PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (**http://bmjopen.bmj.com/site/about/resources/checklist.pdf**) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	System- and patient-level explanations for non-attendance at diabetic retinopathy screening in Sutton and Merton (London, UK): A qualitative analysis of a service evaluation.
AUTHORS	Strutton, Rebecca; du Chemin, Alain; Stratton, Irene; Forster, Alice

VERSION 1 - REVIEW

REVIEWER	Sheena Mc Hugh University College Cork Ireland
REVIEW RETURNED	01-Feb-2016

GENERAL COMMENTS	Objective The stated objective is to identify the factors associated with never-attendance however, as it is a qualitative study there can be no assessment of an association and also the source of the reasons for non-attendance is not clearly defined (GP perspective, family member, what is written in the notes, very rarely is it the patient themselves). Methods The study design is described as qualitative and an audit in different places, this needs further clarification. Why were more traditional qualitative interview methods not used? Patients were identified as having never attended based on the preceding 18 months, this does not seem like a very long time to qualify as a person a 'never attender'. Why was this timescale chosen? Is it possible that they had attended another diabetic screening programme or may have attended 2-3 years before? There is a need for greater clarity in the methods section about the type and sequence of information collected. Given that this paper is described as a qualitative study, there is a need for more detail on the format of data collection. The authors refer to 'detailed notes' being recorded- what did these notes consist of? Were participants' accounts recorded verbatim? Were all patients and staff asked the same questions (if so what were the questions)? There is insufficient depth or detail to consider these telephone interviews. Was a standard form used to extract data from clinical notes? It is difficult to assess how many data sources were accessed for each patient- was every patient and his/her general practice contacted? Were all non-attending patients' records checked? And was there a hierarchy i.e. if you couldn't contact a patient did you then contact the GP? How were first and second rater results managed? Results In the results section, it is difficult to ascertain who's perspective is being reported- e.g. the member of screening staff who spoke to the family member about the patient, member of general practice staff

	who might be guessing the reasons for non-attendance. Whose reasons for non-attendance are actually captured in this study? Similarly, the reasons for non-attendance may be pre-determined by the source of the information e.g. the type of information recorded on clinical notes might not be the real reason a person didn't attend. Were the reasons for non-attendance primarily from clinical notes? Practices only provided reasons for 90/258 patients and most patients were not contactable (159/258). In the majority of cases it was a third party source- the reliability of these sources needs to be discussed particularly as this study is described as a qualitative study which suggests an in-depth understanding of personal experience. Patient factors implies that the reasoning came from the patient but that is not necessarily the case. Who were the general practice staff involved as participants (GPs/nurses/admin)? There appears to be very little richness in the themes presented. One patient reported 'forgetting', however it is not clear from the description of the analysis or the results how this one occurrence is a stand-alone theme. Were there other factors that came up in single instances? The system-level factors largely emerge from the audit of the screening and practice databases- I'm unsure how this aligns with the 'qualitative' component. Discussion There is a need for greater description/clarification of this research to classify it as a qualitative study. How are the system level factors different for community-based clinics versus GP surgeries where previous research has been conducted? Anecdotal evidence should not be put forward in the discussion section unless it was identified as a finding during the analysis and supported by data and/or other research. Are the findings generalizable to the various model of screening within the English programme or programmes in other countries?

REVIEWER	Dr. Soontareeporn Thongsai Naresuan University, Thailand Overall, this is an interesting manuscript with the system-and patient-level factors associated with non attendance at diabetic retinopathy screening in Sutton and Merton. It is well written paper and very easy to read.
REVIEW RETURNED	14-Feb-2016

GENERAL COMMENTS	P.5 I think you need to strengthen the scientific rational. Also, there are some statistics about diabetic prevalence in UK that may be more up to date than the one that you provided such as, diabetes: Facts and stats in UK (2015). P.6 Regarding about research method " you address about this study was based in one South London...only" as this should be appear in the research limitation too. As this may be useful for researcher or people who interested in to be consider about this finding P.6 You should giving more detail about the RS such as "How many RS recruited in this study" " How's the RS qualified. Because most of the result were delivered by the RS. Also, Is there RS have been trained to be a research conductor? If yes should be address. It

	make it more accuracy for qualitative research. Otherwise, it may effect to the research result in-case that more than one RS conduct and had not been trained. P.7 You should giving more detail based on the Ethical consideration for instance, EC No. and name of the EC those gave permission. Also, you defined these participants group as a vulnerable group so you should provided a statement about how's your research protect these people confidential. Additionally, because the data were collected as part of the services evaluation and these may make the participant feeling anxious about giving the real reason for their non-attendance. P.8 Please provide more detail on " How's the data collection were performed such as How's long that participants were need to spending time as it's may effect for the result due to feeling tried and these may avoiding from researcher bias. P.9 You also need to provide a strong argument in the discussion on the new knowledge that results from the study Please ensure a summaries of the contribution to knowledge appear in the abstract and accessible summary

VERSION 1 – AUTHOR RESPONSE

Reviewer 1

Objective
The stated objective is to identify the factors associated with never-attendance however, as it is a qualitative study there can be no assessment of an association and also the source of the reasons for non-attendance is not clearly defined (GP perspective, family member, what is written in the notes, very rarely is it the patient themselves).

