagnostic test as they did not have to go to a hospital. HCA's were seen to take ownership of the project where they were given sole responsibility for DHDS screening. Their expanded role was seen to be appreciated by HCA's, some of whom did

*exactly the same as the practice nurse, she does the whole screening appointment, she doesn't do a bit and pass it on, she does everything, she has been trained (Facilitator 8)*

*We would definitely use a health care support worker to do it; health care assistant enjoyed it because she was doing something really special (Focus group 3)*

Staff unaccustomed to health promotion work enjoyed the patient contact

*Receptionists were interested in doing the work so we trained them as health care assistants (Focus group 4) who were kept on after DHDS finished. Staff dedicated to a particular task appeared to work well*

*it was a team effort, we all had our individual things to do (Focus group 2)*

Happily, the extended role of the HCA was seen as enhancing even though it consisted of tasks which had been tedious for the practice nurse. Initially in some practices the HCA was simply helping a practice nurse, but gradually took on the complete screening except in one practice where

*actually they found it was quicker for the nurse to just get on with it.. especially as we are doing very much a minimised version of it (Facilitator 6)*

Conversely

*the nurses weren't interested at all.. wanted the health care assistant to do it (Focus group 2)*

HCAs were not always seen to be capable of answering all patients' questions. One of the facilitators explained

*If I was sitting in then I might intervene. It's quite difficult to keep your lip buttoned in these cases.. I might say 'Why don't you talk to them about x, y and z?' afterwards.. (Facilitator 7)*

The facilitator in one PCT asked the psychologist to explain to the HCAs how to give advice to patients, including how to deliver the information

*if you can get the patient on board to do one little thing in small steps and get the relationship there then they see a difference, they'll trust you and then they'll move on to other things (Facilitator 1)*

The psychologist was also seen as an important resource in teaching HCAs how to deal with denial in a patient, such as "I'm not obese".

HCAs were seen by some staff as enhancing the primary care team and were seen to communicate well with patients

*if they're a little overweight or they don't take much exercise then the healthcare assistants have been quite good at encouraging them and giving leaflets where appropriate, so I think that's probably one positive side to it (Facilitator 4)*

*I think the patients relate sometimes better to the health care assistant (Focus group 3)*

HCAs overall were delighted with their perceived rise in responsibility and status

*I wanted to be able to answer any question they might ask. I loved the health promotion (Focus group 2)*

*our health care assistant did it all, really enjoyed it, found it quite empowering (Focus group 3)*

*we trained up four health care assistants to do the work and they really, really enjoyed it, got a lot of job satisfaction from it (Focus group 4)*

As the role developed with experience and a practice nurse was not available the HCA took on the sole running of the clinical side, which in turn generated respect from administrative peers and within the nursing team.

### Key points

- GPs regarded diabetes screening as carried out more efficiently as part of a wider health check at a single appointment
- practice managers and GPs were happy to delegate screening and health promotion to HCAs
- efficiency of dedicated staff carrying out a repetitious task increased over time

### DHDS Pilot specific issues

Most of the staff who were interviewed perceived the project name of “Diabetes Heart Disease and Stroke” pilot intervention to be misleading, since they had thought that the ‘heart disease and stroke’ element of the title would be included in screening. Several patients too had believed they would be screened for stroke and heart disease because of the project name. GPs generally believed that it would not be feasible for a programme similar to the DHDS pilot to be rolled out nationally as it did not represent the most cost effective method of screening for diabetes.

Initially HCAs and practice nurses required around 20 minutes, including inputting information onto the computer, to carry out the screening and health promotion with each patient. At the time of the interviews, staff who had been carrying out screening for several months were spending approximately seven minutes with each patient. They explained that the template was time consuming to complete, but their speed increased with familiarity of the format.

Groups felt it was good to be able to see something through from start to finish which successfully creates

*a feel good factor through the organisation (Focus group 6)*

There were suggestions that greater PCT awareness of the pilot could have maximized the use of the data, and also a view that standardized tests should have been specified. While many impaired glucose tolerance patients were identified in the course of the pilots staff were disappointed that these were incorporated into analysis only at the end of the project. Some staff felt they had less involvement than they would have liked

*the practice lost control.. and we're the ones that know the patients better (Focus group 3)*

Problems with keeping staff and lack of PCT interest were perceived as unhelpful

*they didn't buy into it, plus huge amounts of change of staff, you don't know who to ring.. (Focus group 4)*

The timing of the start of the pilot was described as problematic when practices were busy with vaccination clinics, or at the start of the Christmas, Easter, or summer holidays, or when they had a number of to targets to fulfil. Thus it seems there is no “good time” to start a new activity. Some staff felt the pilot had created a significant increase in workload for everyone, for example because of the number of blood test results that had to be put through the system, the number of diagnostics tests required, and the number of test results that the doctors had to act on.

*so it's an increased workload for everyone (GP 4)*

Some GPs were concerned that patients would be diagnosed for whom there would be insufficient treatment resources.

*there's no point in screening if you're then not doing anything about it.. it goes hand in hand, if you go into screening we need the extra resources to deliver the care to those patients. (GP 6)*

The facilitators described how practice managers found it difficult to implement the pilots when the service specification was changed frequently by the NSC Core team. Administration became a major part of the pilots as time had to be given to attending meetings, answering emails, phoning the facilitator, and sending invoices. Although what was expected had been agreed at the start of screening there was confusion about how it would work in practice. The facilitators felt that some practices felt less inclined to take part when they initially saw no clear aim. One facilitator described how she

*felt embarrassed to go into the practices with forever changing goal posts and being asked to fill in a 5 page questionnaire which wasn't what we were being sold in the beginning and therefore wasn't what I sold them when they had signed up (Facilitator 5)*

Facilitators felt that the practices and the DHDS project team had underestimated the amount of work involved

*finding them, sending the letters, contacting them, chasing up results, phoning up, sending out second letters, sending out letters because they haven't been for their blood test, as well doing the audit initially and anonymising, which meant going through tippexing and writing on a number, writing that in a book.. very tedious and labour intensive (Facilitator 3)*

Timing was seen by some staff to play a part in the number of positive screening results

*I did the after-lunch lot, so a lot of highs (Focus group 4)*

It was therefore felt that information about the importance of not eating an hour prior to the test should have been given to patients, but the practices had been asked not do this 'because it was a study.'

*Choice of screening criteria*

GPs tended to view the age criterion of 40 years and over as inequitable where there was a large South Asian population. At the same time, they saw ethical difficulties with attempting to introduce different criteria for certain types of patient. It was considered by one GP that

*..from my reading of the literature probably about 25 or 30 would be a more appropriate cut off. Probably an Asian of 25 to 30s would.. have a similar risk as a Caucasian of 40.. (GP 4)*

Patients with a BMI below 25 were often screened, especially when they had a family history of diabetes, but excluded from the numbers counted for the purposes of the DHDS pilot.

*You can't send them away just because they've got a BMI of 24 (Focus group 4)*

It was less usual, but not exceptional, for patients below 40 years to be screened. However these patients were generally excluded from the reported screening figures. Several staff explained that screening all patients aged 40 and over was often easier than calculating the BMI of patients after measuring their height and weight. Patients who, when weighed and measured, were found to have a BMI below 25 and therefore not eligible for DHDS found it hard to understand why they were not offered a test. They expressed disappointment and a feeling of being denied a health check to which they felt they were entitled.

*..we found out that we had some over 40 who had a strong family history of diabetes - sister, brother, mother - so we screened them if their BMI was less than 25. Plus I wish the criteria - you know the 40 years old - I wish it was like 30 and over because in between 30 and 40 we've had quite a lot of people who have come to us with problems wanting, "Can you check my diabetes?" (PN 6)*

However in one practice where there was a high proportion of South Asian patients it was explained that the criteria were strictly adhered to in order to avoid being swamped by large

numbers of people with newly diagnosed diabetes. This increased the positive predictive value of a raised screening test, reducing the number and proportion of negative diagnostic tests. Some staff expressed concern about how they would manage once the DHDS project was completed when patients continued to ask for the screening. Another issue for practices with a high level of turnover among patients was uncertainty over whether to include new patients as they arrived, or reached their 40<sup>th</sup> birthday, or to draw up a definitive list and accept that a large proportion of those patients might leave the practice before the end of the project

Staff described the benefit of the feeling in the practice that they were contributing to the health of the whole nation and described involvement in DHDS as inspiring because they felt part of a select group. Practical benefits were seen to include the opportunity to give lifestyle advice to patients, promoting early detection and so avoiding diagnosing patients with complications requiring insulin. Some patients in the pilots had

*been diagnosed and they find it quite traumatic now, but it's a lot better than being diagnosed five years later (Focus group 5)*

Benefits included improved recording of ethnicity and waist circumference, and the identification of impaired glucose tolerance in patients who could then be monitored. Several staff thought it a mistake not to have included testing for hypertension and in DHDS as many patients with both conditions were identified.

Control of the project was seen to be taken from GPs by facilitators by some practice staff who were unhappy at not being able to follow up how the pilot was progressing because

*once the pilot study put the IT [person] and the nurse in you lost control of it within the practice (Focus group 3)*

They explained that they knew the patients and were unhappy about the lack of follow up information. The importance of not changing criteria to facilitate recording consistency when patients move to another practice was stressed.

