Author's response to reviews

Title: Patient reported barriers and facilitators to use a self-management booklet for hip and knee osteoarthritis in primary care: Results of a qualitative interview study

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Author's response to reviews: see over
Dear Editor,

We thank the reviewers for reviewing our manuscript. We are grateful for their helpful comments and suggestions. We have addressed each comment in our revised manuscript, and provide a point-by-point response for each of the concerns. We hope that by incorporating the comments this revised manuscript is suitable for publication.

On behalf of all authors,

Sincerely yours,

Nienke Cuperus
1. P. 12 Explain that ‘u’, ‘r’ and ‘n’ means ‘users’, ‘readers’ and ‘non-users’ before using them in the results section.

   -- Answer -
   During the analysis of the interviews we identified that patients’ answers to the question “do you use the booklet” were inconsistent between the questionnaires and the interviews. We decided to categorize booklet use based on the information gathered by the interviews. This resulted in three subgroups: users (u), readers (r) and non-users (n). This categorization emerged from the analysis of the interviews and was not determined by the researchers prior to the interviews. Therefore, we presented this categorization in the result section of the manuscript. However, we agree with the reviewer that it would be more distinct for the reader to present this categorization already in the method section.

   *We included the following line in the data analysis paragraph of the method section: “Patients were then categorized as non-users (n), users (u) or readers (r) of the booklet.”*

2. 2. P. 3, l. 7 Change ‘use’ to ‘using’.

   -- Answer --
   As suggested by the reviewer we changed the word use to using.

3. Since the purpose of the study is to assess barriers and facilitators to patients using a self-management booklet this should be reflected in the title, e.g. ‘Examining the barriers and facilitators for patients to using a self-management booklet for hip and knee osteoarthritis’ I think it would also be useful to emphasise that this was distributed by GPs.

   -- Answer --

   *We thank the reviewer for this suggestion and adjusted the title: “Patient reported barriers and facilitators to use a self-management booklet for hip and knee osteoarthritis in primary care: Results of a qualitative interview study.”*

4. Provide more information on the Integrated Change model (I-Change). What topics were derived from the I-Change model? I know this is in table 1 at the end of the paper but I think it would be useful to outline them here. Explain why the I-Change model is the most comprehensive model for understanding barriers and facilitators.

   -- Answer -
   We used the I-Change model as theoretical framework to structure the interviews. We selected this model as it incorporates insights of several health related behavioural models. Due to the integrated nature of the I-Change model, this model made it feasible to explore a broad spectrum of barriers and facilitators for patients to use the booklet “Care for Osteoarthritis”. The I-Change model postulates that behaviours is influenced by intention, which is in turn influenced by motivation factors, awareness factors, information factors and predisposing factors. The interview guide therefore contained questions regarding behaviour (booklet use), motivation factors, awareness factors and information factors. We did not ask patients about their current intention with regard to using the booklet as patients were interviewed 12 months after they received the booklet. Predisposing factors such as demographic variables were already assessed in the questionnaires of the BART-project and were therefore not assessed during the interviews.

   *We changed the second part of the paragraph regarding the data collection in the method section:*

   “An interview guide with open-ended questions was developed with topics that were derived from a broad behavioural model i.e. the I-Change model, postulating that behaviour...
is the result of a person’s intention which is in turn influenced by motivational factors, awareness factors, information factors and predisposing variables. We selected the I-Change model as the theoretical framework for the current study as it incorporates insights of several behavioural models. Due to its integrated nature, the I-Change model made it feasible to explore a broad spectrum of potential barriers and facilitators for patients to use the booklet. The interview guide contained questions regarding behaviour (i.e. booklet use), motivation factors, awareness factors and information factors. We did not ask patients about their current intention with regard to using the booklet as patients were interviewed 12 months after they had received the booklet; predisposing factors such as demographic variables were already assessed by the questionnaires of the BART-project.”

5. Detailed information about the booklet ‘Care for Osteoarthritis’ may be more suitable in the ‘background’ section. Also consider whether it is necessary to provide information about how the booklet was developed.

--- Answer ---
We agree with the reviewer that information about the booklet might be more suitable in the background section. Besides the information that the booklet was developed in collaboration with users of the booklet i.e. patients and GPs, we agree with the reviewer that it is not necessary to provide detailed information about how the booklet was developed.

As you suggested, we extended information on the booklet in the background section and removed the information on the booklet given in the method section:

“One strategy to enhance self-management in the treatment of chronic diseases is the use of patient booklets. Based on the evidence-based, multidisciplinary, patient-centred, stepped-care strategy for hip or knee OA i.e. BART (Beating osteoARThritis), a patient-friendly self-management booklet “Care for Osteoarthritis” (Zorgwijzer Artrose©) was systematically developed in collaboration with OA patients and GPs and was introduced in primary healthcare in a region of the Netherlands. This booklet consists of three sections. The first section provides information about OA in general and gives an overview of the health care providers involved in OA care. The second section provides information about non-surgical evidence-based treatment options for hip and knee OA and its optimal sequence in three steps which is based on the stepped-care strategy for hip or knee OA. To enhance the patient’s active role in the treatment of OA as well as the communication with health care providers, the third section of the booklet contains tools to monitor symptoms, to evaluate the effect of treatment, to prepare consultations, and to formulate a comprehensive overview of the treatment options that already have been carried out. To successfully introduce this booklet on a large scale, we should evaluate its implementation among the stakeholder group of end users, i.e. the patient.”

