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. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Attitudes, access and anguish: A qualitative interview study of staff and patients' experiences of Diabetic Retinopathy Screening
AUTHORS	Hipwell, Alison; Sturt, Jackie; Lindenmeyer, Antje; Stratton, Irene; Gadsby, Roger; O'Hare, Paul; Scanlon, Peter

VERSION 1 - REVIEW

REVIEWER	Edward Dervan Royal Perth Hospital Department of Ophthalmology Australia
REVIEW RETURNED	20-May-2014

GENERAL COMMENTS	The study is well thought out and results are clear. The conclusions in abstract and discussion are not justified by the results. They need to be rewritten. The discussion needs more work. A qualitative interview study to identify factors that influence uptake DR screening Participants: health professionals, screeners, patients attenders and nonattenders involving multiple practices who undertake DR screening (GPs and optometrists) Interviews: semi structured interviews Analysis: look for themes within the interview process Results: 1. Understanding DR and the purpose of screening 2. Complex factors that influence non-attendance 3. Confusion between formal DR screening and ad hoc screening in optometrists 4. Patient responsibility 5. Easy access to screening 6. Experience of screening – drops and waiting times Discussion: Repetition of results Optometry Strength and limitations Proactive communication Minimal review of literature Mydriasis – what reformulation

Summary:

A well thought out study with clear methodology.
Results are reasonable.
Conclusions in abstract and discussion are not justifiable from the results. They need to be amended
Discussion: requires work as outlined below.

Abstract:

Don't need what is already know
Page 2 line 34. "The differing regional invitation methods and screening locations were discussed, with convenience and transport safety being over-riding considerations for patients. Short appointment times were preferred by patients, some of whom experienced severe side-effects from the mydriasis drops used to dilate their pupils."
May read better as "The differing regional invitation methods and screening locations were discussed, with convenience and transport safety and short appointment times being over-riding considerations for patients. Some patients mentioned significant visual disturbance from the mydriasis drops as a deterrent to attendance.
Conclusion:
Not sure what proactive coordination of care means.
Can't really conclude that educational interventions or "improved drops" may improve uptake as you did not examine this.
What really can say is that multiple factors prior to, during and after screening are involved in the attendance and non-attendance for DR screening which include some of the above

Introduction:

A bit long
Page 3 (line 41) "Initially asymptomatic, this microvascular complication is associated with high blood glucose, high blood lipids, hypertension, smoking, non-attendance at screening, minority ethnicity (15, 16), duration of diabetes (17, 18) and existing diabetic retinopathy (19)" Don't really need this sentence. high blood glucose, high blood lipids, hypertension, duration of diabetes is associated with the development of DR. I don't think smoking is an independent risk factor. Vision loss is associated with non-attendance at screening, minority ethnicity not DR as such. Can start the paragraph with "Adequate diabetes control, regular screening and timely laser treatment can prevent visual impairment (1, 14)."

Mydraisis means to dilate pupils so "Mydriasis drops dilate patients' pupils, affecting their vision for four to six hours" this could read "patients pupils are dilated"
The side effects could be left to discussion.

Methods:
Well written (succinct and clear)
Page 5 line 37. No theme was unique to either regular attenders, or non-regular attenders. Could put this in the results. It is an important finding highlighting the complex nature of why people do or do not attend appointments.

Results:

Characteristics: Clear

	Themes identified: 1. Understanding DR and the purpose of screening 2. Complex factors that influence non-attendance 3. Confusion between formal DR screening and ad hoc screening in optometrists 4. Patient responsibility 5. Easy access to screening 6. Experience of screening – drops and waiting times Discussion: They have identified a number of factors. Have any other studies identify these factors or contradict the findings or have develop interventions to overcome these factors Should look at each finding as per the results For example the discussion is weak about the side effects of mydriasis (what drops do they use tropicamide+/- phenyephrine. Could they alter what they use (tropicamide 0.5%) is associated with less stinging. There is some studies on this. What about using no mydriasis? Pros and cons for that. I don't know the stinging is due to the osmotic effects of the drops (reference) Strengths and limitations are correct. "Several providers now deliver DRS in the UK, and, since this research was conducted, Public Health England is responsible for delivery; the 2014/15 Quality Outcomes Framework now excludes the DRS indicator. This fast-moving field requires monitoring closely. Building on the successful central appointments system and practice factors that affect DRS attendance (33), may prove useful. The national implementation of the new screening pathway should ensure consistent delivery throughout the country, improving the quality of services and reducing variability (32)." I am not sure what this means and what context it has for the paper. It seems out of place. What is a DRS indictaor? Conclusions: "This study uses staff and patients' experiences of Diabetic Retinopathy Screening to start unpicking factors affecting uptake rates. The successful implementation of the new care pathway should ensure proactive care coordination and consistent strategies to identify and address unmet access needs before, during and after screening. Clear guidance from professional bodies, a Public Health media campaign to encourage positive attitudes, and reformulated mydriasis drops, may improve DRS attendance. Used as an international model, this may, in turn, contribute to reducing preventable vision loss globally and its associated costs to individuals and their families, and to primary, secondary and social care providers" This study uses staff and patients' experiences of Diabetic Retinopathy Screening to start unpicking factors affecting uptake rates which are…. These factors should be addressed in the development and implementation of a new care pathway. "Clear guidance from professional bodies, a Public Health media campaign to encourage positive attitudes, and reformulated

	mydriasis drops, may improve DRS attendance" You cannot conclude this as you did not study this. These are possible interventions to your identified factors.

REVIEWER	Michael Summerfield Georgetown University/Washington Hospital Center, USA
REVIEW RETURNED	10-Jun-2014

GENERAL COMMENTS	May be interesting to include specific set of questions that were asked of patients included in this study as a supplemental figure. would recommend including in your discussion section of the paper, differences that were noted by patients in regards to screening at GP vs. optometrist practices (e.g. time of appt, ease of making appt, drops, etc) Obviously, as the authors point out, this study includes a small subgroup of diabetic patients and only includes certain types of care settings. Also, there is a very high specialist/screener to patient ratio in this study. I would recommend that in your discussion section, you translate your results to include how they relate to real-world screening programs.

REVIEWER	Paul Galsworthy Heart of England Foundation Trust, Grading Centre - BSBC DESP
REVIEW RETURNED	13-Jun-2014

GENERAL COMMENTS	I agree with the authors that the paper has the limitations expressed within the article. However in addition the study takes a very small sample size and as such only represents the views of a handful of people. Nationally a similar exercise should be undertaken amongst programmes preferably at a National level to establish like for like data from region to region. Much more work is needed is this field so I applaud the initial efforts of the author.

VERSION 1 – AUTHOR RESPONSE

REVIEWER 1
Abstract:
Don't need what is already know
Page 2 first paragraph of the abstract
We thank the reviewer for this suggestion; we have amended accordingly, deleting the first paragraph of the abstract

Page 2 line 34. "The differing regional invitation methods and screening locations were discussed, with convenience and transport safety being over-riding considerations for patients. Short appointment times were preferred by patients, some of whom experienced severe side-effects from the mydriasis drops used to dilate their pupils."
May read better as "The differing regional invitation methods and screening locations were discussed,

with convenience and transport safety and short appointment times being over-riding considerations for patients. Some patients mentioned significant visual disturbance from the mydriasis drops as a deterrent to attendance.
Page 2 Results section of Abstract
We thank the reviewer for this suggestion to improve clarity and we have deleted and reworded as suggested; added the word ‘pain’.
Page 2 Conclusions section of Abstract
We have added “the pharmacological reformulation of shorter-acting” mydriasis drops

Conclusion:
Not sure what proactive coordination of care means.
Page 2: Conclusion of abstract
We thank the reviewer for this suggestion to improve clarity and we have elaborated upon ‘proactive coordination of care’ by adding “involving patients, primary care and the Screening Programmes”

Can’t really conclude that educational interventions or “improved drops” may improve uptake as you did not examine this.
What really can say is that multiple factors prior to, during and after screening are involved in the attendance and non-attendance for DR screening which include some of the above
Page 2 Conclusion of abstract
We thank the reviewer for highlighting this and we have added this wording and suggested that further research is necessary to see if intervention/shorter-acting mydriasis drops help increase uptake.

