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System- and patient-level factors associated with non-attendance at diabetic retinopathy screening in Sutton and Merton: A qualitative analysis

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TITLE

System- and patient-level factors associated with non-attendance at diabetic retinopathy screening in Sutton and Merton: A qualitative analysis

SHORT TITLE

Reasons for non-attendance at diabetic retinopathy screening

AUTHORS

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CONFLICTS OF INTEREST

None

AUTHORS' CONTRIBUTION

AdC and RS designed the study, with input from AF. RS and AdC collected the data. AF analysed the data with input from all authors. All authors contributed to the interpretation of the results and write up for publication.

DATA SHARING STATEMENT

The dataset from which this study is based is available on request.

ABSTRACT

Objectives

Non-attendance at diabetic retinopathy screening has financial implications for screening programmes and potential clinical costs to patients. We sought to identify factors associated with patients who had never attended a screening appointment (never-attendance) in one programme.

Design

Qualitative study

Setting

One South London diabetic eye screening programme.

Participants and procedure

Patients registered who had been registered with one screening programme for at least 18 months and who had never attended screening within the programme were contact by telephone to ascertain why this was the case. Patients' general practices were also contacted for information about why each patient may not have attended. Framework analysis was used to interpret responses.

Results

Of the 296 patients, 38 were not eligible for screening and of the 258 eligible patients, 159 were not contactable (31 of these had phone numbers that were not in use). We obtained reasons from patients / general practices / clinical notes for non-attendance for 146 (57%) patients. A number of patient- and system-level factors were related to non-attendance. Patient-level factors included having other commitments, being anxious about screening, not engaging with any diabetes care and being misinformed about screening. System-level factors included miscommunication about where the patient lives, their clinical situation and practical problems that could have been overcome had their existence been shared between programmes.

Conclusions

Improved sharing of relevant information between providers has the potential to facilitate increased uptake of screening. Greater awareness of patient-level barriers may help providers offer a more accessible service.

ARTICLE SUMMARY

Strengths and limitations of this study

- Participants were never attenders at one diabetes eye screening, who are rarely researched population, as by definition they do not engage with diabetes eye screening.
- Significant effort was made to attempt to contact all never attenders; there was no limit to the number of contacts attempted until a patient was reached.
- Patients' GPs were also contacted to ascertain why a patient may not have attended diabetes eyes screening, offering a triangulation of findings.
- We ascertained reasons for non-attendance for only 57% of participants; reasons for non-attendance among patients who were not contactable may differ from those who were.
- Responses were recorded as detailed notes by the member of screening staff who contacted the patients and providers; however responses may not have been recorded verbatim.

INTRODUCTION

Around three million individuals in the UK have been diagnosed with diabetes mellitus [1] and an estimated 347 million worldwide.[2] Diabetic retinopathy and maculopathy are complications of diabetes mellitus that can affect vision. Estimates suggest that around five percent of blindness globally is caused by diabetic retinopathy and this is higher in Western European countries (17%).[3] Diabetic eye disease can be detected early and treatments are available to prevent blindness if given at an early stage of the disease.[4, 5] Organised diabetic eye screening programmes exist in a number of Western European countries, including in England. Individuals who have diabetes mellitus, who are over the age of 12 are invited to attend screening every year through a call and recall programme. There is variation across the UK in how screening is delivered: some programmes have dedicated hospital clinics, whereas others are based in GP surgeries or high-street optometrists. Patients who have sight threatening diabetic retinopathy (STDR) detected (defined as moderate or severe non-proliferative retinopathy or proliferative retinopathy or referable maculopathy) are referred for treatment or more frequent monitoring.

Non-attendance at diabetic eye screening is costly to the UK National Health Service (NHS), with one programme estimating that non-attendance cost >£78,000 (\$125,000 or €97,000) over one year.[6] In quarter 3 of 2013/2014 around 83% of patients invited for diabetic eye screening took up the offer.[7] Many of the 17% who were not screened will have attended in previous years, but a proportion of patients have never attended for screening despite being eligible. Patients who do not attend for diabetic eye screening have risk factors that make them more vulnerable to diabetic retinopathy, including having poorer A1C and blood pressure control and are more likely to have been diagnosed with diabetes for longer.[8, 9] Patients who do not attend for screening frequently are at increased risk of STDR.[10]

Research has considered the reasons why patients may not be attending for diabetic retinopathy screening. Barriers reported have included patients believing that they do not have diabetic retinopathy, embarrassment about poor glycaemic control, anxiety about

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3 treatment, conflicting priorities, believing that other hospital eye department or regular
4 optometrist appointments test for diabetic retinopathy and lack of awareness of the
5 importance of screening.[11-14] Service-level barriers have only been considered in the
6 context of screening performed at GP surgeries or high-street optometrists and not
7 community health clinic-based screening.[15] In addition, much of this work was conducted
8 outside of the UK, so may not be reflective of the UK context and the organised, free-at-the-
9 point-of-receipt, service. Previous research has suggested that we need a greater
10 understanding of the communication between retinopathy screening stakeholders.[15]

11
12 We report the findings of a qualitative study of all active patients who were registered with
13 one diabetic eye screening programme for at least 18 months and who had never attended
14 screening at one community health clinic screening programme (n=296). The study sought
15 to answer the following question: What are the patient- and system-level factors associated
16 with never-attendance at diabetic eye screening?