#### *Data template*

Staff in some practices, usually HCAs with little IT knowledge, were happy to fill in the 'Word'-based paper template. Where GPs had become involved with data entry they had generally created their own version of an electronic template so that information collected could be used beyond the remit of the DHDS pilot.

*..we created our own. We felt that in this day and age to actually hold paper records or something that is not searchable is quite ludicrous. (GP 5)*

Facilitators believed that some pilot practices had withdrawn because of the Word paper template, which was seen to be illogical, complicated and lacking a clear sequence. They suggested the template should have been piloted. Some felt that problems with the template reduced the importance of the project and the data. It was stressed that consultation with Primary Care staff when the project was being set up would have been beneficial.

#### *Practice involvement*

Staff other than GPs explained the importance of involving the whole team so that all staff, including receptionists and GPs, would be aware of the criteria for DHDS, and the importance of recording all relevant data for each patient in a usable format. Nurses and HCAs felt uncomfortable about explaining the study to staff who had not been present at any DHDS meetings

*none of the staff knew anything about it. We had to come to the staff here in a meeting, explain to the doctors what we were doing so when we started DHDS most of the doctors had forgotten what they were doing unless you constantly remind them (PN 2)*

## Outcomes of screening pilots

Staff were pleased overall to have had the opportunity to take part in the pilot.

*It has been worthwhile because I think we have saved quite a lot of patients. Well not saved them, I should say helped them to change their lifestyles because we are doing preventative medicine so hopefully we are not going to see so many patients being admitted to hospital with a heart attack or being admitted to hospital with blindness, I think it's really trying to prevent complications. (HCA 3)*

All staff recognised that early intervention meant patients were less likely to suffer complications, and provided an opportunity to educate patients about diabetes. DHDS had also been seen to increase educational opportunities for the HCAs, and for the members of the administration teams that supported the HCAs in calling the patients in and understanding about diabetes.

*I think.. across the whole of the practice it's raised awareness. (PN 3)*

Staff described the satisfaction they felt when comparing statistics on their database over time to see how the health of the patients was improving. One GP described how they had increased detection of hypertension and hyperlipidaemia, as well as having the opportunity to provide advice on smoking interventions. Further, the pilot had focused staff attention onto diabetes

*I think our HCAs.. it has helped their practice development, they've learnt something different they are learning quite a lot of things.. (PN 1)*

GPs with a high proportion of South Asian patients were keen to participate because of the high risk of diabetes in their patient population. All staff in these practices perceived screening to be important

*this is something that is very dear to this community and very prominent in this community and I think that's why we've had such good response because they've probably got a dad who's got diabetes, who had a leg amputated or whatever, and they understand. (PM 4)*

Patients in one practice diagnosed with diabetes were invited to diabetes education sessions by the practice nurse, who delegated the diabetes clinics to the HCA she had trained to carry out this task. Some concern was expressed over the lack of continuity between staff and patients

*I'm trying to get them involved in the diabetes management, because if they've screened the patient, done the GTT, then they don't see the patient again.. (PM 3)*

Providing a good service to patients produced a satisfying working environment for staff. They were pleased to have the opportunity for early intervention so they could identify patients before they developed diabetes

*we have food models where we call perhaps 15 patients and talk to them about how they are cooking, how they are eating, exercise. I personally think, particularly within this high risk environment, that it's something that continues, because to catch these patients now, long term reduces the pressure on the NHS hospitals, our resources, because we are allowed to jump in early. (PM 3)*

Anxiety about possible complaints by patients meant that those not meeting the DHDS criteria who wanted to be included in the screening were sent for a fasting blood sugar and a 'well person' check in one practice, apparently to avoid the risk that if diabetes was diagnosed later the patient would blame the practice for delay in diagnosis

*..then they say, "I came to you. I told you I had it." (PN 1)*

### *Resource implications*

The intervention was described by some GPs as creating an excessive amount of extra work, especially in the form of patients making return visits to the practice to see the nurse when they needed to discuss test results requiring treatment or advice.

*we haven't got the capacity to manage a large number of patients that will be appearing, so if we are going to continue with DHDS and we are going to do something effective with the new patients that are being diagnosed then resources need to be increased. (GP 2)*

It was suggested that these patients had taken appointments that were then unavailable to other patients, who would have to wait longer. Several staff had felt concern that many new patients with diabetes would be identified.

*When there is a significant number of new diabetics coming through that inevitably imposes on the overall care, meeting the demands of the appointments. The recruitment that we've done with the healthcare assistant is purely really to address the DHDS pilot but not to actually do anything with the new diabetics that have been churned out from there, so it does have an impact on it. (GP)*

Staff often mentioned the inevitability that the population with diabetes will increase. This was a particular concern when resources were already inadequate to meet demand

*I know they're waiting about six months to see a chiropodist at the moment. So that's absolutely at bursting point now because the hospital won't do the diabetic foot check. But for the neuropathy check, which the chiropodist does here, the waiting list is dreadful now. All of them should have that annually and we just don't have enough to meet demand.. (PN 3)*

### *Key points*

- staff overall felt job satisfaction from providing preventative care
- HCAs enjoyed their increased responsibility
- awareness of diabetes was raised generally within pilot practices
- screening created extra work and could displace other activity or other patients being seen
- resources were seen to be finite, and inadequate to meet demand
- practices wanted the option of electronic rather than paper recording and to be able to record screening information on their own clinical information system

### **Ethnic minority issues**

The majority of ethnic minority patients visited their practice fairly regularly. Apart from attending various clinics, many Indian patients attended for vaccinations before travelling to India, which they did on a regular basis. Staff utilised these visits to encourage the uptake of screening.

Problematic communication was described as a recurring issue. Staff believed that few of their minority ethnic population were able to read, especially those over the age of 60. Some practices with a large proportion of South Asian patients sent out letters in what they believed to be their native language, but this had not increased uptake. Staff reported that their practices no longer translate leaflets which was expensive and unhelpful because invariably the meaning changed in translation. They found that contacting community groups where there was usually an English speaking person was a more satisfactory means of communication. A good response was reported when an invitation letter was sent in English and included the sentence

*'If you would like this in another language please give us a ring, please let us know' in four languages (Facilitator 8)*

It was therefore felt to be more productive to send out all letters in English. Staff in one practice had believed the main language of the South Asian population at their practice to be Gujarati, but then found that

*we didn't understand the different levels of Gujarati so we had a lot of stuff translated into what we thought was Gujarati and patients came back and said "That's not the Gujarati I speak, I speak this type."* (PN 3)

With over 100 different languages spoken in one PCT, staff were aware that language was a complicating issue in communicating with patients

*you translate the letter from English to Arabic and it never works* (Focus group 5)

Staff generally perceived the poor response to be the result of limited understanding of the information in the letter and advised "*Make it as simple as you can.*" (PN 5)

Practices where several HCAs spoke a range of Gujarati dialects made it possible to offer explanations to a Gujarati-speaking patient population. Contacting patients by phone was seen to work well, as often a patient would ask the practice to phone back when an English speaking family member was available to translate for them. There was overall a perceived raised awareness of diabetes among South Asians and

*family history added to recruitment.. been a huge change in attitude in Bradford.. those that turned up were actually motivated and well informed* (Focus group 5)

An improvement in patient understanding of the way the practice was organised, and especially the importance of keeping appointments and arriving at a specified time, had been noticed by practices with a high proportion of South Asian patients. Older South Asian patients were considered less likely than younger ones to speak and understand English. Practices with a very high South Asian population reported that new family members were constantly joining the practice as they came to live near family already registered with the practice. The implication is that these practices will experience increasing numbers of people with diabetes.

South Asians sometimes carried out testing using other people's machines. A case was described however where a South Asian patient who had ignored the letter of invitation because he felt well, subsequently attended for screening only when he became excessively thirsty, and after realising his mother had diabetes.

Some Asian men brought their wives but had not thought they should be screened, believing they themselves were healthy although they met the DHDS criteria

*telling me their wife was very overweight which was quite embarrassing 'She's fat, she's fat'* (Focus group 4)  
and the husband when invited to be weighed was '*reluctant.*'

It was thought that some South Asians had not attended screening because many spend extended periods in their own country. While the older population often attended the practice a certain group of South Asians was described as difficult because

*their adherence to medication [is poor].. weren't coming for their medication reviews, didn't attend their hospital appointments.. till they have to come because they're really ill* (Focus group 5)

This may have been an effect of the view that

*South East Asian countries.. people used to think that once you have diabetes, that's the end of you. But now we explain that people can have long lives if they comply with lifestyle advice and medication.* (Focus group 6)

### **Ethical issues**

Three main ethical issues were raised by staff. Firstly, that the age cut off (40 years) was too high, especially in areas with a high South Asian population

*I think within a population like this we ought to be able to offer anybody that has a concern and not just if you're over 40.. do away with some of the risk factors, certainly make them lower.* (PN 3)

This appears to reflect differences between a public health view of the purpose of screening (health improvement through earlier detection) and a view that focuses on individual choice and responding to patient concerns.

Secondly, false reassurance for patients that they do not have diabetes (false negatives) and unnecessary anxiety that they do (false positives) was a concern. Although some staff felt that patients might worry that they could have diabetes, and would worry excessively while waiting for the results of the fasting glucose diagnostic test, they had little evidence for this.

