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# Influences on the uptake of diabetes screening:

## a qualitative study in primary care


## Abstract

**Background**
To address the increasing global prevalence of type 2 diabetes healthcare organisations have been contemplating different screening and intervention strategies. Patient acceptability is a key criterion of a screening programme.

**Aim**
To explore the perspectives of those invited to attend the MY-WAIST screening study for type 2 diabetes, particularly explanations for attending or not, and views on the specific screening strategy.

**Design and setting**
Qualitative study with patients from 11 general practices (Leicestershire, UK).

**Method**
Semi-structured interviews were conducted with 24 individuals (40–69 years) invited to attend the MY-WAIST screening study, comprising 13 who attended and 11 who did not attend the screening. Additional data included reply slips from 73 individuals who declined the offer of screening. Analysis was informed by the constant comparative method.

**Results**
Two categories of influence on the decision about attending screening emerged. 1) Beliefs about type 2 diabetes candidacy and severity: perceived susceptibility to type 2 diabetes was more common amongs those who had attended; lack of perceived severity of type 2 diabetes was more common amongs those who did not attend. 2) Practical aspects about the screening strategy: the lengthy, early morning screening appointments were a barrier to uptake; screening attendees found the procedure largely acceptable. Pre-screening waist self-measurement was more memorable than the remainder of the risk-score calculation; neither impacted on uptake.

**Conclusion**
The barriers to screening uptake highlighted contribute to current debates about different screening and diagnostic tests for type 2 diabetes and future risk of type 2 diabetes. The findings are useful for those contemplating implementation of screening programmes for identifying type 2 diabetes and pre-diabetes.


**Keywords**
oral glucose tolerance test; primary care; screening; type 2 diabetes mellitus; waist circumference

## INTRODUCTION

The escalation in the incidence and prevalence of type 2 diabetes is widely documented; the predicted prevalence of diabetes in the UK by 2025 is 4 million, and most of those with the condition will have type 2 diabetes.[1]

The predicted burden of morbidity and mortality resulting from complications associated with type 2 diabetes has led to calls for improving its prevention and early detection. Early intervention has been shown to prevent or delay the progression to type 2 diabetes;[2] the most cost-effective strategy involves concurrent screening for type 2 diabetes and impaired glucose tolerance, with appropriate intervention for people who are identified as having the latter.[3]

Globally, healthcare organisations have been considering different variants of screening and lifestyle intervention programmes that could be implemented.[4,5] The NHS Health Check programme in the UK is inviting adults aged 40–74 years for risk assessment for diabetes, stroke, cardiovascular disease (CVD), and kidney disease.[6,7] The UK National Screening Committee made some implementation recommendations,[8] but there remains flexibility at both trust and practice level about the choice of test type.

Two debates surround current variations in the test type for the risk assessment of type 2 diabetes. Uncertainty pervades regarding the best indicators — alone or in combination — for identifying people at risk of having, or developing, type 2 diabetes, including pre-screening self-assessment measures such as waist measurement and/or risk-score calculators.[9,10] In addition, until recently, diagnostic testing for type 2 diabetes was based on three options: a fasting plasma glucose test, a random plasma glucose test, or an oral glucose tolerance test (OGTT), all with a second confirmatory test in the absence of symptoms.[11–16] The OGTT requires fasting, and a 2-hour wait between blood sampling before and after glucose loading.

After recent debate, the World Health Organization now recommends glycated haemoglobin (HbA1c) for diagnosis, using a cut-off point of 6.5%;[17] however, insufficient evidence has prevented formal recommendation regarding values below this level. Debate remains open about the use of HbA1c, as opposed to impaired fasting glucose or impaired glucose tolerance, to assess future risk of type 2 diabetes or lesser forms of glucose intolerance. Thus, based on current recommendations, concurrent screening for type 2 diabetes and impaired glucose regulation still requires at least a fasting glucose test and, in many cases, an OGTT.