Thank you. We have revised the title and any discussion of the objective in the manuscript. For example the title is now ‘System- and patient-level explanations for never-attendance at diabetic retinopathy screening…’ and we discuss the objective (page 6, paragraph 2) as follows ‘The study sought to explore patient- and system-level reasons for never-attendance at diabetic eye screening’.

Methods
The study design is described as qualitative and a service evaluation in different places, this needs further clarification. Why were more traditional qualitative interview methods not used?

Thank you. The project was conducted as a service evaluation and was not originally intended for research, although systematic methods were used for the service evaluation. The project is more accurately described as a service evaluation and we have now revised this throughout the manuscript, but acknowledging that a qualitative analytical technique was used to explore the data produced from the service evaluation.

Patients were identified as having never attended based on the preceding 18 months, this does not seem like a very long time to qualify as a person a ‘never attender’. Why was this timescale chosen? Is it possible that they had attended another diabetic screening programme or may have attended 2-3 years before?

Thank you. We should clarify that patients were classified as having never attended if they had been

registered with the screening programme for at least 18 months and had not attended in that time. Most patients had been registered for much longer than 18 months and had never attended. There is a possibility that patients had attended screening at another programme and we have now acknowledged this limitation in the discussion.

We now say (page 16, paragraph 1): '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'.

There is a need for greater clarity in the methods section about the type and sequence of information collected. Given that this paper is described as a qualitative study, there is a need for more detail on the format of data collection. The authors refer to 'detailed notes' being recorded- what did these notes consist of? Were participants' accounts recorded verbatim? Were all patients and staff asked the same questions (if so what were the questions)? There is insufficient depth or detail to consider these telephone interviews. Was a standard form used to extract data from clinical notes?

Thank you. Detailed notes were recorded by a member of the screening programme team, but these were not verbatim (as described in the discussion). All telephone conversations to patients and providers were initiated in the same way (although differently for patients and providers), but conversations inevitably differed beyond that. Emails sent to providers were standardised. This is now described in the methods. Clinical notes were examined systematically and all relevant information listed. We now say (page 7, paragraph 1):

Existing clinical notes on primary care and community databases were also searched systematically… 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.

It is difficult to assess how many data sources were accessed for each patient- was every patient and his/her general practice contacted? Were all non-attending patients' records checked? And was there a hierarchy i.e. if you couldn't contact a patient did you then contact the GP?

Thank you. The same number of data sources was accessed for each patient. Concurrently, attempts were made to contact the patient and their provider. Clinical records were searched for all patients. There was no hierarchy (i.e. if contact was made with a patient, their provider was still contacted and clinical notes still searched). We now say (page 7, paragraph 1):

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).

How were first and second rater results managed?

Thank you. A second rater reviewed 10% of codes and Cohen's kappa used to assess reliability. Reliability was good (kappa = 0.71). Disagreements were resolved by discussion. We now say (page 8, paragraph 1):

Reliability between raters was good (Cohen's kappa = 0.71, $p<0.001$). Disagreements were resolved by discussion.

Results

In the results section, it is difficult to ascertain who's perspective is being reported- e.g. the member of screening staff who spoke to the family member about the patient, member of general practice staff who might be guessing the reasons for non-attendance. Whose reasons for non-attendance are actually captured in this study?

Thank you. We have now paid greater attention to clarify whose perspective is being reported in the results section.

Similarly, the reasons for non-attendance may be pre-determined by the source of the information e.g. the type of information recorded on clinical notes might not be the real reason a person didn't attend.

Thank you. We acknowledge that reasons ascertained from any source may not be the 'true' reason for non-attendance, but this is difficult, if not impossible to determine. We have now added this as a limitation to our discussion.

Were the reasons for non-attendance primarily from clinical notes? Practices only provided reasons for 90/258 patients and most patients were not contactable (159/258). In the majority of cases it was a third party source- the reliability of these sources needs to be discussed particularly as this study is described as a qualitative study which suggests an in-depth understanding of personal experience.

Providers gave responses for 90 patients, 78 patients were contactable and gave a meaningful response and clinical notes provided additional information for 47 patients. As discussed in response to Reviewer 1's previous comment, there are limitations in ascertaining if reasons given were accurate reflections of non-attendance (regardless of whether it was the patient responding or someone on behalf of the patient). This is now acknowledged in the discussion section.

'Patient factors implies that the reasoning came from the patient but that is not necessarily the case.

Thank you. We agree that on its own 'patient factors' could be interpreted to mean factors described by the patient, but we hope that with 'system factors' and our accompanying discussion, that it is clear that we mean factors that relate to the patient by 'patient factors'. We have added an explanation the first time the term is used in the main body of the manuscript. We now say (page 5, paragraph 2):

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.