Thirdly, the facilitators recognised that the practice staff involved in screening felt that asking a patient to attend brought an obligation to screen them. Failure to provide the expected screening was seen as breaking trust.

#### *Informed consent*

Staff generally appeared to be unaware of any other ethical issues associated with screening, such as the relevance of informed consent.

*Very few patients asked questions about DHDS, just agreed to take part.* (PM 1)

One staff member did mention the need for “verbal consent” for diabetes screening if a patient had attended for something entirely unrelated (flu vaccination). Few facilitators saw any ethical problems associated with the screening. One, however, recognised the way the practices carried out screening did not always adhere to strict ethical principles, but this

*is the way of general practice, we stick a needle in the arm and while we are there we tick all the boxes.. if British general practice had to play by the ethics game it would grind to a halt. A 45 year old business man who comes in and gets told he's got diabetes and all of a sudden he can't get life insurance or a mortgage or travel insurance or maybe have implications for his work and he hasn't been told that anyone was screening him for diabetes and that looks unethical* (Facilitator 6)

While the ideal of informed consent is to providing adequate information for patients before undergoing any procedure, the majority of patients appeared not to want comprehensive information and to prefer only basic facts. Letters in the simplest terms was thus seen to be essential. The facilitators explained

*and that's not being insulting to patients it's just being practical.* (Facilitator 4)

Some facilitators described how DHDS had appeared to mislead patients, several of whom had been disappointed after believing they had been invited for a check up for three conditions: diabetes, heart disease, and stroke

*A lot of patients come because heart disease is in the family and they felt cheated A lot of our patients are coming in and saying, but my dad died of a heart attack at 58, and there's high blood pressure on my mums side.* (Facilitator 8)

#### *Key points*

- practice staff tended to have a very positive view of the benefits of screening
- patients tended to believe that a negative result gave them an “all clear”
- staff generally viewed the criteria for screening as too restrictive to patients with risk factors such as ethnicity or family history

- opportunistic approaches can be made to patients from minority ethnic groups when they attend for travel-related immunisation
- letters sent in English achieved a better take up than letters in other languages
- staff able to use appropriate minority languages allowed information to be explained in a patient's own language
- equity of access to screening for all patients at the practice was a major concern for staff
- informed consent was not considered to be an important issue and consent was assumed by patients attending for screening, or agreeing to be tested

### **Staff perceptions of patient views**

Staff who had engaged in conversation with patients about the invitation letter believed the format of the letter influenced a patient's decision to attend for screening. Letters with very little text were seen to be better understood by a large proportion of patients than letters containing a comprehensive explanation of the pilot study. Staff described how some patients appeared surprised to be invited for diabetes screening, especially when they found it difficult to get a regular appointment to see the GP. Others were pleased that their GP was, as they believed, personally examining their notes to provide preventative care instead of simply treatments ailments as they arose.

*..a lot of the feedback that I get from patients is "We don't just want to come when we are ill." They like us to be looking after them before they get ill, to try to prevent them from becoming ill.* (PN 1)

*..very positive comments about DHDS from already diagnosed serious diabetics.* (PM 1)

Patients generally were seen to be more interested in their cholesterol level than in diabetes risk, and some had expressed disappointment because they had expected a cholesterol check as part of screening. Some patients were more worried about their weight than the risk of diabetes, and others apparently found it difficult to understand that screening was carried out according to criteria which did not include family history. Patients were, however, pleased overall to be having a "health MOT". Patients with a family history or an acquaintance with diabetes were enthusiastic, and some had asked about the connection between heart disease and salt after seeing the Kelloggs advertisement. Surprise at the complications associated with diabetes had been a typical response from patients, the majority of whose knowledge of the complications of diabetes was virtually zero

*'I had no idea of the implications of having diabetes. I thought you could just ignore it and I had no idea of the problems.. lose your limbs.. lose your eyesight..'* (Facilitator 5)

*a lot of the patients I spoke to thought it was not a serious condition anyway and it wouldn't really matter if they did have it. They don't know how diabetes affects everything.. until I came into DHDS I never ever knew really what diabetes was* (Focus group 2)

Middle class Asian families who find out they have diabetes, because they have been health conscious with diet, often found it difficult to accept their diagnosis

*the shock to their system* (PN 3)

*..think they are alright so long as they don't have sugar 'I'm not diabetic because I don't take sugar in my coffee'.. and these are intelligent people* (Focus group 7)

Some patients had thought there was no choice about attending screening, and were seen to be quite annoyed when told it was not compulsory

*..said 'I wouldn't have come if I'd known'* (Focus group 2)

while patients who attended and were then found not to fit the criteria, usually because of a BMI below 25 were not pleased either

*'What's the point of coming? I've come and I've sat there for 2 minutes and they've done absolutely nothing. Wait till I tell everybody.'* (Facilitator 8)

Some patients had apparently attended simply to be reassured that they did not have diabetes. While happy to have the random blood glucose test, they had not wanted the result, a diagnostic test, nor further intervention.

*they'd come for the initial screening, they didn't have a problem, they want to be told they're alright* (Focus group 4)

but when their finger prick test was high they went into denial. The negative effect of anxiety was mentioned

*some patients argue that it's not a benefit because they just know for longer; one said he wasn't accepting that he was diabetic.. it's such a shock* (Focus group3)

Anxiety about pain from the finger prick test and concern about having a blood test was seen to deter some patients from attending. Patients with a borderline result may not have attended for a diagnostic test because they felt they were unlikely to be at risk.

Staff thought patients had not always been adequately informed about what screening involved

*I don't think they realized they were going to be measured round their waist and I think some of them felt uncomfortable about that; some of them refused to be weighed.. knew they were overweight and were embarrassed. Men - so deluded about their weight; most people didn't understand what a BMI is - waist measurement is simpler* (Focus group 2)

Staff were agreed that

*'Gym' is definitely a turn off for people* (Focus group 6)

### **Non-attenders**

Patients who did not attend screening were seen as being healthy, in work, and rarely attending the practice. It was suggested that a late clinic or walk-in centre and a national awareness programme for example on television might encourage employed people to attend but this was not feasible for DHDS. Staff suggested targeting different ethnic groups, and contacting by age-appropriate methods, for example texting patients aged 25 and under, as possible means of increasing uptake. Describing an age-related check as an 'entitlement' at 40 might help people to place a value on screening. Non-attenders were seen as less well-educated than regular attenders. Patients who insisted they were not diabetic were thought to be unlikely to attend for screening. Patients appeared to ignore the message about diabetes increasing the risk of heart attack, stroke, blindness, and kidney failure but appeared to have convinced themselves that life would deteriorate because

*a lot of the ones I came into contact with were a bit wary of it, they sort of think injections and nothing more* (Focus group 1)

*'I'm going to have to change what I eat, no more sweets and cakes'* (Focus group 1)  
and patients with no knowledge of diabetes assume they are healthy

There was no apparent recognition of vascular risk among patients and

*we had to get them over the first base, so that [HCA] could explain it fully* (Focus group 1)  
and so it was seen to be better to invite patients opportunistically rather than by telephone or letter. Other patients commented

*'I'm too young to worry about that'* (Focus group 1)

Education was widely seen to be the key to increasing understanding.

### **Key points on patients**

- a majority of patients were generally ignorant about diabetes
- adapting the invitation to the characteristics of the practice and the patient was successful
- some patients with positive results do not attend for a diagnostic test

- regularly attending patients are likely to attend screening
- healthy employed patients who rarely attend the practice are unlikely to attend screening
- educating patients about diabetes may improve screening uptake

### 5.3.2 Patient interviews

The patient interviews covered the patient's experience of the invitation and screening process and also explored the patients' understanding of screening. A large amount of data was gathered from over forty interviews, representing a rich source of data for further analysis to explore the issues that matter to patients and how they understand and interpret the screening process. There is clearly potential for further work on this data. We have provided a summary of the main themes generated in this report, but given the volume of material collected, this is only a summary, with illustrative quotes, of some key points.

The major issues covered were

- Reasons for attending or not attending screening
- Reasons for attending or not attending for diagnostic testing
- Knowledge and understanding of the implications of a diagnosis of diabetes

In all these areas there were some concerns that were specific to, or more significant for, the South Asian patients.

#### Awareness of the purpose of screening

Staff views on the lack of understanding of the invitation letter were endorsed by patients who reported a lack of knowledge of the content of the letter they had received. Patients who were invited opportunistically while they were at the practice for another reason demonstrated awareness of why they had been invited for screening. Similarly, there appeared to be little confusion among patients who had been invited by telephone and had the opportunity to ask questions. While some patients who had responded to a letter by phoning the practice to make an appointment had understood the purpose of their visit, others showed confusion about the invitation. One patient had thought she was attending the practice for a routine hypertension check

*..I was amazed to find out it was something completely different (P 1)*

Some patients had wanted to be screened in the expectation that they did not have diabetes, and to be reassured of this. Several patients however, often with a family history of diabetes, were clearly keen to detect diabetes in its earliest stage and reported having had their blood sugar level checked at both the chemist and the doctor

*because you could start treatment right away .. as you get older you don't know what's around the corner, do you? (P 2)*

A few patients had called at the practice and seen a leaflet. They were pleased to have the opportunity to find out if they had diabetes without making a special appointment. Some patients experienced no anxiety about the result

*I'm quite happy to take part as long as there's no needles involved.. because it was giving me a guarantee (P 3)*

at the same time showing how some patients believe that a negative test result gives them an 'all clear' for diabetes.

