

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Health professionals' and service users' perspectives of shared care for monitoring wet age-related macular degeneration: a qualitative study alongside the ECHoES trial
AUTHORS	Townsend, Daisy; Reeves, Barnaby; Taylor, Jodi; Chakravarthy, Usha; O'Reilly, Dermot; Hogg, Ruth; Mills, Nicola

VERSION 1 - REVIEW

REVIEWER	Dr Amy Burton Staffordshire University United Kingdom
REVIEW RETURNED	14-Jan-2015

GENERAL COMMENTS	<p>Intro:</p> <p>- "In 2010 it was estimated that 608,213 people in the UK were suffering with AMD" - I advise the removal of the term 'suffering' as this is making assumptions about the experience of AMD for patients. My own research has highlighted that not all individuals with the condition would perceive themselves to be suffering.</p> <p>- Paragraph 4 "However, even if community optometrists can be shown to have levels of diagnostic accuracy and management competence equivalent to ophthalmologists there are many other reasons why a change in service provision may not be possible. These include the need to establish rapid access to HES in the event of reactivation, a lack of confidence from the respective groups of professionals or lack of acceptability from patients." - These points need to be supported by appropriate evidence and citations.</p> <p>Method (recruitment and sampling)</p> <p>- Paragraph 2 does not read well and requires rephrasing. The authors need to clarify what is meant by "the possibility of sampling more groups depending on emerging findings".</p> <p>- The authors also need to further explain their purposive sampling strategy - were service user/health care professional characteristics assessed as the study progressed and particular groups/individuals targeted? Were some interested service users/health care professionals turned down if a particular characteristic was already over represented in the sample?</p> <p>Method (data collection)</p> <p>- Further detail about how the focus groups were conducted is needed. It would also be useful for the interview schedule to be included as an appendix.</p> <p>Method (data analysis)</p> <p>- The authors seem to describe grounded theory techniques (cycles</p>
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	<p>of sampling and analysis, saturation etc), however they only reference constant comparison. Further references to grounded theory literature should be included to clearly explain the analysis process. Qualitative research is strengthened by being transparent - the authors may find it useful to look at Lucy Yardley's work on quality in qualitative research.</p> <p>Results: The Authors could amend their tables to make it clear to the reader which participants were involved in interviews and which in focus groups AND which participants were in a focus group together (to help understand the influence of the group members on the data produced).</p> <p>"particularly for those who lived further away from the hospital or were very elderly" - I advise the removal of the term 'elderly' as the term has negative associations. The more accepted term would be "oldest old".</p> <p>The authors use a lot of speech marks in their commentary - suggesting that the comments are direct quotes from participants. If this is the case it is important to highlight which participant the statement came from. This could be done in brackets following the data extract.</p> <p>Some of the themes contain mainly quotes from health care professionals or mainly quotes from service users with little integration between the two. The authors could improve this by including more commentary as many of the quotes are left to speak for themselves. Some extracts also need additional context (e.g. the quote regarding NHS.net needs explanation as not all readers will be familiar with this). I also have some concerns about the theme relating to service costs. The authors need to emphasise that the points raised are just the perceptions of the interviewees and not based on any objective measure of cost. What is interesting here is that the perception of cost is being used as a barrier to trialling this type of integrated service!</p> <p>Overall I think the themes here need re visiting as some extracts included are under explained and some add little new knowledge or insight, in addition some of the themes are very short/underdeveloped (e.g. the pushed to the limit theme). To me the data suggests that (1) the patient's needs and preferences are at odds with the current service being provided (2) there are a number of barriers to the exploration of possible joint services/shared care, one is the ophthalmologists perceptions of optometrists and the optometrists perceptions of ophthalmologists, another is the NHS/non-NHS divide. Rather than combining the data from both service users and health care professionals I think the write up would read better as themes based on service user data (illustrating that how care is delivered needs to be reviewed), then themes based on professional data (how could this new type of service work and what the barriers might be) with the overlap/crossovers highlighted in the discussion.</p> <p>I'd encourage the authors to revise and resubmit this work. With some more rigour in the write up and clearer presentation of the data this has the potential to be a great paper.</p>
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REVIEWER	Tom Margrain Cardiff Centre for Vision Sciences College of Biomedical and Life Sciences Maindy Road Cardiff University
REVIEW RETURNED	22-Jan-2015