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METHODS

The audit was based in one South London diabetic eye screening programme (there are 61 such programmes in the UK). In this programme screening is organised centrally and appointments offered in dedicated community health clinics. In 2012/2013 this screening programme had 18,334 registered patients on their database, and an uptake rate of 84%. The screening programme identified all active patients, registered on the screening database for at least 18 months, who had never attended diabetic eye screening within the programme as of 31st March 2012 (n=296). Patients and general practice staff were contacted by a female member of the screening programme staff (RS) to ascertain why patients had not attended for screening. RS was qualified to make such enquiries as it was part of her usual job, but this means that she was also interested in increasing attendance. As patients were never attendees at this service, RS did not have a relationship with patients prior to the

study. Detailed notes were recorded for each contact made with patients and providers. Existing clinical notes on primary care and community databases were also searched. A review of consent and eligibility coding on primary care databases was undertaken and this information was cross-referenced with patients' status on the screening database to indicate where further relevant information may be held by primary care. Reasons given to explain why patients wanted to opt out of the programme during the period were recorded for those who returned opt-out forms. Three emails were sent to non-responding practices and each practice received two phone calls. The member of screening staff attempted to contact eligible patients between 1st October 2012 and 31st March 2013, including on weekends (there was no limit to the number of contacts attempted; mean number of contacts 2.5 per patient). Patients' age, gender and ethnicity were collected where available.

Framework analysis was used to qualitatively organise the patients' and providers' responses and identify categories that arose from the data.[16] This flexible method of coding allows easy retrieval of information both within and between cases. The process of charting is transparent allowing others to judge the reliability of the interpretation of the data. Analysis comprises five stages: familiarisation, the development of a thematic framework, indexing, charting and mapping. Patients' and providers' responses were coded using the thematic framework in Microsoft Excel. A second rater reviewed 10% of cases. Quotes are provided to give examples of the content of the codes. The quotes are taken from the detailed notes of telephone/email contact with the patient or general practitioner or as recorded in clinical notes.

These data were collected as part of a service evaluation (CQUIN) and performed in line with the provider's Trust guidelines.

RESULTS

Descriptive characteristics of the sample

There were 296 active patients registered on the screening database for at least 18 months who had never attended diabetic eye screening within the programme as of 31st March 2012 (at this one screening programme). Contact with patients and providers during the study identified 38 patients who were ineligible for screening, including patients who were not diabetic, who had attended previously and so were not due to be screened, who were under ophthalmology care, who were deceased and who were being seen at another eye screening programme. Of the remaining 258 patients, practices provided reasons for non-attendance for 90 patients. During the period, 159 patients were not contactable (31 of these had telephone numbers that were not in use/had no contact number) and 21 patients did not give a meaningful reason for their non-attendance. We obtained reasons from patients, providers or clinical notes for 146 (57%) patients.

The gender split was balanced in the sample (53% men). The greatest proportion of patients was in the age group 54 to 74 years (40%; Table 1). Patients' ethnicity and main language spoken was available for 162 (62%) and 78 (30%) patients respectively. Where known, most patients were from a White ethnic background (36%), followed by patients from an Asian or Asian British background (19%). Of patients whose first language was known, most spoke English (81%). There were 35 patients who were identified as having no general practitioner (16%; Table 1). During the study, 15 patients opted out of the screening programme (6%) by returning a signed opt-out form in line with national policy.

Table 1 – Patients’ demographic characteristics (n=258)

	n	%
Ethnicity		
White	94	36.4
Black or Black British	15	5.8
Asian or Asian British	49	19.0
Mixed	4	1.6
Unknown	96	37.2
Main language spoken		
English	63	24.4
Other	15	5.8
Unknown	180	69.8
Age (group in years)		
12 to 34	33	12.8
35 to 54	80	31.0
55 to 74	103	39.9
≥75	41	15.9
Missing	1	0.4
No general practitioner	35	13.6

Qualitative analysis

A number of patient- and system-level factors were identified as related to non-attendance.

Patient-level factors

Other commitments

For a number of patients, competing factors were prioritised more than screening, including having work and childcare commitments, personal or family illness and bereavements. Others were out of the area or country for a period of time and so could not attend.