Patients in the study felt they had received adequate information about DHDS screening before the test was carried out, although their recall of the information was generally minimal. The finger prick test result was recorded in the notes of some patients who had no memory of receiving the letter or attending the practice for screening. When prompted by the researcher they agreed that they had attended for screening but their recall of why they had attended or any implications or even the way in which they had been invited was limited or non-existent.

It was usual for patients who had not attended screening to say they would have attended if they had been invited by the practice, but the following was a common response

*I had a letter maybe a year ago but I can't remember.. because I am very healthy.* (P 4)  
and denial appeared to be a part of the rationalisation process of several patients who had not been screened. Another patient said she would have attended if invited, but apparently already had impaired glucose tolerance and was currently taking medication for diabetes, which indicates an inadequate IT system (or operator) and incorrect information on the status of at least one patient.

An inability to differentiate between the screening and the consequent diagnostic test was common in several patients who referred to the diagnostic test as 'screening'. Another patient who thought the OGTT was the screening expressed uncertainty about the validity of result as she had eaten shortly prior to the test thus showing both some knowledge of diabetes and denial about her own result.

### **Non-attendance at screening**

It is not possible to know whether several patients who had no recall of receiving a letter of invitation had received it and forgotten. At least one patient who was aged 38 and so not, according to the criteria, eligible for screening had been invited so similar IT or clerical errors may have been responsible for some letters not being sent to eligible patients. Misunderstanding the letter was commonplace, and some patients had thought it was telling them they already had diabetes

*Thought I may have misinterpreted letter and thought "Oh have I got diabetes?"* (P 5)

Several patients had received the letter but had not made an appointment. When the receptionist phoned to ask if they would be willing to be interviewed by a researcher they had thought the interview appointment was for diabetes screening.

One patient explained that he could not read without spectacles, which he had lost. He used a magnifying glass as a substitute to assess the importance of a letter. The important information about what to do in response to the letter was at the end of a dense A4 page of text, and he had read only the first sentence at the top of the letter before deciding it was not important. Poor eyesight inevitably affects people as they grow older and not everyone has a pair of spectacles so it may be useful to print short letters in a large font size.

### **Non-attendance at diagnostic test**

A substantial number of patients who had screened positive and so been asked to attend for a diagnostic test, either at the practice or at the hospital, had failed to attend. Various explanations were given. One woman when asked why she had not returned for a diagnostic test was worried about the outcome and preferred to focus on her need to lose weight, while at the same time

*I hope I'm not [diabetic]* (P 6)

Refusal to accept that they may have diabetes, supported by their reported low sugar intake, was a common characteristic among those not attending the diagnostic test

*because I'm not diabetic that's why; I did not attend because I don't eat sweets or anything like that; I know quite a bit about diabetes* (P 7)

### **Knowledge of diabetes**

Patients have varying levels of knowledge, sometimes related to direct experience of relatives with diabetes. The majority of patients thought diabetes was not a serious condition, and most mentioned the importance of regulation 'sugar'. The exceptions were patients who knew someone who suffered from diabetes, especially if this was a close family member.

*especially when you have insulin or something.. because my father was like that* (P 6)

Patients employed as health professionals demonstrated the most informed knowledge of diabetes. Many of the South Asian patients who were interviewed had knowledge from other family members. Messages about diet appeared to be accepted by many in this community, but they placed almost total reliance on dietary changes to remain healthy

*We've cut down sugar completely, more boiled food and less fried food; I don't it's that much to really worry about (P 7)*

Several patients appeared to have a fear of diabetes because of what they had heard from others

*serious because I've heard people can go into a coma if their sugar levels have gone low, I don't know much else about it (P 8)*

*you can get eye problems and even die.. all we hear is diabetic, diabetic; I don't even let her eat sugar.. no matter how much you tell ladies they still eat it (P 7)*

*she's got very bad diabetes and she has to have about 2 injections a day and I think perhaps people are frightened.. people I think can't cope with those sort of thoughts (P 9)*

Most patients described their own risk of diabetes as low and expressed anxiety about having a blood test rather than being diagnosed with diabetes.

### **Issues specific to South Asian patients**

Both cultural and language issues were identified as barriers to participating in the screening programme or understanding why they had received an invitation to be screened. There was a practical issue around understanding both letters and phone calls from the practice for some South Asian patients. Others with poor English had arrangements in place for a family member to translate for them, although this was not always available on a daily basis.

Access to interpreters was nevertheless an issue, and some patients felt that others did not attend through lack of understanding. Increased access to information was described as a possible influence to attending the practice for screening and it was suggested that information provided at the local cultural centre would be the best means of information reaching the greatest number of people. It was felt by some South Asians that

*If a person is aware of what problems can happen after you get diabetes, then they would attend.. consequences of diabetes should be explained in the letter (P 10)*

### **Key points from patient interviews**

- Patients who do not attend may not have received or understood the letter of invitation.
- Patients who believed their risk was very low attended for screening for reassurance
- A positive screening did not always influence patients to pursue diagnostic testing and they rationalised this in terms of not feeling at risk or having other strategies (eg weight loss)
- Knowledge of diabetes tended to be associated with having family members with the condition
- There was a widely held view that more information and education about diabetes would encourage attendance for screening
- communication with minority ethnic populations may be enabled through local organisations rather than direct translation of written information

## **5.4 Overall summary of key qualitative findings**

### **5.4.1 Identifying patients at risk**

- an updated searchable clinical database is crucial for identifying eligible patients
- staff generally viewed the criteria for screening as too restrictive and unfair to patients with other risk factors such as ethnicity or family history
- justification for adhering strictly to the criteria was to limit new cases to a number the practice could reasonably cope with
- some staff had concerns that records were not always made when patients had been invited and screened opportunistically
- equity of access to screening for all patients at the practice was a major concern to staff

### **5.4.2 Inviting patients to be screened**

- letters were generally not understood by patients and perceived as too long or complicated
- sending letters was costly in terms of both money and staff time
- letters sent in English to minority ethnic patients achieved a better take up than letters in other languages
- some letters were returned as the patient was no longer at the recorded address
- contacting patients to remind them of an appointment was seen as useful but many patients were unwilling to provide a telephone number, especially for a mobile phone
- opportunistic invitation was popular because of the perceived high success rate with patients already attending the practice for an unrelated reason
- opportunistic approaches to patients from minority ethnic groups can be made when they attend for travel-related immunisation
- adapting the method of invitation to the type of patient population and ensuring it was appropriate to the practice generated more attendances
- it was felt that no single strategy will be appropriate for all patients
- patients who do not attend may not have received or understood the letter of invitation

### **5.4.3 Barriers to attendance for screening and diagnostic tests**

- a lack of availability during evenings and weekends was seen as limiting uptake
- times when screening was available was critical, as it meant many employed patients could not attend
- retired people, women, and the 'worried well' were most likely to attend for screening
- patients from deprived areas were least likely to attend for screening
- patients who believed their risk was low still attended for screening, expecting reassurance
- regularly attending patients are more likely to attend screening
- healthy employed patients who rarely attend the practice are unlikely to attend screening
- educating patients about diabetes may improve screening uptake
- practices were not always able to follow up patients with positive screening tests to ensure they were encouraged to attend for diagnostic testing
- a positive screening blood test did not always influence patients to pursue diagnostic testing; they could rationalise this in terms of not feeling at risk or having other strategies (eg weight loss)

### **5.4.4 Organisation of screening**

- screening created extra work and could displace other activity or other patients being seen
- a number of staff needed to be involved in identifying eligible patients, inviting patients to be screened and providing screening and diagnostic testing
- practice managers and GPs were happy to delegate screening and health promotion to HCAs who were seen to be the appropriate staff to carry out diabetes screening
- staff overall felt job satisfaction from providing preventative care and HCAs enjoyed their increased responsibility
- the efficiency of dedicated staff carrying out a repetitious task increases over time

- GPs regarded diabetes screening as carried out more efficiently as part of a wider health check at a single appointment
- resources were seen to be finite, and inadequate to meet demand
- practices want to be able to record screening information on their own clinical information system, rather than paper forms or a separate database

#### **5.4.5 Understanding of diabetes and screening**

- practice staff tended to have a very positive view of the benefits of screening
- informed consent was not identified as an important issue by staff: consent was assumed if patients attended for screening or agreed to be tested and tests were sometimes ordered without any explicit discussion or explanation
- patients tended to believe that a negative result gives them an “all clear”
- patient anxiety while awaiting results was a concern to staff
- awareness of diabetes was raised generally within pilot practices
- staff able to use appropriate minority languages are a useful resource in explaining information in patients’ own language
- communication with minority ethnic populations may be enabled through local organisations rather than direct translation of written information
- patients were generally ignorant about diabetes; knowledge of diabetes tended to be associated with having family members with the condition
- There was a widely held view that more information or education about diabetes would encourage attendance for screening

## Section 6: Implications for policy and practice

### 6.1 Introduction

In general, cardiovascular risk reduction programmes have proved feasible and popular with both patients and policy makers, despite a limited impact on outcomes in randomised trials (Langham et al 1996, Wonderling et al, 1996). Similarly screening for diabetes has proved popular and feasible despite the lack of a robust evidence base for screening. However current trials will add to the evidence base for diabetes screening (Lauritzen et al, 2005) and there is a developing evidence base for screening and intervention in impaired glucose tolerance (IGT) (Davies et al, 2004; Gillies et al, 2006). It is therefore likely that primary care will in future have an increasing responsibility for primary prevention and early detection of diabetes and cardiovascular risk. Future cardiovascular and diabetes risk reduction programmes will be more effective if lessons are learnt from the experience of evaluated pilot programmes (Finch et al, 2003).