GENERAL COMMENTS	<p>I really enjoyed reading this manuscript. It is well written, clear and informative. This qualitative research has provided a really useful insight into the issues surrounding shared care in the management of patient with nAMD. The quotes really helped clarify the issues raised. These findings make a useful contribution to the literature and should be published.</p> <p>The article could be published as it is. There are just a few very minor points / typos the authors might like to consider:</p> <ol style="list-style-type: none"> 1) Table 1 is very informative. Is it worth referring to it in the text? 2) It might be worth double checking the format of some of the references, some have a doi number others don't. In most but not all references the volume number is in bold, it would be good to keep the referencing consistent. 3) some of the quotes indicate [laughter]; go for upper or lower case but don't mix. 4) The manuscript refers to the work load associated with nAMD management, and 'shared care' is a model that might reduce the workload in the HES. I wonder is it worth mentioning the "treat and extend" protocols that are used in the United States as another way of reducing the overall workload / number of visits e.g. Rayess et al, Treatment Outcomes After 3 Years in Neovascular Age-Related Macular Degeneration Using a Treat-and-Extend Regimen. Am J Ophthalmol. 2015;159(1):3-8. Its not directly relevant to the substance of this paper but, it might be worth flagging that there are alternative models that don't require monthly follow up.
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REVIEWER	Alison Binns City University London
REVIEW RETURNED	28-Jan-2015

GENERAL COMMENTS	<p>This paper provides a fascinating insight into the potential barriers facing the implementation of a shared care scheme for nAMD. Given the ever-increasing burden placed on NHS resources by the condition, this is a timely and relevant investigation. The results are well presented, and the quotes are illuminating.</p> <p>A few minor suggested modifications:</p> <p>Methods: It would be good to clarify the inclusion criteria for service users i.e. Line 22 states that service users had to have nAMD, but it would be helpful to state whether they had to be receiving current treatment / had to have received treatment in the past, or whether they could have end stage, untreatable nAMD.</p> <p>Data Collection: Please clarify whether the topic guide was the same for all groups, or whether particular topics were specific to certain groups i.e. to reflect their different experiences.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer Name: Dr Amy Burton

Institution and Country: Staffordshire University, United Kingdom

Please state any competing interests or state 'None declared': None Declared

Intro:

- "In 2010 it was estimated that 608,213 people in the UK were suffering with AMD" - I advise the removal of the term 'suffering' as this is making assumptions about the experience of AMD for patients. My own research has highlighted that not all individuals with the condition would perceive themselves to be suffering.

Response: Thank you for pointing this out - we agree that the experiences of living with AMD vary considerably, and in light of this, have changed the statement to '608,213 people in the UK had AMD.'

- Paragraph 4 "However, even if community optometrists can be shown to have levels of diagnostic accuracy and management competence equivalent to ophthalmologists there are many other reasons why a change in service provision may not be possible. These include the need to establish rapid access to HES in the event of reactivation, a lack of confidence from the respective groups of professionals or lack of acceptability from patients." - These points need to be supported by appropriate evidence and citations.

Response: This sentence has been rewritten so that it includes potential challenges as identified by a study exploring alternative models of AMD care.

Method (recruitment and sampling)

- Paragraph 2 does not read well and requires rephrasing. The authors need to clarify what is meant by "the possibility of sampling more groups depending on emerging findings".

Response: We have rewritten this paragraph, and have deleted the phrase "the possibility of sampling more groups depending on emerging findings" since we had already stated in the analysis section that data collection continued until saturation was considered to have been achieved.

- The authors also need to further explain their purposive sampling strategy - were service user/health care professional characteristics assessed as the study progressed and particular groups/individuals targeted? Were some interested service users/health care professionals turned down if a particular characteristic was already over represented in the sample?

Response: Thank you for this suggestion. We have now added further information to the paragraph and hope that this is now clearer.

Method (data collection)

- Further detail about how the focus groups were conducted is needed. It would also be useful for the interview schedule to be included as an appendix.

Response: In the article, we have stated that focus groups were conducted separately for optometrists and ophthalmologists at the specialist conferences, and that focus groups with service users were held alongside the Macular Support local meetings in a separate room. We have also stated that DT conducted all of the focus groups, provided information about the topic guide that was used, and stated the average length of times for both the health professionals' and service users' focus groups. However, we agree that more detail could be provided about how DT facilitated the focus groups and interviews, and have provided more information about this. We also agree that a copy of the topic guides would improve the transparency of the research (now in the appendix).

Method (data analysis)

- The authors seem to describe grounded theory techniques (cycles of sampling and analysis, saturation etc), however they only reference constant comparison. Further references to grounded theory literature should be included to clearly explain the analysis process. Qualitative research is

strengthened by being transparent - the authors may find it useful to look at Lucy Yardley's work on quality in qualitative research.