Introduction:
A bit long
We have considered this perspective but feel that the introduction contains important contextual information underpinning our research. The introduction currently stands at under 500 words which is consistent with other published papers in this journal.

Page 3 (line 41) “Initially asymptomatic, this microvascular complication is associated with high blood glucose, high blood lipids, hypertension, smoking, non-attendance at screening, minority ethnicity (15, 16), duration of diabetes (17, 18) and existing diabetic retinopathy (19)” Don’t really need this sentence. high blood glucose, high blood lipids, hypertension, duration of diabetes is associated with the development of DR. I don’t think smoking is an independent risk factor. Vision loss is associated with non-attendance at screening, minority ethnicity not DR as such. Can start the paragraph with “Adequate diabetes control, regular screening and timely laser treatment can prevent visual impairment (1, 14).”
Page 3, paragraph 2 of Introduction
We have removed this sentence as per the reviewer’s suggestion.

Mydraisis means to dilate pupils so “Mydriasis drops dilate patients’ pupils, affecting their vision for four to six hours” this could read “patients pupils are dilated”
The side effects could be left to discussion.
Last line of page 3 – first line of page 4
Thank you for this helpful suggestion; we have amended the start of this sentence – but left side effects in, as it contextualizes an important finding of the study.

Methods:
Well written (succinct and clear)
We thank the reviewer for this comment.

Page 5 line 37. No theme was unique to either regular attenders, or non-regular attenders. Could put this in the results. It is an important finding highlighting the complex nature of why people do or do not attend appointments.
Page 5-6.
We thank the reviewer for this comment. We agree that this sentence may better fit in Results, so we have moved it to Results after the sample description before the first theme on page 6, adding R1's comment about importance of this.

Discussion:
Have any other studies identify these factors or contradict the findings or have develop interventions to overcome these factors
Page 11
We thank the reviewer for this suggestion, and to improve clarity and we have inserted that we've confirmed 'previous findings' to make it clear that we are discussing our results in the context of the literature.
Whilst we are aware that there are few evaluated/published and unpublished intervention and qualitative studies, the evidence that exists is discussed in relation to our own findings in the discussion.

Should look at each finding as per the results
Discussion
We agree that this is ideally how Findings should be Discussed; however, there is insufficient space within the prescribed word limit, so we have picked out the most salient results to discuss considered of greatest interest to the journal readership.

For example the discussion is weak about the side effects of mydriasis (what drops do they use tropicamide+/- phenyephrine. Could they alter what they use (tropicamide 0.5%) is associated with less stinging. There is some studies on this. What about using no mydriasis? Pros and cons for that. I don't know the stinging is due to the osmotic effects of the drops (reference)
Page 13 Future Research
We thank the reviewer for highlighting this. All programmes within the English Screening Programme perform 2-field mydriatic photography. There is no option in the English Programme not to dilate. Scotland have a three stage screening procedure and dilate those that have poor quality images which amounts to about 34%. Those who one can get good quality images in without mydriasis tend to be younger people and so Northern Ireland dilate at the age of 50 years and older, which may have some logic as younger people seem to be more debilitated by drops.
We have amended our Future Research section
Strengths and limitations are correct.
We thank the reviewer for this comment

"Several providers now deliver DRS in the UK, and, since this research was conducted, Public Health England is responsible for delivery; the 2014/15 Quality Outcomes Framework now excludes the DRS indicator. This fast-moving field requires monitoring closely. Building on the successful central appointments system and practice factors that affect DRS attendance (33), may prove useful. The national implementation of the new screening pathway should ensure consistent delivery throughout the country, improving the quality of services and reducing variability (32)."
I am not sure what this means and what context it has for the paper. It seems out of place. What is a DRS indictaor?
Page 12
We thank the reviewer for this observation and agree that the relevance of this statement required strengthening. We have simplified this section and added the phrase "These changes may affect future practice involvement and patient uptake"