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6 *"I [screening staff] called patient and his mother said that he is very ill at the*
7 *moment... She said that he vomits a lot so it is difficult to get to appointments". Male,*
8 *35 to 54 years.*

11
12 *"... patient ... said it's difficult to attend because her daughter has had a break down*
13 *and she is looking after her children". Female, 55 to 74 years.*

16
17 *"Patient called to apologise for missing his appointment this morning as he is ... on*
18 *business at present. He said he was aware he has missed a few now and needs to*
19 *be seen". Male, 35 to 54 years.*

22 23 24 25 26 27 *Anxiety about screening*

28
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30 The most common anxiety expressed was that of patients disliking the eye drops used
31 during screening (some anticipated disliking them, whereas others may have received drops
32 if screened by another programme previously). Other patients expressed a preference to
33 have a family member accompany them, and it was their family member's unavailability that
34 had prevented them from attending (in spite of transport being offered by the screening
35 programme).

36
37
38 *"Patient apologised for causing any problems and said she had the drops once and*
39 *remembers it was ok but has since read that they can sting and she has built up a*
40 *phobia about it". Female, 35 to 54 years.*

43 44 45 46 47 48 49 50 51 52 53 *Disengagement with diabetes care in general*

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56 Some relatives of patients and general practice staff reported that patients had disengaged
57 with their diabetes care in general.

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3 *"[Patient] is refusing to even discuss his condition, so all you can do is keep sending*
4 *invites". Male, 55 to 74 years.*

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8 *"[Father] told me [screening staff] that she [patient] refuses to go to any appointments*
9 *even though both he and her mother encourage her. He said that the diabetes nurse*
10 *told them she is in denial about her diabetes and that she has been this way since*
11 *she was diagnosed". Female, 12 to 34.*

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20 *Misinformed about screening*

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22 A number of patients and a few general practice staff provided reasons for their/their
23 patients' non-attendance that demonstrated them being mis-informed. These included: not
24 understanding that diabetic retinopathy screening is not performed as part of a standard
25 optician eye test, not knowing where the screening clinic is, patients believing that they are
26 not diabetic (although confirmed by GP) and patients being seen in glaucoma clinic and
27 perceiving this to be sufficient diabetes eye care.

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35 *"Patient said ... her opticians do all her eye checks". Female, 35 to 54 years.*

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41 *Forgetting*

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43 One patient reported that their non-attendance at screening was due to them forgetting to
44 attend.

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52 *System-level factors*

There were also a number of system-level factors that were related to screening non-attendance. Many of these could have been overcome had there been better communication between services.

Miscommunication about patients' residence

Some patients were reported by general practice staff to be known to be out of the area/country, some permanently. A small number of patients were known to have no fixed abode.

Practical problems

There were also practical problems that were barriers to screening attendance among patients, but could have been overcome had the screening programme been aware of them. These included patients being housebound and having transport problems (transport problems included general practice staff not knowing how to book patient transport).

"[Patient] called the GP to say that his transport has not turned up. I [screening staff] called... transport and they said that they went to an address but there was no answer (this was his old address). I advised that this is not his address... He apologised and said he will call the patient and get him here today." Male, 55 to 74 years.

Invitation letter not received/not received in time

For some patients, issues with their post made it difficult for them to attend. It is important to note that appointment letters are sent out three to four weeks in advance of appointments.

"[Patient] said that normally when she receives our letters it is the day before the appointment so there is not enough notice. She believes there may be a problem with her post." Female, 35 to 54 years.

"[Patient] says he does not receive our letters because someone where he lives throws them away. He asked for them to be sent to his work." Male, 35 to 54 years.

Clinical notes not being shared

Eligibility and consent codes applied to patients' primary care records were cross-referenced with patients' statuses on the screening database. This identified one patient whom their GP had recorded 'not indicated for diabetic retinopathy screening', 1 patient who was coded as being unsuitable for digital retinal photography, 31 patients whom their GP had recorded as having 'refused diabetic retinopathy screening' and 40 patients who were 'exempted from diabetes quality indicators' in the practice. All of these patients were recorded as eligible for screening on the screening database system.

DISCUSSION

This qualitative study sought to explain the patient- and system-level factors associated with never attendance at diabetic eye screening at this programme. Patient-factors identified during the study included having other commitments, being anxious about screening, patients not being engaged with any of their diabetes care and being misinformed about screening. System-level factors included miscommunication about patients' residences and

practical problems that could have been resolved if they were communicated between service providers.