Response: We agree that we should have stated that the method of analysis was derived from grounded theory methodology, particularly as we had cited a book on this (reference 13: Strauss A, Corbin J. Grounded theory methodology In: Denzin NK LY, editor. Handbook of Qualitative Research. London: Sage; 1994). We have now made this clearer in the text.

Results:

The Authors could amend their tables to make it clear to the reader which participants were involved in interviews and which in focus groups AND which participants were in a focus group together (to help understand the influence of the group members on the data produced).

Response: Thank you for this suggestion. To provide further context to the data, we have added rows to both tables to identify who took part in each focus group and who took part in an interview.

"particularly for those who lived further away from the hospital or were very elderly" - I advise the removal of the term 'elderly' as the term has negative associations. The more accepted term would be "oldest old".

Response: We appreciate you bringing this to our attention. We have removed 'elderly' and instead used the term 'older participants'.

The authors use a lot of speech marks in their commentary - suggesting that the comments are direct quotes from participants. If this is the case it is important to highlight which participant the statement came from. This could be done in brackets following the data extract.

Response: We had used speech marks where many participants used the same phrases and have removed most of the speech marks to prevent it distracting from the commentary. Where a quote was used from only one or two individuals, we have stated which participant(s) the quote came from in brackets.

Some of the themes contain mainly quotes from health care professionals or mainly quotes from service users with little integration between the two. The authors could improve this by including more commentary as many of the quotes are left to speak for themselves. Some extracts also need additional context (e.g. the quote regarding NHS.net needs explanation as not all readers will be familiar with this). I also have some concerns about the theme relating to service costs. The authors need to emphasise that the points raised are just the perceptions of the interviewees and not based on any objective measure of cost. What is interesting here is that the perception of cost is being used as a barrier to trialing this type of integrated service!

Response: Thank you for bring this to our attention. We have now added more quotes from service users and health professionals to integrate the data. We have also explained what NHS .net and NHS.co.uk are (with a footnote), and have added more commentary and quotes to give this point more context. Regarding the theme around the financial implications of shared care, we have used words in the commentary to make it clear that this is the health professionals' opinions (by stating that participants 'believed' or 'perceived') and have stated in the discussion that this is not an objective measure of cost.

Overall I think the themes here need re visiting as some extracts included are under explained and some add little new knowledge or insight, in addition some of the themes are very short/underdeveloped (e.g. the pushed to the limit theme). To me the data suggests that (1) the patient's needs and preferences are at odds with the current service being provided (2) there are a number of barriers to the exploration of possible joint services' shared care, one is the ophthalmologists perceptions of optometrists and the optometrists perceptions of ophthalmologists, another is the NHS/non-NHS divide. Rather than combining the data from both service users and health care professionals I think the write up would read better as themes based on service user data

(illustrating that how care is delivered needs to be reviewed), then themes based on professional data (how could this new type of service work and what the barriers might be) with the overlap/crossovers highlighted in the discussion.

Response: Thank you for your constructive comments. To address these concerns, we have extended analysis and added more commentary and quotes all to the themes, particularly the pushed to the limit theme. We originally presented the findings from health professionals and service users separately. However, we felt that many of the themes overlapped and felt it was best to combine the findings to avoid repetition and present a stronger piece of qualitative research by providing an overview of the key stakeholders' perceptions of the shared care model. By including more commentary and quotes from both groups for each theme, we hope to demonstrate how integrated the first four themes were (the remaining two, relating to the practicalities of training and the costs of shared care, were unique to the health professionals' discussions).

I'd encourage the authors to revise and resubmit this work. With some more rigour in the write up and clearer presentation of the data this has the potential to be a great paper.

Reviewer Name: Tom Margrain

Institution and Country: Cardiff Centre for Vision Sciences, College of Biomedical and Life Sciences
Maindy Road, Cardiff University, CF24 4HQ

Please state any competing interests or state 'None declared': None declared

Reviewer comments:

I really enjoyed reading this manuscript. It is well written, clear and informative. This qualitative research has provided a really useful insight into the issues surrounding shared care in the management of patient with nAMD. The quotes really helped clarify the issues raised. These findings make a useful contribution to the literature and should be published. The article could be published as it is. There are just a few very minor points/typos the authors might like to consider:

1) Table 1 is very informative. Is it worth referring to it in the text?

Response: We're pleased that table 1 is explanatory but felt it was necessary to refer to it in the text as we needed to specify why some participants' information was omitted (to protect anonymity due to their unique roles) and to provide some context about how varied the group was (in terms of geographic location and years of profession).