Conclusions:
“This study uses staff and patients’ experiences of Diabetic Retinopathy Screening to start unpicking factors affecting uptake rates. The successful implementation of the new care pathway should ensure proactive care coordination and consistent strategies to identify and address unmet access needs before, during and after screening. Clear guidance from professional bodies, a Public Health media campaign to encourage positive attitudes, and reformulated mydriasis drops, may improve DRS attendance. Used as an international model, this may, in turn, contribute to reducing preventable vision loss globally and its associated costs to individuals and their families, and to primary, secondary and social care providers”
This study uses staff and patients’ experiences of Diabetic Retinopathy Screening to start unpicking factors affecting uptake rates which are….
These factors should be addressed in the development and implementation of a new care pathway.
“Clear guidance from professional bodies, a Public Health media campaign to encourage positive attitudes, and reformulated mydriasis drops, may improve DRS attendance”
You cannot conclude this as you did not study this. These are possible interventions to your identified factors.
Page 13 Conclusions
We thank the reviewer for this suggestion and have added (briefly) which factors we identified, using some of R1’s wording. We have removed the sentence about co-ordinated care, Public Health campaign etc.

REVIEWER 2
May be interesting to include specific set of questions that were asked of patients included in this study as a supplemental figure.
We thank the reviewer for this helpful suggestion and will upload patients & health professionals semi-structured interview schedules, as suggested

would recommend including in your discussion section of the paper, differences that were noted by patients in regards to screening at GP vs. optometrist practices (e.g. time of appt, ease of making appt, drops, etc)
Page 12 1st paragraph
We have considered the reviewer’s suggestion and note that participants themselves didn’t notice differences between GP/optometry as they only had experience of one programme – but we did observe differences in our analysis, so we have added “We observed differences between patients screened at GP vs. optometrist practices, identifying that ease of making the appointment, including its time, navigating home after the mydriasis drops, etc. appeared less problematic at GP practices.”

Obviously, as the authors point out, this study includes a small subgroup of diabetic patients and only includes certain types of care settings. Also, there is a very high specialist/screener to patient ratio in this study. I would recommend that in your discussion section, you translate your results to include how they relate to real-world screening programs.
Page 12 Discussion: Strengths and Limitations paragraph
We are unclear about the ratio to which the Reviewer is referring, and feel there has been a misunderstanding of the data provided. We have achieved a fairly even spread of numbers between professional and patient Participants, as detailed in ‘Characteristics of the sample’ on page 5. Our purposive sample did not intend to replicate specialist/screener to patient ratios found in real-world screening programmes. We have added (pg.12) “amongst our Participants” to highlight that we were not trying to be representative/ generalisable.

REVIEWER 3

I agree with the authors that the paper has the limitations expressed within the article. However in addition the study takes a very small sample size and as such only represents the views of a handful of people.
Page 12 Discussion: Strengths and Limitations paragraph
We thank the reviewer for this comment. We do not, however, agree that 62 participants is a small sample for qualitative research (in fact it is rather more than often found in published studies). We have clarified the role of qualitative analysis on p 12 to help the reader unfamiliar with qualitative research methods, which “highlight socio-cultural meanings of health and illness experiences, not simply their frequency”
Nationally a similar exercise should be undertaken amongst programmes preferably at a National level to establish like for like data from region to region.

Much more work is needed is this field so I applaud the initial efforts of the author.
Page 12 Discussion: Future Research
We thank the reviewer for this helpful suggestion and we have amended the first two sentences of this section to include some of R3’s wording: “Much more work is needed is this field. A similar exercise should be undertaken amongst a representative national sample of programmes, taking into account demographic variables that we found to be relevant, including ethnicity, delivery-mode, deprivation etc.“

IN ADDITION TO THE REVIEWERS’ HELPFUL COMMENTS, WE HAVE ALSO IDENTIFIED AN AMENDMENT THAT WE WISH TO MAKE.
We noted that the wording introducing the 1st subtheme contradicted other findings/ Discussion points Page 6 Results ‘Understandings of Diabetic Retinopathy’
Page 12 Implications for clinicians and Policy Makers - 1st sentence
Replaced “people with diabetes understood causal factors and the potential consequences of Diabetic Retinopathy” with “Some (but not all – see later subthemes) people with diabetes
Added ‘some patients’ understand retinopathy

WE HAVE ALSO HAD TO DELETE/REWORD THROUGHOUT, INCLUDING SEVERAL PARTS OF QUOTES, AS THE AMENDMENTS PUT US OVER THE 4000 WORD LIMIT
Throughout