Many of the patient-level barriers to diabetic eye screening have been reported previously, [11-13] however the system-level factors rarely come out of the published literature.[14, 15] Where they have been considered, communication issues between GPs and Diabetes Eye Screening Programmes have previously been reported in the context of GP surgery-based services.[15] In our study, a number of patients were found to be either temporarily or permanently ineligible for screening. Many of the telephone numbers available for patients were no longer in use, suggesting that this population is highly mobile. Better communication between GP surgeries and screening programmes involving more streamlined methods of transferring relevant information will help ensure that screening lists only include eligible individuals. It may be useful for commissioners and general practices to review the systems currently in place to communicate this information to the screening programmes, to make sure that it is intuitive and simple for practices to do. Screening providers are currently penalised for the non-attendance of patients who are actually ineligible for screening. Better communication could also facilitate patients who require transport to attend screening. It would also be useful for general practices to inform screening programmes if they know that their patient will be out of the country for a period of time. Previous research has also raised the concern that patients being abroad for periods of time means that they miss the annual screening cycle.[15] Some patients were known to have no fixed abode; these patients are a vulnerable group and screening programmes and GPs need to find ways to support their attending screening. Some of the patient-level factors influencing screening attendance will be more difficult for screening programmes to surmount, particularly personal or family illness and bereavement. Currently diabetes eye screening programmes continue to invite patients regardless of non-attendance (unless an opt-out form is returned) and such a strategy may be beneficial to patients with temporary personal issues, as the findings of this study suggest that they will attend when they are able to. Patients' work commitments being

a barrier to screening attendance could be overcome by increased awareness of extended opening hours. Some of the non-attendees were misinformed or anxious about screening. Screening programmes may be able to improve their invitation letter or information materials so that anxiety is better managed. It might be useful to review existing patient information with a group of patients to ensure that directions to the screening clinics and accessibility information are easily understood.

A number of patients were considered to be disengaged with all of their diabetes care, and as such represent a vulnerable group of patients as it is known that non-attenders are more likely to have poorer A1C and blood pressure control and are more likely to have been diagnosed with diabetes for longer.[8, 9] These 'hard to reach' groups have been described previously.[15] Anecdotal evidence from the phone conversations with patients during the present study also suggests that some patients would not come if all of their barriers to screening were addressed (e.g. one patient gave transport issues as a reason for non-attendance, but when transport was offered the patient provided a second reason, which was followed by a third reason when a solution to the second barrier was provided). We are not able to explore the intricacies of such patients' beliefs from this type of study and a more in-depth interview study would be a useful approach for future work. Disengaged and very resistant patients are a difficult group for screening programmes to engage, and it might be easier or more appropriate for the GP or practice nurse to persist in encouraging these patients to participate in their diabetes care, while recognising that it is patients' choice and responsibility to look after their health.

There are some notable limitations to this study. We were only able to ascertain reasons for non-attendance for 57% of eligible patients. Non-attenders are a notoriously difficult population to conduct research with and our findings provide insight into the reasons for their non-attendance. However, the reasons for non-attendance among patients who were not contactable may differ from those who were. Responses were recorded as detailed notes by the member of screening staff who contacted the patients and providers; however there

remains the possibility that responses were not recorded verbatim. The reasons that patients' provided may have been subject to responder bias, whereby they gave answers that they thought the screening programme wanted to hear. It would have been interesting to explore associations between patients' reasons for non-attendance and their diabetes care or control; however the UK diabetes eye screening programmes do not routinely have access to clinical data. All patients spoken to during the audit could speak English (although some had limited English). The information provided to patients about the screening programme is available in languages other than English, but this is not made clear on the standard information. Previous research has indicated that language barriers affect attendance,[15] but we were unable to explore this in our study.

Conclusions

Improved sharing of relevant information between healthcare services has the potential to facilitate increased uptake of diabetic eye screening in patients who have not previously attended screening. Increased awareness of patient-level barriers may be used by screening programmes to provide a more accessible service.

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CONFLICT OF INTERESTS

None.

FUNDING

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No	Item	Guide questions/description	Page number
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	6
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	6
3.	Occupation	What was their occupation at the time of the study?	6
4.	Gender	Was the researcher male or female?	6
5.	Experience and training	What experience or training did the researcher have?	6
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	6
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	n/a
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	6
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	7
Participant selection			
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	6
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	6
12.	Sample size	How many participants were in the study?	8
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	8
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	6

15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	n/a
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	8
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	n/a
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	n/a
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	7
20.	Field notes	Were field notes made during and/or after the interview or focus group?	7
21.	Duration	What was the duration of the interviews or focus group?	n/a
22.	Data saturation	Was data saturation discussed?	n/a
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	7
25.	Description of the coding tree	Did authors provide a description of the coding tree?	n/a
26.	Derivation of themes	Were themes identified in advance or derived from the data?	7
27.	Software	What software, if applicable, was used to manage the data?	7
28.	Participant checking	Did participants provide feedback on the findings?	n/a
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>	9-13
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	9-13
31.	Clarity of major themes	Were major themes clearly presented in the findings?	9-13
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	12-13

BMJ Open

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The project was funded by a NHS England Commissioning for Quality and Innovation (CQUIN) scheme. The funded had no role in the study design, data collection, analysis, manuscript preparation or the decision to submit this manuscript for publication. AF is funded by a Cancer Research UK – BUPA cancer prevention Fellowship awarded to AF (C49896/A17429).

CONFLICTS OF INTEREST

None

AUTHORS' CONTRIBUTION

AdC and RS designed the study, with input from AF. RS and AdC collected the data. AF analysed the data with input from all authors. All authors contributed to the interpretation of the results and write up for publication.