The aim of this final section is to draw together the practical implications of the main findings from both quantitative and qualitative evaluation of the pilots and highlight the main potential implications for future policy around screening or risk reduction programmes in primary care. Overall the impact of the pilots in terms of increased diagnosis was less than practices had anticipated and we reflect on the possible explanations for this finding. The qualitative analysis identified a number of crucial issues that may need further development to support systematic risk assessment and screening in general practice and these are also discussed.

However caution must be applied in attempting to generalise from the pilot findings as the pilot practices were not randomly selected, nor typical, general practices. They were all volunteer practices and they were all based in relatively deprived inner-city and urban areas. Unlike practices that undertake diabetes screening as part of routine practice activity, they were given additional resources to provide systematic screening and the practices were all supported by PCT pilot facilitators. It should also be recognised that data collection was incomplete and so some analyses are based on a potentially biased sub-set of practices or individuals.

### 6.2 Overall impact of the DHDS pilots

Overall the successful implementation of screening in the pilot practices demonstrated that, given funding and practical support, it was possible for practices to undertake systematic screening to detect new cases of diabetes. The overall number of new cases reported by practices as due to DHDS screening was 358, equivalence to an additional two cases per thousand practice population (ie 3-4 extra cases per general practitioner). However, the overall increase in prevalence was only one case per thousand more than in the comparison practices over the two year of the pilot.

The overall impact of the DHDS screening programme appears to be lower than expected, if based on the assumption that half to one third of all cases of diabetes are undiagnosed. Some PCTs expected a much higher prevalence of undiagnosed diabetes in the screened population and an epidemiological survey in Manchester suggests that up to 13% of adults in a deprived multi-ethnic community may have undiagnosed diabetes on the basis of an OGTT (Riste 2001).

However there are a number of possible explanations for a lower than anticipated yield, some of which are supported by the information collected by pilot and comparator practices:

**1. Low prevalence of undiagnosed diabetes:** there are actually fewer undiagnosed cases in the screened population in the pilot practices because more have already been identified or are being identified by other means.

This was thought possible at baseline as the practices reported a fairly high and increasing level of risk factor based screening before the pilots started. The information about the overall increase in prevalence during the pilots (0.5%) and the high proportion of new cases diagnosed with pre-

existing risk factors, whether or not a practice was a DHDS pilot, confirms a high level of screening activity, which increases the opportunities for cases to be picked up outside the DHDS pilots. It is likely to be particularly true for practices where all CHD or hypertensive patients are screened annually.

**2. Selection bias:** with those at higher risk being less likely to take up the offer of screening.

This appears a less likely explanation based on the available information about the screened and unscreened populations. Those screened had a high level of risk factors in terms of age, ethnicity and BMI. The audit of practice attendance suggested that, if there was any bias, it was towards the less healthy, regular attenders (those with repeat prescriptions) being more likely to attend for screening. Moreover, the 61% response rate in these practices is only slightly lower than the minimum response rate observed in the Manchester study of 67% (Riste, 2001).

**3. Insensitive screening test:** the random capillary blood glucose cut-off of 6 mmol/l was higher than has been used in some other screening programmes. Use of a lower threshold, for example 5.5 mmol/l, would have increased the sensitivity of the screening test. However, even with the higher cut-off, a third of those screened still needed diagnostic testing. Reports of the performance of a random capillary blood glucose suggest sensitivity around 80-90% at cut-offs of 5.5 to 6 mmol/l, so reducing the threshold might have influenced yield but not as much as ensuring adequate diagnostic testing in those with a RCBG>6 mmol/l.

**4. Inadequate diagnostic testing:** up to a third of those with positive screening tests may have missed out on diagnostic testing and, even where diagnostic testing was performed the lack of access to OGTTs in some of the practices will reduce the diagnostic yield by up to 15-20% (as cases will be missed if they have a normal fasting glucose). Equally it appears that the diagnosis was often made on a basis of only one diagnostic result, so some cases might not have had the diagnosis confirmed on further testing.

Overall, it seems likely that the main reason for the relatively low yield from the systematic screening programme was the high level of screening activity outside the specific-pilot-related activity. This would also account for the lack of any measurable differences between the cases detected by DHDS activity and all other new cases diagnosed between 2000 and 2005 and included in the new case audit.

### **6.3 Key differences between screening in a research context and in clinical practice**

The case studies, interviews and focus groups identified some practical issues around screening activity in primary care which arise when screening is done outside a research context and which have not been widely discussed or addressed in practice. Issues that tend not to be problematic in a research setting because of the prescriptive nature of a research protocol may be much more problematic in normal clinical practice. The diversity of general practice makes it difficult to generalise across all primary care provision, but four major issues emerged for the DHDS practices which have not be previously identified, probably largely because they do not arise to the same extent in a research context.

1. *Identification of high risk individuals:* Staff found it difficult to justify limiting blood tests to a specific group defined by their BMI, and generally viewed the criteria for screening as unfair to patients with other risk factors such as ethnicity or family history. Whilst in a research context it is possible to specify strict inclusion criteria for those who receive blood tests, in clinical practice patients often expected a risk assessment to involve blood tests. Staff may be unwilling to restrict blood testing, for example where cholesterol measurement is regarded as an essential part of cardiovascular risk assessment.
2. *Informed consent:* In a research context written consent is generally obtained and patients are told what will happen if the screening test is positive. In usual practice, patients trust their general practice to do what ever is best for their health and well-being and tests are

often done without explicit explanation. This is one potential explanation for why a high proportion of those screened positive did not subsequently receive a diagnostic test.

3. *Data collection and audit:* The major barrier to efficient screening in practice appeared to be the lack of an approach to data collection that facilitated either the identification of eligible (high risk) individuals or the subsequent audit of screening and diagnostic activity. Practices have developed effective systems for audit of chronic disease management. Development of similar systems for recording risk factor and risk assessment information on the registered population so that activity can be effectively audited is still required and standardised data definitions and consistent approaches to coding will need to be agreed, as they have been for chronic disease management audit in general practice.
4. *Availability and uptake of diagnostic tests:* A large number of those who had a capillary blood glucose of 6 mmol/l or greater did not subsequently have complete diagnostic testing and of those who did have a fasting blood glucose measured, only a minority all had an oral glucose tolerance test (a blood glucose measured two hours after a glucose load). This results in a proportion of those with diabetes by WHO criteria, and most of those with impaired glucose tolerance not being detected (and so arguably not benefiting from advice about their risk of diabetes or early intervention).

## 6.4 Lessons for screening and risk assessment policies for general practice

The qualitative findings related to the practical issues raised, and particularly barriers to effective screening, are important issues that any screening programme will need to address. The evaluation findings could therefore usefully inform future policy around screening and primary prevention in general practice. Some specific suggestions are outlined below.

- **Uptake of screening:** Screening invitation letters should be as simple as possible. There may be limited value in using letters in languages other than English. Opportunistic invitation may increase uptake and represent a more cost-effective strategy for both practices and patients. Patients who are in work may find it difficult to attend within normal practice opening hours.
- **Inclusion criteria for screening:** Limiting screening to those at highest risk is only likely to be feasible if risk information can be obtained without patients being invited to attend the surgery and if the criteria are understood by practice staff. Age criteria may be more feasible to use to identify risk groups than BMI, ethnicity or other criteria which are not universally recorded. Individuals may still be able to use their discretion to screen younger patients who have other risk factors (based on BMI, ethnicity and family history).
- **Understanding the purpose of screening:** The objective of diabetes screening might be better understood if the language of “risk reduction” was used so that all patients expected to be given advice about what they could do to reduce future risks, rather than the reassurance of an “all-clear” result. There is also a need to manage patient expectations to avoid increasing dissatisfaction, due to unrealistic assumptions about the nature or purpose of risk assessment. Patients attending for cardiovascular or diabetes risk assessment may expect a physical examination and generally expect a blood test. Staff focused on the importance of “fairness” and the “right to know” you have diabetes rather than the public health benefits of earlier detection or the potential dis-benefits of a chronic disease label if diagnosed.
- **Impact of screening:** The overall impact of screening will vary widely between practices depending on both the underlying prevalence of undiagnosed diabetes and the screening strategies adopted. Deprivation (based on practice postcode) and, to a lesser extent population

ethnicity, predict the proportion of those screened who have positive screening and diagnostic tests. But the most important issue to consider is the level of ad hoc testing, which if high will limit the additional impact of any systematic screening policy.