Patients Semi-structured Interview Schedule (v3)

• Tell us about yourself and your life at present (Prompts: living alone/ with others; working, caring or retired; social activities)
• Can you describe a typical day living with diabetes? (Prompts: Examples of how it affects your daily life? Compared to how you were before becoming ill/other people who are well?)
• Can you describe a good/bad day living with diabetes?
• Is there anything that you can do to improve your experience of living with diabetes?
• When did you last see your nurse/ GP about you diabetes - and what did you talk about?
• What do you know about eye screening & diabetes?
• How did you first find out about diabetic eye screening?
• Do you know why are you asked to go?
• How do you know when and where you should go?
• Do you know what it involves? (For those who did attend screening: describe in as much detail as possible the last screening they went to)
• How does this screening fit in with the rest of your diabetes care and treatment?
• What happens after your screening – how do you find out your results?
• Have you ever missed an eye screening appointment?
• Have you ever needed any further treatments on your eyes? How did you find out what you needed,

what your options were?
• What do you think is responsible for any deteriorating eye sight you might have? Why
• Are there any changes to the service that you could suggest - from invitation to screening, receiving results/treatments options etc. that would make the screening process better for you? (E.g. link with opticians at annual eye test)
• How would you feel about going once every two years, instead of annually?
• What would you like to be able to do differently, that would make the screening process better for you?
• What (if anything) puts you off going?
• Have you ever been invited for any other type of health screening e.g. cervical/ breast /bowel – if so, how does it compare?
• Is there anything you'd like to add that we haven't covered in the interview?

Health Professionals Provisional Interview Schedule (Primary Care and Screening Professionals) (v1)

• What is your role in the diabetic retinopathy screening programme? What routines and procedures does it involve you doing?
o perceptions of relative usefulness of procedures
• Do you know how many patients attend for retinal screening here? What do you think influences this?
• Do you know what information patients receive about retinal screening, what's involved, why it's important for them? (Patient information/preparation for retinal screening)
• From your perspective, what happens when the patient attends for screening?
o What (if anything) do you have to do if they don't attend?
• Are you involved in informing patients about the results and any further actions?
• Are there any changes that you can suggest to improve the way your patients are invited to / informed about retinal screening and the service delivered, which would improve uptake?
• Are there any changes that you can suggest regarding (this) practice's response to patients, following communication of screening results?
• How important do you feel retinal screening is for patients alongside their other diabetes screening activity (Prioritisation)
• Why do you think some patients don't attend?
• How big a part of your job is retinal screening?
• How useful do you think the screening results are for informing future patient care?
• What do you think about screening once every two years, instead of annually?
• Is there anything you'd like to add that we haven't covered in the interview?

VERSION 2 – REVIEW

REVIEWER	Edward Dervan Department of Ophthalmology Royal Perth Hospital Perth
REVIEW RETURNED	07-Jul-2014

GENERAL COMMENTS	Much improved intro and discussion. Left out any discussion about non-mydriatic and mydriatic photographs in relation to the side effects of drops. For instance in Scotland they obtain non-mydriatic photos which avoids side effects but can affect quality of photos. Might be worth adding to discussion.

VERSION 2 – AUTHOR RESPONSE

We have:

- inserted two additional sentences in our Discussion, as suggested, in the 'Implications for clinicians and policy makers' section (Page 12 clean copy).
    - 'In Scotland, a 3-stage screening procedure is used; stage one is one field non-mydriatic photography, stage two is dilation, with the Scottish Screening Programme dilating approximately 34% of their population. The English Screening Programme developed following the evidence provided for 2-field digital photography by the Scanlon (32) study which recommended dilated two-field imaging.' (pp. 12-13 clean copy)
- Inserted an additional reference to support this statement:
    - 32. Scanlon, P. H., Malhotra, R., Thomas, G., Foy, C., Kirkpatrick, J. N., Lewis-Barned, N., Harney, B. & Aldington, S. J. The effectiveness of screening for diabetic retinopathy by digital imaging photography and technician ophthalmoscopy. Diabetic Medicine. 2003; 20 (6), 467-474. (p.16 of clean copy)