ABSTRACT

Objectives

Non-attendance at diabetic retinopathy screening has financial implications for screening programmes and potential clinical costs to patients. We sought to identify explanations for why patients had never attended a screening appointment (never-attendance) in one programme.

Design

Qualitative analysis of a service evaluation.

Setting

One South London (United Kingdom) diabetic eye screening programme.

Participants and procedure

Patients who had been registered with one screening programme for at least 18 months and who had never attended screening within the programme were contact by telephone to ascertain why this was the case. Patients' general practices were also contacted for information about why each patient may not have attended. Framework analysis was used to interpret responses.

Results

Of the 296 patients, 38 were not eligible for screening and of the 258 eligible patients, 159 were not contactable (31 of these had phone numbers that were not in use). We obtained reasons from patients / general practices / clinical notes for non-attendance for 146 (57%) patients. A number of patient- and system-level factors were given to explain non-attendance. Patient-level factors included having other commitments, being anxious about screening, not engaging with any diabetes care and being misinformed about screening. System-level factors included miscommunication about where the patient lives, their clinical situation and practical problems that could have been overcome had their existence been shared between programmes.

Conclusions

This service evaluation provides unique insight into the patient- and system-level reasons for never attendance at diabetic retinopathy screening. Improved sharing of relevant information

between providers has the potential to facilitate increased uptake of screening. Greater awareness of patient-level barriers may help providers offer a more accessible service.

ARTICLE SUMMARY

Strengths and limitations of this study

- Participants were never attenders at one diabetes eye screening, who are a rarely researched population, as by definition they do not engage with diabetes eye screening.
- Significant effort was made to attempt to contact all never attenders; there was no limit to the number of contacts attempted until a patient was reached.
- Patients' GPs were also contacted to ascertain why a patient may not have attended diabetes eyes screening, offering a triangulation of findings.
- We ascertained reasons for non-attendance for only 57% of patients; reasons for non-attendance among patients who were not contactable may differ from those who were.
- Responses were recorded as detailed notes by the member of screening staff who contacted the patients and providers; however responses may not have been recorded verbatim.

INTRODUCTION

Almost four million individuals in the UK have been diagnosed with diabetes mellitus [1] and an estimated 347 million worldwide.[2] Diabetic retinopathy and maculopathy are complications of diabetes mellitus that can affect vision. Estimates suggest that around five percent of blindness globally is caused by diabetic retinopathy and this is higher in Western European countries (17%).[3] Diabetic eye disease can be detected early and treatments are available to prevent blindness if given at an early stage of the disease.[4, 5] Organised diabetic eye screening programmes exist in a number of Western European countries, including in England. Individuals who have diabetes mellitus, who are over the age of 12 are invited to attend screening every year through a call and recall programme. There is variation across the UK in how screening is delivered: some programmes have dedicated hospital clinics, whereas others are based in GP surgeries or high-street optometrists. Patients who have sight threatening diabetic retinopathy (STDR) detected (defined as moderate or severe non-proliferative retinopathy or proliferative retinopathy or referable maculopathy) are referred for treatment or more frequent monitoring.

Non-attendance at diabetic eye screening is costly to the UK National Health Service (NHS), with one programme estimating that non-attendance cost >£78,000 (\$125,000 or €97,000) over one year.[6] In quarter 3 of 2013/2014 around 83% of patients invited for diabetic eye screening took up the offer.[7] Many of the 17% who were not screened will have attended in previous years, but a proportion of patients have never attended for screening despite being eligible. Patients who do not attend for diabetic eye screening have risk factors that make them more vulnerable to diabetic retinopathy, including having poorer A1C and blood pressure control and are more likely to have been diagnosed with diabetes for longer.[8, 9] Patients who do not attend for screening frequently are at increased risk of STDR and risk increases with the duration that an individual is unscreened.[10]

Patients who do not attend for screening are a vulnerable population and some research has sought to consider the reasons why patients may not be attending for diabetic retinopathy

screening. Barriers reported have included patients believing that they do not have diabetic retinopathy, embarrassment about poor glycaemic control, anxiety about treatment, conflicting priorities, believing that other hospital eye appointments or regular optometrist appointments test for diabetic retinopathy and lack of awareness of the importance of screening.[11-14] Service-level barriers have only been considered in research that has been conducted in the context of screening performed at GP surgeries or high-street optometrists and not community health clinic-based screening.[15] In addition, much of this work was conducted outside of the UK, so may not be reflective of the UK context, where screening is offered free-at-the-point-of-receipt through an organised call and recall system. Research that has considered service-level barriers has suggested that we need a greater understanding of the communication between retinopathy screening stakeholders (i.e. general practice and screening programmes).[15]

We report the findings of a service evaluation of all active patients who were registered with one diabetic eye screening programme for at least 18 months and who had never attended screening at one community health clinic screening programme (n=296). The study sought to explore the patient- (i.e. those determined to some extent by the patient) and system-level (i.e. those determined by the healthcare provider) reasons for never-attendance at diabetic eye screening.