2) It might be worth double checking the format of some of the references, some have a doi number others don't. In most but not all references the volume number is in bold, it would be good to keep the referencing consistent.

Response: Thank you for bringing this to our attention - we have updated the references. In line with the BMJ Open's referencing style, we have now removed bold formatting and the dois.

3) Some of the quotes indicate [laughter]; go for upper or lower case but don't mix.

Reponses: We agree that should be consistent and have changed all instances to lower case.

4) The manuscript refers to the work load associated with nAMD management, and 'shared care' is a model that might reduce the workload in the HES. I wonder is it worth mentioning the "treat and extend" protocols that are used in the United States as another way of reducing the overall workload / number of visits e.g. Rayess et al, Treatment Outcomes After 3 Years in Neovascular Age-Related Macular Degeneration Using a Treat-and-Extend Regimen. Am J Ophthalmol. 2015;159(1):3-8. Its not directly relevant to the substance of this paper but, it might be worth flagging that there are alternative models that don't require monthly follow up.

Response: Thanks you for raising this. We agree that it is important to acknowledge that there are many potential models which could be implemented to relieve the hospital eye service burden and

that 'shared care' is just one of them. We have therefore referenced an article in the second paragraph which reviews possible models of AMD care, and in the paragraph introducing the proposed model of care stated that monitoring in the community is one possible strategy that could be considered.

Reviewer Name: Alison Binns

Institution and Country: City University London

Please state any competing interests or state 'None declared': None declared

Reviewer comments:

This paper provides a fascinating insight into the potential barriers facing the implementation of a shared care scheme for nAMD. Given the ever-increasing burden placed on NHS resources by the condition, this is a timely and relevant investigation. The results are well presented, and the quotes are illuminating.

A few minor suggested modifications:

Methods: It would be good to clarify the inclusion criteria for service users i.e. Line 22 states that service users had to have nAMD, but it would be helpful to state whether they had to be receiving current treatment / had to have received treatment in the past, or whether they could have end stage, untreatable nAMD.

Response: Thank you for your feedback. We apologise that this was not clear in the original submission. We have now stated in the methods section that service users with any form of nAMD were invited to join the study (regardless of whether they had nAMD in one eye or both, whether they also had dry AMD in their other eye, or whether they were currently receiving treatment or had had any in the past).

Data Collection: Please clarify whether the topic guide was the same for all groups, or whether particular topics were specific to certain groups i.e. to reflect their different experiences.

Response: Thank you. We have now stated that topic guides were developed for service users, optometrists and ophthalmologists (with specific questions for each profession) and other health professionals. We have also provided a copy of these in the appendix.

VERSION 2 – REVIEW

REVIEWER	Amy Burton Staffordshire University UL
REVIEW RETURNED	02-Mar-2015

GENERAL COMMENTS	<p>I'm happy to hear that my initial comments on this paper were of use to the authors. This is a greatly improved paper which I really enjoyed reading. I would recommend this paper for publication.</p> <p>Just a few very minor formatting issues:</p> <p>P 9, Line 43 - please replace the term "elderly" with older P 9, Line 53 - Check formatting (no space between quotes). For the patient quotes here more indication of what the participant is talking about is needed. For Mandy "oh [parking's] terrible". For Robert - indicate what his sentence is leading to? P 12, Line 36 - Check formatting (no space between quotes) P 16, Line 33 - Check formatting</p> <p>Some of the data fits very closely with my own research which may be of interest to the authors: Burton, A. E., Shaw, R. L., Gibson, J. M. (2013) Experiences of patients with age-related macular</p>
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	degeneration receiving anti-vascular endothelial growth factor therapy: A qualitative study. British Journal of Vision Impairment, 31(3), 178-188
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VERSION 2 – AUTHOR RESPONSE

We thank the reviewer for her constructive comments, and have listed our responses to the points raised and highlighted the changes made to the manuscript. We look forward to your response.

P 9, Line 43 - please replace the term "elderly" with older

Response: This has now been changed.

P 9, Line 53 - Check formatting (no space between quotes). For the patient quotes here more indication of what the participant is talking about is needed. For Mandy "oh [parking's] terrible". For Robert - indicate what his sentence is leading to?

P 12, Line 36 - Check formatting (no space between quotes)

P 16, Line 33 - Check formatting

Response: There is no space between Mandy and Robert's quotes as these conversations were from a focus group discussion. To make it clear that the comments were taken from a conversation between these participants, we have now stated that it was a focus group extract at the end of the quote (and have done this for the other two instances on page 12 and page 16). To provide more context for Robert and Mandy's quotes we have added the surrounding comments from the discussion.