- **Diagnostic testing:** There were major problems identifying the results of diagnostic tests and no consistency about the use of diagnostic tests. OGTTs were only used in half of the pilot practices in diagnosis. Although screening research projects and epidemiological surveys in the UK have usually used OGTTs, these are employed less in the US and are rarely done in France even in research settings (Cogneau et al, 2006). Around 15-20% of cases with isolated post-prandial hyperglycaemia will be missed if they are not used. Also, if interventions to delay or prevent the development of diabetes are to be offered to those with impaired glucose tolerance in future, then provision of OGTTs will need to be developed.
- **Screening personnel:** Health care assistants can be recruited and trained to offer screening and health promotion advice to healthy people. The employment of health care assistants was associated in pilot practices with an increase in the positive predictive value of a positive screening test. This appears to be because practices with health care assistants who had been trained and employed to provide screening were more likely to do oral glucose tolerance testing in the practice. Further work is needed to assess the effectiveness of health promotion/risk reduction interventions offered to individuals at increased risk by health care assistants.
- **Audit of screening:** The DHDS pilot practices found it extremely difficult to collect or report adequate information on their screening activity. Adequate audit and quality assurance is vital to any screening programme and practices need to be able to record screening activity in a consistent way and in a format that allows for audit of the screening process. Any guidance related to systematic screening activity should be accompanied by guidance about how such activity can be adequately recorded and subsequently audited. Any screening programme needs a suitable supporting information infrastructure including data definition, coding, clinical information systems, data extraction and reporting methods, as has been developed for all the national screening programmes in the UK. Ideally ad-hoc screening activity as well as any systematic screening should be subject to regular audit.

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## Appendix A: Baseline screening survey

### Screening Activity in Your Practice

The extent to which diabetes screening and diagnosis occurs is of interest to the UK National Screening Committee. Please help us by filling in the following questionnaire about the screening and diagnosis of diabetes. Since there is no universal established means of screening for diabetes, we are interested in whatever you do. Thank you!

1. Trust \_\_\_\_\_ 2. Date \_\_\_\_/\_\_\_\_/\_\_\_\_  
3. Practice/Location \_\_\_\_\_ 4. Number of doctors in practice \_\_\_\_\_

5. Number of registered patients \_\_\_\_\_ 6. Number of patients with diabetes \_\_\_\_\_

7. Please provide the date on which numbers of patients determined \_\_\_\_/\_\_\_\_/\_\_\_\_

8. How many new patients with diabetes has the practice detected in the last year? \_\_\_\_\_

9. What **proportion** of the patients would you estimate had the following recorded in the past year

Under 18s Ethnicity \_\_\_\_\_ Height \_\_\_\_\_ Weight \_\_\_\_\_ Waist circumference \_\_\_\_\_

Over 18s Ethnicity \_\_\_\_\_ Height \_\_\_\_\_ Weight \_\_\_\_\_ Waist circumference \_\_\_\_\_

10. What **diagnostic** tests for diabetes does the practice use? Please list, including what the practice deems a “positive” (diabetes present) for each test.

**Diagnostic Test**

Criteria for a **positive diagnostic test** for diabetes

_____	_____
_____	_____
_____	_____

11. Please describe which factors determine which patient receives a given diagnostic test?

\_\_\_\_\_  
\_\_\_\_\_

12. Does anyone in the practice screen for diabetes (i.e. identify those at risk for diabetes)?

Yes \_\_\_\_\_ No \_\_\_\_\_ Unknown \_\_\_\_\_ *If no or unknown, skip to Number 22.*

13. How many patients do you estimate you screen in a one year period? \_\_\_\_\_ Don't know \_\_\_\_\_

14. Over the past two years, has the volume of diabetes screening you perform or supervise

Increased \_\_\_\_\_ Stayed about the same \_\_\_\_\_ Decreased \_\_\_\_\_ Don't know \_\_\_\_\_

15. If the volume of screening has changed, what are the reasons for this?

\_\_\_\_\_ Don't know \_\_\_\_\_

16. What **screening** test for diabetes (e.g., risk score, random capillary blood glucose, combination) does the practice use? - you need not limit yourself to these examples

**Screening Test**

Criteria for a **positive** screening test

_____	_____
_____	_____

17. Do you screen any group(s) of patients *systematically*? (systematic refers to routine screening in a given group of people, e.g., all South Asians with CHD, everybody with a family history of diabetes)

Yes \_\_\_ No \_\_\_ Unknown \_\_\_ No systematic screening \_\_\_

18. If yes, please describe which patients get screened systematically

---

---

19. Does the practice have a recommended starting age for screening for diabetes?

Yes \_\_\_ No \_\_\_ Don't know \_\_\_ If yes, what age? \_\_\_ years.

20. Is there an age at which you no longer recommend screening?

Yes \_\_\_ No \_\_\_ Don't know \_\_\_ If yes, what age? \_\_\_ years.

21. Does the practice screen any groups at regular intervals? Yes \_\_\_ No \_\_\_ Unknown \_\_\_

If yes, please list Patient group Screening interval in years

---

---

22. For patients from the practice who get an **oral glucose tolerance test (OGTT)** -

*if none of the patients from your practice get an OGTT, skip to 23*

a. Does the practice perform OGTTs in the surgery?

Yes \_\_\_ No \_\_\_ Don't know \_\_\_

b. Does the practice refer patients elsewhere for OGTT (in addition or instead)?

Yes \_\_\_ No \_\_\_ Don't know \_\_\_

c. What proportion of OGTTs are done in your surgery? \_\_\_ (0-100%)

d. If OGTTs are done outside of your surgery at another facility, where are they done?

e. How long is the wait for an appointment for an OGTT, on average?

At your surgery \_\_\_ At other facility \_\_\_

f. How would you describe the capacity of the other facility and personnel that do OGTTs?

More than enough to meet demand \_\_\_ Just about right to meet demand \_\_\_

Inadequate to meet demand \_\_\_ Don't know \_\_\_

23. For patients from the practice who have **fasting blood** taken -

*if none of the patients from your practice get fasting blood taken, please skip to 24*

a. Does the practice perform fasting bloods in the surgery?

Yes \_\_\_ No \_\_\_ Don't know \_\_\_

b. Does the practice refer patients elsewhere for fasting bloods (in addition or instead)?

Yes \_\_\_ No \_\_\_ Don't know \_\_\_

c. What proportion of fasting bloods are done in the surgery? \_\_\_ (0-100%)

d. If fasting blood work is done outside of surgery, where is it done?

e. How long is the wait for a fasting blood appointment, on average?

At your surgery \_\_\_ At other facility \_\_\_

f. How would you describe the capacity of the other facility and personnel?

More than enough to meet demand \_\_\_ Just about right to meet demand \_\_\_

Inadequate to meet demand \_\_\_ Don't know \_\_\_

24. Please use the reverse to provide other comments you have about the screening and/or diagnosis of diabetes in your practice or in general

## Appendix B: Practice level baseline survey

Please complete one form for each practice as fully as possible with respect to the CURRENT practice situation as far as it is relevant to the diabetes screening programme and with respect to CURRENT and PLANNED diabetes screening activity.

Any queries contact Liddy Goyder on 0114 222 0783 or email: [e.goyder@sheffield.ac.uk](mailto:e.goyder@sheffield.ac.uk)

**About the practice:** (this includes all locations where screening is done eg branch surgeries,)

Where is the practice located geographically? (eg city centre, high street, housing estate)

.....

How do most patients travel to the practice? (if known, eg on foot/by bus/by car, any access problems)

.....

How many consulting rooms are available (ie rooms suitable for screening appointments)? .....

Is there a computer in every consulting room (ie every room that might be used for screening)?

Yes • No • Not known •

Is there access to interpreting/translating services Yes • No • Not known •

**Are there any recent or expected changes that could affect diabetes screening activities eg staff leaving, retirements, computer system changes, building works? (if so, please give details):**

.....

.....

What are the main reasons that the practice volunteered for pilot (if known)?

.....

**About the practice population:**

What are the main ethnic groups? (approx % population if known).....

.....

What are the main languages spoken (besides English).....

.....

Does the practice serve asylum seekers and/or refugees? Yes • No • Not known •

Approx current number and ethnic origin (if known).....

Does the practice serve nursing/residential homes? Yes • No • Not known •

Approx no of patients in nursing/residential homes (if known) .....

Does the practice consider they have a high turnover of patients? Yes • No • Not known •

Approx no new patients/yr (if known) .....

## Practice Staff and their involvement in screening

	No.	WTEs in post + any vacancies (eg 3 WTE+1 vacancy)	Ethnicity/ Languages spoken if known  (unless White/English only)	Involved in diabetes pilot?  (ü if yes)	Attended any training for diabetes pilot?  (ü if yes)
<b>Practice manager(s)</b>					
<b>GP(s)</b> 1  2  3  4					
<b>GP registrar (if a training practice)</b>					
<b>Practice nurse(s)</b> 1  2					
<b>Health care assistant(s)</b>					
<b>District nurse(s)</b>					
<b>Admin/reception staff</b>					
<b>Other(s)</b> (if involved in DHDS pilot)  Give job description					

**DHDS Pilot activities**

**Which patients are being offered screening within DHDS pilot?** (tick all that apply and give details if needed)

Age range: Over 40 years • Over 30 years • Other .....