METHODS

The service evaluation was based in one South London diabetic eye screening programme (there are 61 such programmes in the UK). In this programme screening is organised centrally and appointments offered in dedicated community health clinics. In 2012/2013 this screening programme had 18,334 registered patients on their database, and an uptake rate of 84%. The screening programme identified all active patients, registered on the screening database for at least 18 months, who had never attended diabetic eye screening within the

programme as of 31st March 2012 (n=296). Patients and general practice staff were contacted by a female member of the screening programme staff (RS) to ascertain why patients had not attended for screening. General practice staff were GPs, nurses and administrative staff. RS was qualified to make such enquiries as it was part of her usual job, but this means that she was also interested in increasing attendance. As patients were never attendees at this service, RS did not have a relationship with patients prior to the study. Detailed notes were recorded for each contact made with patients and providers. Existing clinical notes on primary care and community databases were also searched systematically. A review of consent and eligibility coding on primary care databases was undertaken and this information was cross-referenced with patients' status on the screening database to indicate where further relevant information may be held by primary care. Reasons given to explain why patients wanted to opt out of the programme during the period were recorded for those who returned opt-out forms. Three standardised emails were sent to non-responding practices and each practice received two phone calls which were initiated in the same way. The member of screening staff attempted to contact eligible patients between 1st October 2012 and 31st March 2013, including on weekends (there was no limit to the number of contacts attempted; mean number of contacts=2.5 per patient). Patient phone conversations were initiated in the same way, but conversations inevitably differed beyond that. Patients' age, gender and ethnicity were collected where available. The same number of data sources was accessed for each patient; there was no hierarchy (i.e. if contact was made with a patient, their provider was still contacted and clinical notes still searched).

Framework analysis was used to qualitatively organise the patients' and providers' responses and identify categories that arose from the data.[16] This flexible method of coding allows easy retrieval of information both within and between cases. The process of charting is transparent allowing others to judge the reliability of the interpretation of the data. Analysis comprises five stages: familiarisation, the development of a thematic framework, indexing, charting and mapping. Patients' and providers' responses were coded using the

thematic framework in Microsoft Excel. A second rater reviewed 10% of cases. Agreement between raters was moderate (Cohen's kappa = 0.71, $p < 0.001$). Disagreements were resolved by discussion. Quotes are provided to give examples of the content of the codes. The quotes are taken from the detailed notes of telephone/email contact with the patient or provider or as recorded in clinical notes.

These data were collected as part of a service evaluation (CQUIN) and performed in line with the provider's Trust guidelines.

RESULTS

Descriptive characteristics of the sample

There were 296 active patients registered on the screening database for at least 18 months who had never attended diabetic eye screening within the programme as of 31st March 2012 (at this one screening programme). Contact with patients and providers during the study identified 38 patients who were ineligible for screening, including patients who were not diabetic, who had attended previously and so were not due to be screened, who were under ophthalmology care, who were deceased and who were being seen at another eye screening programme. Of the remaining 258 patients, practices provided reasons for non-attendance for 90 patients. During the period, 159 patients were not contactable (31 of these had telephone numbers that were not in use/had no contact number) and 21 patients did not give a meaningful reason for their non-attendance. We obtained reasons from patients, providers or clinical notes for 146 (57%) patients.

The gender split was balanced in the sample (53% men). The greatest proportion of patients was in the age group 54 to 74 years (40%; Table 1). Patients' ethnicity and main language spoken was available for 162 (62%) and 78 (30%) patients respectively. Where known, most patients were from a White ethnic background (36%), followed by patients from an Asian or

Asian British background (19%). Of patients whose first language was known, most spoke English (81%). There were 35 patients who were identified as having no general practitioner (16%; Table 1). During the study, 15 patients opted out of the screening programme (6%) by returning a signed opt-out form in line with national policy.

Table 1 – Patients’ demographic characteristics (n=258)

	n	%
Ethnicity		
White	94	36.4
Black or Black British	15	5.8
Asian or Asian British	49	19.0
Mixed	4	1.6
Unknown	96	37.2
Main language spoken		
English	63	24.4
Other	15	5.8
Unknown	180	69.8
Age (group in years)		
12 to 34	33	12.8
35 to 54	80	31.0
55 to 74	103	39.9
≥75	41	15.9
Missing	1	0.4
No general practitioner	35	13.6

Qualitative analysis

A number of patient- and system-level factors were given to explain non-attendance.

Patient-level factors

Other commitments

For a number of patients, competing factors were prioritised more than screening, including having work and childcare commitments, personal or family illness and bereavements. Others were out of the area or country for a period of time and so could not attend. Such reasons were reported by both patients and providers.

"I [screening staff] called patient and his mother said that he is very ill at the moment... She said that he vomits a lot so it is difficult to get to appointments". Male, 35 to 54 years.