The effectiveness of any screening strategy is dependent on successful uptake; for type 2 diabetes, previous studies in the UK have shown that the uptake of screening

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## How this fits in

Due to the increasing prevalence of type 2 diabetes, healthcare organisations have been contemplating which screening and intervention programmes to implement, and debating which tests to recommend for diagnosis of type 2 diabetes and other forms of glucose intolerance. Patient acceptability of a screening programme will affect uptake, thus it is crucial to ascertain patients' views. This qualitative study highlights likely barriers to uptake of the oral glucose tolerance test as a screening strategy, and points out a likely negative impact on addressing health inequalities.

ranges from 22% to 61%.[4,18] A key influence on uptake and a key criterion in the assessment of a screening strategy is patient acceptability.[19,20] Salient reasons for accepting the offer of screening, reported by qualitative research into other conditions, including cervical and bowel cancers and Chlamydia, have included:

- knowing someone with the condition;
- positive previous experience of screening;
- a feeling that it is one's duty to attend screening; and
- seeking reassurance.[21–23]

Explanations for declining the offer of screening have included:

- not having symptoms;
- lack of time;
- concerns about the reliability of the test; and
- fear of the outcome.[21–23]

In the case of screening for type 2 diabetes, there is evidence of limited psychological impact on patients,[24–26] but less is known about the acceptability of specific screening strategies.

This qualitative research was embedded in the Measure Your Waist (MY-WAIST) study, which aimed to assess the effectiveness, feasibility, and acceptability of a primary-care-based screening programme for risk of type 2 diabetes (see Box 1 for further details of the aims and methods). MY-WAIST involved an invitation to engage in pre-screening waist self-measurement and risk-score calculation (based on FINDRISC; Box 1),[10] followed by a screening appointment at the general practice, including an OGTT and waist measurement by a healthcare professional. MY-WAIST screening uptake was low: 8% uptake rate from those invited (Box 1). During the course of this qualitative research, people were invited to contribute to it even if they did not want to be screened; such individuals could opt to participate in a qualitative interview or complete a reply slip providing reasons why they decided not to accept the screening invitation. This article explores the perspectives of those invited for screening (including some who declined to attend), examining, in particular, explanations for attending/not attending, as well as views on this particular screening strategy, including receipt of a pre-screening self-assessment tool.

## METHOD

A qualitative design was chosen to explore people's views in depth; data were gathered through two approaches:

- a qualitative interview; and
- a reply slip.

### Qualitative interview

The screening invitation included the option of indicating willingness to participate in a qualitative interview study. Of the total sample of individuals invited to screening (*n* = 1993), 14% returned a reply slip indicating their willingness to be interviewed. From those who volunteered, purposive sampling guided selection of a sample varied in sex, age, and decision about screening attendance.

A non-clinical researcher conducted the interviews, which were semi-structured and facilitated by using a flexible topic guide (Box 2). With responders' consent, all interviews were audio-recorded and transcribed verbatim. One was conducted in the Gujarati language by an additional non-clinical researcher; this was transcribed with simultaneous translation into English. The decision to stop interviewing was guided by saturation of important themes across the combined sample of screening attenders and non-attenders.

Data analysis was informed by the constant comparative approach; transcripts were read and re-read by three researchers to develop an initial coding frame.[27] Transcripts were coded by one of these researchers, who then discussed the coded data with the other two researchers. Charting helped with organising the coded data to enable detailed exploration of key themes.[28] NVivo 7 (QSR International) was used to facilitate analysis.

## Box 1. The Measure Your WAIST (MY-WAIST) study

**Aims**

- To test the feasibility, uptake, and accuracy of a screening strategy — which included pre-screening self-measurement of waist circumference — in order to identify people with type 2 diabetes and pre-diabetes, for a multi-ethnic UK population
- To investigate the effectiveness of including a tape measure in invitation packs (in a nested randomised controlled trial [RCT])
- To explore the attitudes of patients and primary care health professionals towards the strategy, in particular relating to its acceptability

**Method**

*Recruitment*

- 11 general practices in Leicestershire, UK
- Eligibility: patients aged 40–70 years (30–70 years for people of South Asian and African-Caribbean origin) were identified through practice registers by practice staff
- Invitations were sent to 1993 eligible patients, in batches following random selection, from their general practice
- Nested RCT: in eight practices, those invited were randomly selected to receive or not receive a tape measure in their invitation pack
- All invitations included a patient information sheet that explained the purpose of the MY-WAIST study and details of the screening tests involved
- All invitations contained a risk-score questionnaire for self-completion[a]
- All invitations included the opportunity to respond by returning a brief questionnaire giving feedback about reasons for declining