BMI: Known BMI over 25 kg/m<sup>2</sup> • BMI not recorded • BMI not a criteria • Other.....

Other groups included in DHDS screening: Known CHD • Family history • Other.....

Exclusion criteria: Known diabetes • Known CHD • Blood glucose measured in previous 2 years •

Blood glucose recorded in previous 2 years and known to be <6 mmol/l •

Other groups not included (eg frail elderly) .....

**How are patients identified as eligible before inviting for assessment/screening? (tick all that apply)**

Computer searches • Notes review • Other .....

Details (if searches done eg on BMI, previous glucose): .....

**How are they invited for screening? (tick all that apply)**

Letter • Who sends?..... (if possible provide example of letter including translations)

Phone call • Who calls? .....

Face to face: By receptionist • By GP • By practice nurse • Other.....

Any follow-up planned if they do not respond to initial approach? 2<sup>nd</sup> letter • Phone call •

Other .....

**Who usually does screening?** Practice nurse • Healthcare assistant • GP • Other .....

**Where is screening usually done?** Practice consulting room • Other .....

**What test is done?** RCBG with cutoff 6 mmol/l (DHDS protocol) • Other .....

**What diagnostic tests are done if screening test above cutoff?** FBG x2 • OGTT • Other .....

**Who does diagnostic tests?** Practice staff • Local hospital • Other .....

**Which, if any, other checks or tests are done at the screening visit?** (tick all that apply)

None • Blood pressure • Total cholesterol • Full lipid profile • Other .....

**Is verbal advice on diet or physical activity given to patients?** Never • Sometimes • Always •

**Is any written information given to patients?** Yes • No • (please provide a copy or describe below)

.....

**Is information provided in languages other than English?** Yes • No • (please provide a copy or describe)

.....

Are local pharmacies (ie those used by the practice's patients) offering screening for diabetes?

Yes • No • Not known •

**Please add additional information if anything different is done currently for inviting or screening these specific patient groups for diabetes:**

Patients with known CHD.....

.....

Patients with known CVD (stroke, TIA, peripheral vascular disease) .....

.....

Patients in nursing/residential homes.....

.....

Patients unable to attend the surgery (eg patients who usually require home visits for non-urgent care)

.....

Patients with IGT/IFG? .....

.....

**OPTIONAL:**

Any additional information (anything potentially relevant to screening for diabetes in the practice)

.....

.....

.....

.....

.....

Who contributed to completing this form?

.....

.....

Please return to Dr Liddy Goyder, Public Health, ScHARR, Regent Court, 30 Regent St, Sheffield S1 4DA

by 27 AUGUST 2004.

Any queries contact me on: Email: [e.goyder@sheffield.ac.uk](mailto:e.goyder@sheffield.ac.uk) Tel: 0114 222 0783

**Appendix C: PCT facilitator survey**

**Own role in DHDS pilot**.....  
.....  
.....

**Hours per week PAID for DHDS facilitation** .....

**Views on initial development of DHDS pilot**

**Strengths of pilot?**

.....  
.....

**Weaknesses of pilot?**

.....  
.....

**Opportunities for implementation (ie helpful factors)?**

.....  
.....

**Threats to implementation (ie barriers)?**

.....  
.....

**Major issues influencing initial progress of pilot locally?**

.....  
.....

**Training provided for DHDS screening activities (within or outside PCT)**

Who provided: .....

Topics covered: .....

Who attended: .....

Costs (staff time and financial).....

## Appendix D: Final Activity Audit

PCT..... Practice .....

### 1. Baseline total population aged over 40 (or over 30) .....

(if this is unobtainable for start of DHDS and cannot be estimated because of a changing baseline or is inappropriate then an estimate of the average number of patients over 40 registered during the pilot is an appropriate alternative)

### 2. Number of patients not invited because they could be excluded using information in their clinical records

**TOTAL excluded** .....

#### Reasons for exclusions:

- a) Known diabetes:                      Number of patients                      .....
- b) CHD (screened at review) :      Number of patients                      .....
- c) Hypertension (screened at review) : Number of patients                      .....
- d) Recorded BMI < 25:                      Number of patients                      .....
- e) Blood glucose in last 2 yrs: Number of patients                      .....
- f) Other reasons:                      Number of patients                      .....

Give reasons.....

Brief explanation of how identified if known (eg searches of clinical information system, notes                      review,                      hospital                      lab reports).....

### 3. Total number of patients offered screening during pilot .....

Number by type of invitation                      (if not known then put "N/K")

- a) Invited with 1 letter only                      .....
- b) Invited with letter plus reminder letter                      .....
- c) Invited by telephone                      .....
- d) Invited when attending surgery                      .....
- e) Invited by other means                      .....

(explain how invited .....) )

### 4. Total number of patients screened during DHDS pilot .....

(can include those screened opportunistically so long as recorded by practices as DHDS screening)

## Appendix E: Staff time spent on DHDS activities

This form should be completed by the facilitator in consultation with the practice staff would were involved in running the DHDS pilots in each practice.

The time devoted to each activity can be estimated EITHER

1. from the total number of days or clinic sessions over the whole pilot OR
2. from an estimate of the time per patient times the number of patients for whom the activity happened

Activity	Who did (HCA/practice nurse/GP/receptionist/practice manager/facillitator)	Time spent on this activity during whole period of pilot	Training required? (yes/no)
<b>Offering screening:</b>			
Sending out letters			
Telephoning			
Organising screening appointments			
<b>Doing Screening:</b>			
Screening patients			
Arranging further testing/follow-up			
Doing blood tests			
Chasing blood test results			
<b>Other:</b>			

**Appendix F: Audit of recently diagnosed diabetes**

PCT Code:  Practice Code:  ID No.:

Age:  Sex: Male / Female BMI:  If Known Ethnic group:

Diagnosed since 1/1/2000? If YES, date:  and INCLUDE in audit  
 Note: Include as type 2 if diagnosed over age 25 AND not started on insulin at diagnosis

Recorded risk factors? FH diabetes   
 Hypertension (before diagnosis)   
 CHD/IHD (before diagnosis)   
 Previous gestational diabetes   
 Ethnicity

Symptoms recorded at diagnosis: Yes  No  N/K

Where tested: GP Surgery  Pharmacy  Other .....

CHD review  DHDS  N/K

Identified through screening? Yes  No  N/K

Results at diagnosis?: non-fasting blood glucose .....

fasting blood glucose .....

OGTT .....

HbA1c .....

Other .....

Most recent blood results ..... date.....

Treatment regime:

Diet only ..... Date started: .....

Oral hypoglycaemics (tablets only) ..... Date started: .....

Insulin..... Date started: .....

## Appendix G: Topic guide – patient interviews

### Explanation of the purpose of the interview

You may be aware that your GP practice has taken part in a pilot screening programme for people over 40 to see if they have diabetes. We have been asked to find out how the programme is working and to evaluate it so that the government can decide if it is worthwhile for all practices in England. We have selected 5 practices for detailed study, and I am talking to 3 or 4 practice staff and 3 or 4 patients in each of these practices. We selected these practices so that we could gather the views from a range of different situations. For our discussion now I would like to find out how you think the intervention affects you particularly as a patient who has been invited to take part in the screening for diabetes.

**Confidentiality; and consent to quote verbatim:** Everything you tell me is in confidence, and all information will be restricted to the research team. Nobody will know who you are in the report that we write, although we may quote some of your actual words if you are happy about that?

### Request to tape and expected duration

I would like to tape record our discussion, just for my own use, because I won't be able to remember everything that you say, and so that I don't make any mistakes about what you tell me. Is that alright with you? The discussion lasts for around 30 minutes or as long as you wish to talk, but you can tell me if you want to end it at any time. Is there anything you would like to ask me about the study, or about our discussion, before I turn on the tape?

**Demographic information:** age    ethnic group                      gender                      tenure  
employment status of    a) self                                      b) household

### 1 Check method of invitation and any repeat invitations

Could you start by describing the way in which you were invited for the screening test?

Were you invited on just one occasion, or more than once?

#### Prompts

*If more than once* - was that invitation by [*as described above*]

Have you been invited at all by

- letter                                      (*from whom?*)
- telephone call                      (*from whom?*)
- seeing a notice on a board or a leaflet
- in person [*ask who invited them*]

Has anyone else you know been invited for the test?

- a) method of invitation    b) relationship    c) ethnicity
- d) age group

### 2 Possible factors influencing attendance for the screening test

How did you feel when you were invited for the screening test?

Surprise/expected that you might be asked  
Worried;                      pleased

Did you feel that you had the right kind of information to make a decision about whether to go?

When you were invited did you feel that you had enough information to decide whether or not you wanted to go for the test?

Would you say you were quite keen to be screened for diabetes, or really not interested in being screened?

#### Prompt

Would it have made any difference to you if the information had been presented differently?

Did you have any knowledge or experience of diabetes before being invited for screening?

Know people who already have it  
Family; friends  
Seen anything on tv, in newspapers, magazines etc

How did you think about diabetes before receiving the invitation?

Think it mild,                      serious – given it any thought at all?

Thought they might be 'at risk', or immune to risk

Did you receive any encouragement or discouragement from anyone else?