"... patient ... said it's difficult to attend because her daughter has had a break down and she is looking after her children". Female, 55 to 74 years.

"Patient called to apologise for missing his appointment this morning as he is ... on business at present. He said he was aware he has missed a few now and needs to be seen". Male, 35 to 54 years.

Anxiety about screening

The most common anxiety expressed was that of patients disliking the eye drops used during screening (some anticipated disliking them, whereas others may have received drops if screened by another programme previously). This was reported by both patients and

providers. Other patients expressed a preference to have a family member accompany them, and it was their family member’s unavailability that had prevented them from attending (in spite of transport being offered by the screening programme).

“Patient apologised for causing any problems and said she had the drops once and remembers it was ok but has since read that they can sting and she has built up a phobia about it”. Female, 35 to 54 years.

Disengagement with diabetes care in general

Some relatives of patients and general practice staff reported that patients had disengaged with their diabetes care in general.

“[Patient] is refusing to even discuss his condition, so all you can do is keep sending invites”. Male, 55 to 74 years.

“[Father] told me [screening staff] that she [patient] refuses to go to any appointments even though both he and her mother encourage her. He said that the diabetes nurse told them she is in denial about her diabetes and that she has been this way since she was diagnosed”. Female, 12 to 34.

Misinformed about screening

A number of patients and a few general practice staff provided reasons for their/their patients’ non-attendance that demonstrated them being mis-informed. These included: not understanding that diabetic retinopathy screening is not performed as part of a standard optician eye test, not knowing where the screening clinic is, patients believing that they are not diabetic (although confirmed by GP) and patients being seen in glaucoma clinic and perceiving this to be sufficient diabetes eye care.

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3 *"Patient said ... her opticians do all her eye checks". Female, 35 to 54 years.*
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8 *Forgetting*

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11 One patient reported that their non-attendance at screening was due to them forgetting to
12 attend.
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15 *System-level factors*

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18 There were also a number of system-level factors that were related to screening non-
19 attendance. Many of these could have been overcome had there been better communication
20 between services.
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23 *Miscommunication about patients' residence*

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25 Some patients were reported by general practice staff to be known to be out of the
26 area/country, some permanently. A small number of patients were known by general
27 practice staff to have no fixed abode.
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30 *Practical problems*

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33 There were also practical problems that were barriers to screening attendance among
34 patients, but could have been overcome had the screening programme been aware of them.
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36 These included patients being housebound (reported by providers) and having transport
37 problems (transport problems included general practice staff not knowing how to book
38 patient transport; reported by both patients and providers).
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“[Patient] called the GP to say that his transport has not turned up. I [screening staff] called... transport and they said that they went to an address but there was no answer (this was his old address). I advised that this is not his address... He apologised and said he will call the patient and get him here today.” Male, 55 to 74 years.

Invitation letter not received/not received in time

For some patients, issues with their post made it difficult for them to attend. It is important to note that appointment letters are sent out three to four weeks in advance of appointments.

“[Patient] said that normally when she receives our letters it is the day before the appointment so there is not enough notice. She believes there may be a problem with her post.” Female, 35 to 54 years.

“[Patient] says he does not receive our letters because someone where he lives throws them away. He asked for them to be sent to his work.” Male, 35 to 54 years.

Clinical notes not being shared

Eligibility and consent codes applied to patients’ primary care records were cross-referenced with patients’ statuses on the screening database. This identified one patient whom their GP had recorded ‘not indicated for diabetic retinopathy screening’, one patient who was coded as being unsuitable for digital retinal photography, 31 patients whom their GP had recorded as having ‘refused diabetic retinopathy screening’ and 40 patients who were ‘exempted from diabetes quality indicators’ in the practice. All of these patients were recorded as eligible for screening on the screening database system.

DISCUSSION

This service evaluation sought to explore patient- and system-level explanations for never attendance at diabetic eye screening at this programme. Patient-factors identified during the service evaluation included having other commitments, being anxious about screening, patients not being engaged with any of their diabetes care and being misinformed about screening. System-level factors included miscommunication about patients' residences and practical problems that could have been resolved if they were communicated between service providers.

Many of the patient-level barriers to diabetic eye screening have been reported previously, [11-13] however the system-level factors rarely come out of the published literature and our study provides new knowledge in this area.[14, 15] Where they have been considered, communication issues between GPs and Diabetes Eye Screening Programmes have previously been reported in the context of GP surgery-based services.[15] Uniquely, in our service evaluation, a number of patients were found to be either temporarily or permanently ineligible for screening. Many of the telephone numbers available for patients were no longer in use, suggesting that this population is highly mobile. Better communication between GP surgeries and screening programmes involving more streamlined methods of transferring relevant information will help ensure that screening lists only include eligible individuals. It may be useful for commissioners and general practices to review the systems currently in place to communicate this information to the screening programmes, to make sure that it is intuitive and simple for practices to do. Screening providers are currently penalised for the non-attendance of patients who are actually ineligible for screening. Better communication could also facilitate patients who require transport to attend screening. It would also be useful for general practices to inform screening programmes if they know that their patient will be out of the country for a period of time. Previous research has also raised the concern that patients being abroad for periods of time means that they miss the annual screening cycle.[15] Some patients were known to have no fixed abode; these patients are a