*Screening appointment*

- Patients accepting the invitation for screening were asked to make an appointment at their general practice and to bring with them their completed sheet recording their self-measured waist circumference and risk-score questionnaire
- 166 patients attended for screening (8% uptake rate)[b]
- All screening participants had an oral glucose tolerance test and assessment of fasting lipids, electrolytes, and urine albumin creatinine ratio
- A waist-circumference measurement was taken by a practice health professional, who was trained in standard operating procedures
- Weight, height, and blood pressure were also measured, and participants were asked to complete a set of study questionnaires at the screening appointment

*[a]The risk-score questionnaire used was a revised version of the Finnish Diabetes Risk Score,[10] with an additional question on ethnicity and a revised illustration. [b]An uptake rate of 2.6% was recorded across three practices serving predominantly South Asian communities. The MY-WAIST study was approved by the LNR REC (reference number: 07/H0402/66).*

### Reply slip

The screening invitation also included a reply slip entitled: 'Reply slip for people who do not want to be screened'. It emphasised the optional nature of completion, and invited people to answer as many or as few questions as they wished. The first question was: 'Please give any reasons you may have for deciding not to accept screening as part of the MY-WAIST study,' and pointed out that the information would be useful for this research. A box was provided to encourage people to write a free-text response; these answers were analysed using open coding to identify common themes. The remainder of the slip comprised questions about demographic factors.

For the purpose of this article, data collected using the two approaches have been combined but, in the main, it was the richer data derived from the interviews on which the researchers drew. When presenting data, the data source is referred to in parenthesis — interview data are labelled with the responder's participant number, relationship to screening, sex, and age; reply slips are labelled with the reply slip number.

## RESULTS

A total of 24 interviews were conducted with 13 individuals who attended for screening and 11 individuals who did not. Interviewees ranged from 40–69 years; three were South Asian and the remainder white European.

Of 1827 individuals who were sent an invitation to the screening but did not attend, 73 (4%) returned a reply slip with a free-text response providing one or more reasons for not attending the screening.

### Screening attendance: beliefs about diabetes and the 'diabetes candidate'

When reflecting on the decision to attend for screening or not, interviewees' accounts were characterised by factors related to perceived candidacy for type 2 diabetes. Some interviewees specifically used the term 'candidacy/candidate':

'*I'm probably a candidate in future … .*' (R13, screened, female, 50–59 years)

Attributes of likely candidates emerged across four areas: age, heredity, lifestyle, and physical build. Interviewees considered these attributes in relation to themselves, drawing on those that were most relevant to their decision. For example, about half of the interviewees, who were mainly those that attended screening, mentioned type 2 diabetes being more likely in later middle age and, having reached this age themselves, regarded screening as appropriate:

**Box 2. Flexible topic guide for interview**

- Reflection of perceptions of risk prior to MY-WAIST invitation
- Reaction to MY-WAIST invitation and reflection on making the decision to attend or not
- Recall and experience of doing self-assessment of risk (waist measurement, risk score)
- Reflections on, and experience of, screening appointment and receipt of test results
- Thoughts on attending similar screening in future

*MY-WAIST = Measure Your Waist.*

*'I was getting to an age when I'm quite likely to get those sorts of problems.'* (R10, screened, male, 50–59 years)

About half of all interviewees reported a family history of type 2 diabetes; most of these indicated an associated sense of inevitability that they had to attend the screening:

*'My mother became diabetic type 2. She was diagnosed as being glucose intolerant first of all ... Her aunties became diabetic in older age ... and because, you know, she's had these problems, I've thought to myself, well, you know, you do inherit things and, you know, it could happen to me. So when this survey came, I thought well I'd like to take part.'* (R1, screened, female, 40–49 years)

Lack of family history was emphasised by many who did not attend for screening. Interviewees who mentioned a family history of CVD, largely, did not associate this with increased risk of type 2 diabetes; many of these also did not attend:

*'Both my parents had heart problems ... The diabetes ... there's nothing in the family ... so it had never bothered me at all. I didn't really think that I was going to be a candidate.'* (R14, screening non-attendee, female, 60–69 years)

Almost half of all interviewees described their lifestyle, particularly diet, as healthy and distinct from that of a likely type 2 diabetes candidate. For some, this was sufficient reason for not attending:

*'People who tend to be overweight perhaps, have too much sugar in their diet ... they're all risk factors for developing type 2 diabetes, but since I have a healthy diet and I'm slim and I exercise then, hopefully, I won't get it.'* (R7, screening non-attendee, female, 50–59 years)

Others, however, attended due to a stronger concern based on family history.

Slightly fewer interviewees (*n* = 8) admitted to being less healthy than they wanted to be, particularly regarding weight and size. Most interviewees linked being overweight with increased risk of type 2 diabetes, but about half made this association when talking about other people, rather than themselves:

*'There's the obesity thing, is it connected with diet, erm ... lack of exercise erm ... sitting in front of the TV excessively. Yeah, I can see that it would be a person who ... what's the phrase? "Couch potato" ... I would say that that is probably the kind of person.'* (R9, screening non-attendee, male, 50–59 years)

Weight was not specifically mentioned as a reason for attending; rather the waist-measurement aspect of the screening emphasised size and weight to a few individuals (as demonstrated in the next section).

It may be that some people invited to screening saw themselves as likely candidates, but wanted to avoid confirmation of this. A small number of reply slips noted potential consequences of the screening as a reason for not attending; for example, on one reply slip it was noted:

*'I am also concerned that if I am found to be pre-diabetic this may affect my life insurance/holiday insurance policies.'* (reply slip 22).

Nine interviewees described diabetes as less serious than other health conditions; a greater importance and fear appeared to be attached to cancer and, to some extent, CVD and stroke:

*'I just sometimes worry about strokes and cancer and things like that ... but not, erm, no, not diabetes ... no, 'cause I relate it to, as I said, diet.'* (R9, screening non-attendee, male, 50–59 years)

As such, screening for type 2 diabetes was viewed as less necessary than screening for cancer and for risk of stroke. This was associated with the belief that risk of type 2 diabetes is possible to modify and that, once diagnosed, the condition can be controlled by treatment:

*'If you've got diabetes and you, you listen to what people tell you, you can control that ... I'm aware that diabetes in, in our current age, is quite treatable, hopefully, erm, so therefore, you know, even if I was diagnosed with diabetes, there's ways and means that I could continue to live a normal life.'* (R22, screening non-attendee, male, 40–49 years)

All but one of these nine interviewees who felt that other conditions were more serious had not attended for screening.

Preoccupation with current (unrelated) health problems appeared to help minimise the perceived seriousness of type 2 diabetes; one non-attendee stated that they,

*'Already have heart and lung problems'* (reply slip 31). This featured as a reason for declining the invitation on 11 reply slips and by six interviewees. For some people, more immediate current health concerns were prioritised over prevention.

### MY-WAIST study screening process and procedures

All but two interviewees reported measuring their waist for the risk-score questionnaire that accompanied the screening invitation. Half of the interviewees reported awareness of the link between this measure and type 2 diabetes (eight others associated it with obesity and/or general bad health) but the only prior experience of waist measurement mentioned was limited to clothes-fitting (and by just three interviewees). Reactions to the measurement varied: some interviewees described feeling embarrassed, disconcerted, and, even, surprised at the result:

*'I was a bit shocked ... I just didn't think it was going to be that big. Erm ... like I say, it's not massive but er ... I did do it two or three times to make sure it was right."* (R12, screening non-attendee, female, 40–49 years)

Interviewees were roughly evenly split between those who remembered, vaguely remembered, and did not remember completing the remainder of the risk-score questionnaire.