Who were the general practice staff involved as participants (GPs/nurses/admin)?

Thank you. General practice staff were GPs, nurses and administrators. This has been added to the method. We now say (page 6, paragraph 1):

General practice staff were GPs, nurses and administrative staff.

There appears to be very little richness in the themes presented. One patient reported 'forgetting', however it is not clear from the description of the analysis or the results how this one occurrence is a stand-alone theme. Were there other factors that came up in single instances?

Thank you. There were no other factors that come up as standalone themes, so 'forgetting' could not be combined with an 'other' theme of factors that were mentioned once. We thought it interesting to report that forgetting was only discussed as a reason for non-attendance on one occasion.

The telephone conversations with patients and providers were brief and the lack of depth in the themes presented is a true reflection on the reasons given. While the findings may require further detail to be added if interventions to increase uptake of screening are to be developed, they do provide areas for further exploration. We feel strongly that this is a difficult to reach population and this manuscript has provided a rare opportunity to start to understand reasons for never attendance.

The system-level factors largely emerge from the audit of the screening and practice databases- I'm unsure how this aligns with the 'qualitative' component.

Thank you. As described above, we now describe the project throughout the manuscript as a service evaluation.

Discussion
There is a need for greater description/clarification of this research to classify it as a qualitative study.

Thank you. As described above, the term service evaluation is now used throughout the manuscript.

How are the system level factors different for community-based clinics versus GP surgeries where previous research has been conducted?

Thank you. The system level factors are likely to be different as programmes that screen within GP surgeries will undoubtedly have closer relationships to GP practice staff, and of course they will be co-located for a period. However, both models have their strengths and weaknesses. We have added this as a limitation to our discussion. We now say (page 16, paragraph 1):
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.
Anecdotal evidence should not be put forward in the discussion section unless it was identified as a finding during the analysis and supported by data and/or other research.

Thank you. We have removed this from the discussion.

Are the findings generalizable to the various model of screening within the English programme or programmes in other countries?

It is likely that our findings are generalisable to other screening programmes with similar populations. In our discussion we already discuss similarities between our study and published studies that have been conducted in services that use other screening models. For example, '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'. Screening programmes in other countries are likely to have differing set-ups and populations, which may limit the generalisability of our findings. We have added this to our limitations section. We now say (page 16, paragraph 1):

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 also may not be generalisable to programmes in other countries that employ both different models of screening and have a different screening population.
Reviewer 2

P.5 I think you need to strengthen the scientific rational. Also, there are some statistics about diabetic prevalence in UK that may be more up to date than the one that you provided such as, diabetes:

Facts and stats in UK (2015).

Thank you. We have made an effort to strengthen the rationale for the study. We have also included the ‘diabetes: facts and stats in the UK’ document recommended by the reviewer.

P.6 Regarding about research method " you address about this study was based in one South London...only" as this should be appear in the research limitation too. As this may be useful for researcher or people who interested in to be consider about this finding

Thank you. We have now acknowledged this as a limitation. We now say (page 16, paragraph 1):

Our findings may not be reflective of patients registered with other screening programmes.

P.6 You should giving more detail about the RS such as "How many RS recruited in this study" " How's the RS qualified. Because most of the result were delivered by the RS. Also, Is there RS have been trained to be a research conductor? If yes should be address. It make it more accuracy for qualitative research. Otherwise, it may effect to the research result in-case that more than one RS conduct and had not been trained.

Thank you. RS denotes the initials of the lead author for this study. Only one individual (the lead author) collected the data. We have already described why this individual was qualified to perform this part of the service evaluation in the methods.

P.7 You should giving more detail based on the Ethical consideration for instance, EC No. and name of the EC those gave permission. Also, you defined these participants group as a vulnerable group so you should provided a statement about how's your research protect these people confidential. Additionally, because the data were collected as part of the services evaluation and these may make the participant feeling anxious about giving the real reason for their non-attendance.

Thank you. The service evaluation did not require ethical approval as it was classed as a service evaluation. The service evaluation protocol was reviewed by the Trust and approved as a service evaluation. When we describe the patient as ‘vulnerable’, we mean this in the sense that they are at risk of diabetic eye disease. We acknowledge that patients may not have been honest with RS when explaining why they did not attend and have added this to the limitation section of the discussion.

P.8 Please provide more detail on " How's the data collection were performed such as How's long that participants were need to spending time as it's may effect for the result due to feeling tried and these may avoiding from researcher bias.

Thank you. We did not collect precise information on how long patients were engaged in conversation on the phone, however this was always brief (less than 5 minutes). We do not feel this duration would fatigue patients.

P.9 You also need to provide a strong argument in the discussion on the new knowledge that results from the study. Please ensure a summaries of the contribution to knowledge appear in the abstract and accessible summary

Thank you. We believe we have discussed the knowledge that this service evaluation contributes to the research field in the discussion (page 14, paragraph 2), but we have now attempted to make clearer where this is done. We have now explained the new knowledge that this service evaluation provides in the abstract.