vulnerable group and screening programmes and GPs need to find ways to support their attending screening. Some of the patient-level factors influencing screening attendance will be more difficult for screening programmes to surmount, particularly personal or family illness and bereavement. Currently diabetes eye screening programmes continue to invite patients regardless of non-attendance (unless an opt-out form is returned) and such a strategy may be beneficial to patients with temporary personal issues, as the findings of this study suggest that they will attend when they are able to. Patients' work commitments being a barrier to screening attendance could be overcome by increased awareness of extended opening hours. Some of the non-attendees were misinformed or anxious about screening. Screening programmes may be able to improve their invitation letter or information materials so that anxiety is better managed. It might be useful to review existing patient information with a group of patients to ensure that directions to the screening clinics and accessibility information are easily understood.

A number of patients were considered to be disengaged with all of their diabetes care, and as such represent a vulnerable group of patients as it is known that non-attenders are more likely to have poorer A1C and blood pressure control and are more likely to have been diagnosed with diabetes for longer.[8, 9] These 'hard to reach' groups have been described previously.[15] Disengaged and very resistant patients are a difficult group for screening programmes to engage, and it might be easier or more appropriate for the GP or practice nurse to persist in encouraging these patients to participate in their diabetes care, while recognising that it is patients' choice and responsibility to look after their health.

There are some notable limitations to this service evaluation. We were only able to ascertain reasons for non-attendance for 57% of eligible patients. Non-attenders are a notoriously difficult population to conduct research with and our findings provide insight into the reasons for their non-attendance. However, the reasons for non-attendance among patients who were not contactable may differ from those who were. Responses were recorded as detailed notes by the member of screening staff who contacted the patients and providers; however

there remains the possibility that responses were not recorded verbatim. The reasons that patients' provided may have been subject to responder bias, whereby they gave answers that they thought the screening programme wanted to hear. Similarly, clinical notes and general practice staff perceptions' may not accurately reflect patients' reasons for non-attendance. It would have been interesting to explore associations between patients' reasons for non-attendance and their diabetes care or control; however the UK diabetes eye screening programmes do not routinely have access to clinical data. All patients spoken to during the service evaluation could speak English (although some had limited English). The information provided to patients about the screening programme is available in languages other than English, but this is not made clear on the standard information. Previous research has indicated that language barriers affect attendance,[15] but we were unable to explore this in our study. While patients were considered to be non-attenders at this one screening programme, it is possible that they had attended screening at least 18 months previously at another screening programme. Our findings may not be reflective of patients registered with other screening programmes. Finally, while our results are likely to be generalisable to other programmes in the England that have similar populations, the system factors may differ between programmes that employ different screening models. Our results may also not be generalisable to programmes in other countries that employ both different models of screening and have a different screening population.

Conclusions

Improved sharing of relevant information between healthcare services has the potential to facilitate increased uptake of diabetic eye screening in patients who have not previously attended screening. Increased awareness of patient-level barriers may be used by screening programmes to provide a more accessible service.

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CONFLICT OF INTERESTS

None.

FUNDING

The project was funded by a NHS England Commissioning for Quality and Innovation (CQUIN) scheme. The funded had no role in the study design, data collection, analysis, manuscript preparation or the decision to submit this manuscript for publication. AF is funded by a Cancer Research UK – BUPA cancer prevention Fellowship awarded to AF (C49896/A17429).

DATA SHARING STATEMENT

The dataset from which this service evaluation is based is available on request.

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No	Item	Guide questions/description	Page number
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	7
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	7
3.	Occupation	What was their occupation at the time of the study?	7
4.	Gender	Was the researcher male or female?	7
5.	Experience and training	What experience or training did the researcher have?	7
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	7
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	n/a
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	7
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	7
Participant selection			
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	6/7
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	7
12.	Sample size	How many participants were in the study?	8
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	8
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	6

15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	n/a
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	8
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	n/a
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	n/a
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	7
20.	Field notes	Were field notes made during and/or after the interview or focus group?	7
21.	Duration	What was the duration of the interviews or focus group?	n/a
22.	Data saturation	Was data saturation discussed?	n/a
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	7
25.	Description of the coding tree	Did authors provide a description of the coding tree?	n/a
26.	Derivation of themes	Were themes identified in advance or derived from the data?	7
27.	Software	What software, if applicable, was used to manage the data?	7
28.	Participant checking	Did participants provide feedback on the findings?	n/a
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>	10-13
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	10-13
31.	Clarity of major themes	Were major themes clearly presented in the findings?	10-13
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	10-13