As few interviewees could recall their score, most recalculated it during the interview. Reported scores ranged from low to high risk by interviewees who had attended the screening, but none of the interviewees who did not attend reported a score above moderate risk:

*'Well I think I was in the low one ... you know, as I said, I'm quite active so I expected it to be quite low and I'll go for it now, erm* [pause while looks at risk-score questionnaire again] *yeah I was low.'* (R18, screening non-attendee, male, 40–49 years)

The OGTT emerged as a barrier, not due to a dislike of blood tests, but because of:

- the lengthy appointment and the 2-hour wait between tests: *'I was just concerned about the amount of time, you know, to have the actual screening and everything. I thought, "oh, sounds a bit time-consuming," so that put me off.'* (R20, screening non-attendee, female, 40–49 years);
- the requirement to fast and, hence, attend an early morning appointment: *'I had* [an OGTT] *when I was pregnant with both my children and I remember those tests and that's why I didn't want to do this one because, that, it was so horrible because I couldn't eat. I have to eat within about 20 minutes of getting up.'* (R3, screening non-attendee, female, 40–49 years); and
- a dislike of Lucozade which is used in the OGTT.

Reply slips from those who declined to be screened supported these findings, with six individuals citing their reason for non-attendance as appointment length and five citing the OGTT. Other barriers included work commitments (23 reply slips), family commitments (n = 5), or being 'unavailable' (n = 8). For some interviewees, a perceived lack of severity or symptoms made overcoming such negative perceptions about the OGTT even less appealing:

*'I can't think there's many people, erm, you know, who have got busy lives, who are gonna give up, er, 2 or 3 hours to go and have the test unless they feel ill.'* (R18, screening non-attendee, male, 40–49 years)

However, having made the decision to attend the screening, interviewees appeared to have accepted any negative aspects of the OGTT, and seemed satisfied with the process when they experienced it:

*'... and then I went in and she did another test and sent off or whatever. And, yeah, it was just straightforward, no problem at all really.'* (R11, screened, female, 60–69 years)

These interviewees reported satisfaction with the waiting period for results, but there appeared to be uncertainty regarding the process of receiving results; several interviewees assumed a stance of 'no news is good news':

*'The actual waiting time, I just sort of put it to the back of my mind and was of the opinion* [that] *if anything was desperate they'd get in touch with me sooner rather than later.'* (R21, screened, female, 40–49 years)

## DISCUSSION

### Summary

Interviewees' accounts highlighted two overall categories of influence on the decision about whether to attend screening for risk of type 2 diabetes:

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## Ethical approval

The MY-WAIST study was approved by the Leicestershire, Northampton and Rutland Research Ethics Committee (reference number: 07/H0402/66).

## Provenance

Freely submitted; externally peer reviewed.

## Competing interests

All authors declare that: none has support from any company for the submitted work; Helen Eborall, Margaret Stone, Navneet Aujla, and Nicholas Taub have no non-financial interests that may be relevant to the submitted work; Kamlesh Khunti and Melanie Davies are advisers to the National Screening Committee that informed some elements of the NHS Health Check programme and are currently conducting studies as part of NIHR Collaboration for Leadership in Applied Health Research & Care on early detection of diabetes and cardiovascular disease.

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- beliefs about susceptibility to type 2 diabetes with reference to heredity and lifestyle, accompanied by perceptions about the seriousness of the condition; and
- practical aspects of the screening appointment, particularly the lengthy, early-morning appointment required for the OGTT.

Those who made the decision to attend, however, found the screening test largely acceptable. Regarding pre-screening self-assessment, the self-measurement of waist circumference was more memorable than the risk-score calculation.

It is of note that seeing oneself as a candidate did not necessarily trigger screening attendance; as indicated by some reply slips, suspicion of candidacy deterred some people from attending for fear of the consequences. Beliefs about candidacy appeared to help responders explain and justify their decision about whether or not to attend the screening; for example, reaching an age when type 2 diabetes is more likely or having a known family history of type 2 diabetes helped explain attendance, while lack of a family history could justify non-attendance.

Data from free-text responses on reply slips from those who did not wish to accept the offer of screening supported and supplemented the interview findings.

### Strengths and limitations

This qualitative study helped to explain reasons for a low uptake of the MY-WAIST screening. A key strength was the inclusion of the views of people who did not attend for screening. The views of this hard-to-reach group are especially important for assessing acceptability of specific screening strategies.