Family (NB S Asian); elders; friends

Previous relationships with health professionals/ health care system

Good/bad experiences; trust

Or if you had been given more/less or a different kind of information?

If ethnic minority

*Would you say there are any issues to do with screening that might have an influence on whether people from minority ethnic communities attend for screening? Or any other groups?*

Do you feel that any special attempts were made to encourage people from ethnic minority groups to be screened? Or any other groups?

How well do you think this worked?

Can you think of any ways the invitation to attend screening might be offered differently in the future to increase the numbers of people from ethnic minority groups attending for screening? Or any other groups?

### 3 Outcome of invitation

Did you decide to go for the diabetes screening? Yes/no...reasons

If yes – have you actually had the test? How long since?

If yes - have you been given the result of your screening?

If yes – how were you given that result?

Letter, telephone, called to attend the practice to see – who?

Who from

How long after

### 4 Follow up

Have you returned to the practice as a result of your screening for diabetes?

If yes – Can you tell me a bit about what that involved for you?

Travel, time off work, different lifestyle suggested, starting medication

### 5 Costs to patients of attending for screening and subsequent treatment

Would you say you have had any additional costs associated with attending for the screening? For example  
travel costs

loss of income

If test result positive

any costs associated with subsequent treatment?

medication

changes you have made to your lifestyle - joined a gym

diet

Has it had any effect on your social or home life? What about work?

### 6 Patient perception of rationale for screening

I know you have read the information sheet and the nurse will have told you a bit about why you have had the screening test, but I would like you to just tell me in your own words as though you were telling, say, your neighbour why you think you were offered screening for diabetes..

Can you think of any better ways of inviting people for screening in the future?

Do you feel as though you would benefit from more information, education, or support?

Patients who do **not** test positive: has the experience of being invited for screening/being screened changed the way in which you think about your personal chances/susceptibility to diabetes?

That is all I wanted to ask you, but if there is anything else at all that you think is important please do tell me. Is there anything you would like to say, or to ask me before we finish?

**Thank you very much for your help**

## Appendix H: Topic guide – staff interviews

### Explanation of the purpose of the interview

We want to find out about the potential costs and benefits of rolling out the programme of cardiovascular risk reduction that includes screening for diabetes in all people aged over 40 who have cardiovascular disease or a BMI above 25. We have selected 5 practices for case studies, and I am talking to between 3 and 5 practice staff and between 3 and 5 patients in each of these practices. We selected these practices so that we could gather staff and patient views from a range of different situations. Your practice was selected as one of the study sites because it was [small/large, in a small/large city, in the north/south, has a large south Asian population] etc.

Other elements of our study include assessing the costs and benefits in economic terms, as well as the feasibility of the programme. But for our discussion now I would like to find out how you think the intervention affects the overall management and running of your practice.

**Confidentiality, and consent to quote verbatim:** Everything you tell me is in confidence, and all information will be restricted to the research team. You will not be identifiable in the report that we write, although we may quote some of your actual words if you are happy about that?

I would like to tape record our discussion, just for my own use, because I won't be able to remember everything that you say, and so that I don't make any mistakes about what you tell me. The discussion lasts for around 30 minutes or as long as you wish to talk. Is there anything you would like to ask me about the study, or about our discussion, before I turn on the tape?

### 1 Check method of identification and invitation

Have you found it useful to identify eligible patients by the age/BMI criteria?

Any other ways that patients to be invited have been identified?

Could you start by describing the way in which patients in your practice have been invited for screening?

Have you used any variation of this method?

Might some patients have been invited more than once?

By [method described above] or by different method?

Have you a view on which kind of invitation yields the greatest response?

Or does it vary according to the type of patient?

For example age, ethnicity, gender, social situation, employment status, location - distance from the practice

### 2 Estimate of the proportion of patients who have taken up the offer of screening

Do you feel able to make an estimate of the kind of take up there has for screening? Or noticed any differences in relation to

a) age group      b) ethnicity      c) gender      d) number/proportion of positive and negative results

Did you expect so many/few patients to come for the diabetes screening?

Did you expect to find so many/few positive results?

Have you any ethical concerns about any elements associated with the screening project?

### 3 Effect of the screening programme on the quality of clinical care for people with diabetes and cardiovascular disease

Would you say there has been any change at all in the quality of the care available to patients in the practice with cardiovascular disease?

Or patients with diabetes?

Or as a result of increased detection of hypertension and other risk factors?

Do you see any difference between the effects of the intervention on other patients (not necessarily identified by screening) with diabetes or with cardiovascular disease?

Any other effects - not necessarily good or bad

Would you say there is anything at all which you believe may affect the quality of care for these groups either positively or negatively?

Insufficient resources such as follow up clinics, dieticians

### 4 Costs of screening and subsequent treatment in terms of staff time in setting up the programme

Would you say that the project facilitator was able to set up the programme single handed, or do you think that some practice staff also had to spend some time on it? Where was the extra input needed?

Which, if any, practice staff have been involved? (GP, nurse, health care assistant, other) - which appears to most effective in terms of time per patient?

How long has the screening been operational?

How many patients have been a) identified? b) screened?

Have you seen any effects of the programme, such as patients identified as at risk who have taken advantage of treatment?

In your opinion, would you say that the effects of the intervention make it worth the staff input so far?

**5 Any effects on the practice staff of running the intervention programme**

Have you found that the intervention generates any problems for you as [*job title*]?

Do you anticipate any difficulties associated with the intervention in the future?

Have you found any benefits from running the intervention?

Would you say the programme brings any unanticipated benefits to staff or the practice more generally?

As far as you are aware, has carrying out the intervention had an impact on any other practice staff? [*If yes, make a note to speak to these*]

In what kind of way?

Accommodation adequate?

Do you use the 'Word' template? Happy with it? Complete it fully? Average time taken per patient?

- or created own system for recording information?

**6 Major organisational issues influencing the primary care team or facilitator**

Would you say that the intervention affects the overall management and running of your practice in any way at all?

What would you see as the most effective way of managing this?

- any way in which the intervention could be implemented more simply?

**7 Major service development issues for primary care team or facilitator**

Do you think that any patients were surprised that they had been asked to attend for screening?

Do you think that any patients were surprised that they had *not* been asked to attend for screening?

Would you say that patients who were invited to attend for screening felt they had enough information to know why they had been selected?

Do you see any way in which the intervention could be implemented more effectively? (ie have a higher take up)

Would you say there are any issues associated with take up of screening by members of minority ethnic communities? Or any other groups?

Were any special attempts made to encourage people from ethnic minority groups to be screened? Or any other groups? For example younger people.

How well do you think this worked? Would you do anything differently in the future to increase ethnic minority participation? Or any other groups?

**8 Costs to patients of attending for screening and subsequent treatment**

Do you have a view on how patients have coped with any additional costs associated with attending for the screening?

Have you noticed any costs for patients associated with subsequent treatment? Travel costs/loss of income  
Financial costs for patients associated with changes they have made to their lifestyle as a result of having a positive result?

Any other kinds of costs, such as a less full social life [*visiting the pub, eating out, at work*]

For example earlier diagnosis; leads to improved prognosis?

What would you see as the most positive effect on the quality of care for this group of patients?

Have you noticed any negative effects at all, on any kind of patient?

For example anxiety about the possibility of disease

Refusal of patient to acknowledge test result

Picked up any other conditions - hypertension

Can you recall any patients making any comments at all about the intervention?

Think it a good idea; waste of money/time; like extra health check

That is all I wanted to ask you, but if there is anything else at all that you think is important please do tell me. Is there anything you would like to say, or to ask me before we finish?

**Thank you very much for your help**

## Appendix I: Topic guide – focus groups

### 1 Identification and invitation

- a) What strategies worked well in terms of identifying patients eligible for screening?
- b) What strategies worked well in terms of inviting patients eligible for screening?
- c) What strategies worked less well?
- d) Do you think take-up is due to specific characteristics of your practice or patients (ethnicity, education, socioeconomic circumstances etc) or would you expect similar experiences in any practice?

### 2 View on the proportion of patients who took up the offer of screening

- a) We estimate that around 50% of the eligible population were screened. How do you feel about the take-up?
- b) Which factors might have had an influence on uptake?  
Prompt
  - age - gender
  - level of understanding (eg of the letter)
- c) How could uptake be improved?
- d) Some patients have suggested that giving patients some information about diabetes would aid take-up - eg S Asian people are more likely to suffer; complications include eye, kidney and foot problems - what do you think?

### 3 How do you think patients felt about being asked to come for screening?

- Prompt
- surprised - adequately informed

### 4 Overall impact on the practice staff of running the programme

- a) What strategies worked well in terms of organising screening?
- b) What strategies worked less well?
- c) Health care assistants appeared to be most appropriate in terms of cost-effective use of staff time - have you anything to say about this?  
Prompt
  - training - confidence
- d) Are there any particular service development issues for primary care teams?

### 5 Overall impacts (positive and negative)

- a) What have been the main benefits of the programme for staff?
- b) Were there impacts on other staff?  
Prompt
  - reception - accommodation
  - training - raising awareness
- c) What would you say were the main impacts on patients?  
Prompt
  - raising awareness - earlier diagnosis
  - improved prognosis - negative effects (eg anxiety)