The interview sample was subject to response bias and only comprises those who were willing to participate — a bias inherent in many qualitative interview studies. Although the number of completed reply slips was relatively small compared with the total sample, and the response rate would be considered inadequate if the data were quantitative in nature, the 73 free-text written responses provided more data relating to barriers to screening than if data had derived from interviews alone.

The MY-WAIST screening programme was research-based and, by encouraging attendance, this may have influenced both views and uptake, as found previously.[29] However, these findings about the practicalities of the OGTT are likely to be directly translatable to the use of this test in routine practice.

### Comparison with existing literature

The findings extend Davison *et al*'s (coronary) candidacy construct[30] to type 2 diabetes and, specifically, to the screening context: responders' reflections on being invited for screening revealed certain physiological and lifestyle factors that they associated with a likely type 2 diabetes candidate, through a lay epidemiology process of comparing themselves to others.[30,31]

Similar to Davison *et al*'s coronary candidacy, there were notable anomalies in the construct. Although the risk factors for type 2 diabetes and CVD were often mentioned interchangeably, responders tended not to link them when considering their own type 2 diabetes candidacy (as demonstrated by the lack of significance given to family history of CVD). In addition, although overweight was usually included in the candidacy for type 2 diabetes, some responders did not regard it as increasing their own candidacy (despite admitting to being more overweight than ideal). These anomalies featured more in the accounts of non-attendees, which is understandable, as it could be argued that recognising one's own risk yet not attending could appear to be contradictory behaviour requiring justification.

A tendency to consider type 2 diabetes as lacking in severity and being easily controllable was evident, particularly in non-attendees. Previous studies argued this perception to be more pronounced in the screening context, which aims to identify type 2 diabetes at an early stage and, as such, may minimise the impact of diagnosis.[32] In this study, responders used lack of perceived severity to explain their non-attendance at screening in the first place, and severity was further minimised by the presence of other health issues.

Responders' reports of the acceptability of the self-measurement of waist circumference are in line with previous findings.[33] Furthermore, it was reportedly more memorable than the remainder of the risk-score calculation (including the score) and, in some instances, appeared to have influenced awareness of risk. The pre-screening self-assessment aspect of the MY-WAIST screening strategy was specifically designed to trigger consideration of key risk factors and, as such, may have influenced — consciously or subconsciously — responders' ideas about

candidacy. However, overall, responders' accounts indicated limited recall of the risk-score calculation aspect of the self-assessment, suggesting that although the measure has high levels of reported acceptability, it is likely to have had a low impact on perceptions about candidacy.

Responders' beliefs about type 2 diabetes were often coupled with practical barriers to attending — most typically the timing and length of appointment — which are an unfortunate consequence of using OGTTs. Although the perceived importance of screening overcame this practical barrier for some participants, the low uptake of MY-WAIST screening indicates that many people were not willing, or able, to overcome the time barrier. This barrier is likely to be more pronounced in people for whom taking a morning off work means losing a morning's pay, so may predominantly disadvantage those from lower socioeconomic backgrounds.[34] If this is the case, including OGTTs in first- or second-line screening tests is not promising in terms of addressing health inequalities.

### Implications for practice

This study highlighted barriers to the uptake of a specific primary-care-based screening programme for type 2 diabetes, including beliefs about susceptibility to, and severity of, the condition, and practical barriers related to the OGTT. The findings contribute to two important debates relating to type 2 diabetes prevention.

Although the study context means that the findings are directly relevant to those implementing the UK's NHS Health Check programme, they are widely applicable to healthcare organisations globally that are contemplating different screening strategies for type 2 diabetes. The findings are also relevant to the ongoing debate about diagnostic tests to assess the risk of developing type 2 diabetes in the future and impaired glucose regulations.

The most cost-effective strategy may involve concurrent screening for type 2 diabetes and impaired glucose regulation, followed by intervention; however, in the absence of clear recommendations regarding HbA1c values below 6.5%, identification of impaired glucose regulation still requires, at least, a fasting glucose test and, in many cases, an OGTT. This study's findings demonstrate problems with this test and, in terms of addressing health inequalities, highlight the potential negative impact of using it.

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