6. Reconsider the sentence p. 9, l. 4 ‘No other relationship existed with the participants prior to the interviews, thus excluding possible influences on the participants’ responses during the interview’. There are a number of other factors that may influence the participants’ responses during the interview, e.g. gender of the interviewer, position of seniority etc. We cannot therefore assume that all bias has been removed.

--- Answer ---
Thank you. Indeed, we cannot assume that all bias has been removed only by reporting that there were no other relationships between the participants and the researchers.

As suggested by the reviewer, we rephrased this line:

“Both researchers were also responsible for the data collection in the BART-project; no other relationship existed with the participants prior to the interviews.”

7. Reconsider p. 9, l. 13-14 ‘the questions had an open-ended format to prevent the prejudiced interpretation of the researchers while allowing participants to tell their stories’. I know what you mean but perhaps it could be a bit clearer, e.g. ‘open ended questions provided participants with the scope to express themselves freely’. 
As suggested by the reviewer we rephrased this line:
“The questions had an open-ended format to provide patients with the scope to talk about their experiences and perspectives freely and in their own words, with minimal prejudiced interpretation of the researchers”.

8. I would be reluctant to conclude that data saturation was reached after 17 interviews. Most qualitative studies use between 20-30 interviews so this is a relatively small number.

-- Answer -
We agree with the reviewer that 17 interviews is relatively small. During the development of the study design for the current study we decided to stop the data collection when the researchers were not able to identify any “new” information i.e. when analytical saturation had been achieved. After each interview had taken place, the interviews were analysed by two researchers. The researcher decided that analytical saturation was achieved after the 17th interview and therefore we ended the recruitment of patients. However, it might be possible that we would have found any new information in additional interviews.

The following line was rephrased and added to the data collection paragraph of the method section:
“The number of interviews performed was determined by consensual agreement of the researchers that analytical saturation had been achieved i.e. the coding process (as described below) revealed no new information”.

9. P. 17, l. 20 Why do you think it was more valid to categorize booklet use based on the interviews rather than the questionnaires?

-- Answer --
We think it is more valid to categorize booklet use based on the interviews rather than on the questionnaires because in the interviews we were able to explore in more detail how patients used the booklet.

The following line was rephrased and added to the limitations paragraph of the discussion section:
“We chose to categorize booklet use based on the interviews as we considered these answers most valid because in the interviews we were able to explore in more detail how patients used the booklet”.

10. P. 17, l. 20 Were barriers and facilitators explored in the questionnaires as well? I don’t think this was mentioned elsewhere.

-- Answer -
In the questionnaire of the BART-project we only asked patients who answered “no, never” to the question “Do you use the booklet “Care for Osteoarthritis”?” to report their reason(s) for this. This resulted in a broad variety of reasons which inspired us to perform this qualitative research.
Reviewer 2

Comments to the author:
This paper presents a highly relevant topic: supporting patients in their self-management behaviour, while interacting with their health care providers. A number of issues can to be clarified, to improve the quality of the paper. These will be listed below.

We thank the reviewer for the helpful comments and suggestions. On the basis of the comments we made multiple corrections.

1. The title and research aim of the study, is not aligned with the results that are presented in this paper. It is suggested that the content of the booklet is the study objective, i.e. “patients’ perceptions of a self-management booklet”, whereas the study is mainly about achieving self-management. The booklet is just the tool. The authors are encouraged to rephrase the research objective and outcomes throughout the manuscript.

-- Answer --
We understand the abovementioned concerns of the reviewer. The primary aim of the current qualitative study was to evaluate the introduction of the booklet “Care for Osteoarthritis” by exploring barriers and facilitators for patients to use this booklet and not to assess patients perceptions towards achieving self-management. This qualitative study is part of the umbrella BART-project (Beating osteoARThritis) that aims to implement the stepped-care strategy for hip and knee OA in primary care in a region of the Netherlands and to evaluate this implementation. In the BART-project several implementation activities have been developed and implemented in clinical practice. One of these implementation activities is the introduction of the self-management booklet “Care for Osteoarthritis”. As part of the BART-project, we evaluated the introduction of this booklet in the current qualitative study. Since the booklet “Care for Osteoarthritis” aims to support patients in their self-management behaviour, patients perceptions towards achieving self-management are represented in this study. Especially in theme 2, the patient’s attitude towards self-management emerged from the data analysis.

To clarify the research objective of the current study, we made multiple corrections:
- We rephrased the title: “Patient reported barriers and facilitators to use a self-management booklet for hip and knee osteoarthritis in primary care: Results of a qualitative interview study”.
- At the end of the second paragraph of the introduction we added the following line: “To successfully introduce this booklet on a large scale, we should evaluate its implementation among the stakeholder group of end users, i.e. the patient”.
- We rephrased the objective of the study in the last paragraph of the introduction: “The aim of this qualitative interview study was to evaluate the introduction of the booklet “Care for Osteoarthritis” by 1.) exploring how patients used the booklet and 2.) identifying patient reported barriers and facilitators to use het booklet”.

2. The aim of the booklet is 3-fold: (i) educate patients about OA; (ii) enhance patients’ active role in the treatment course; and (iii) improve communication with healthcare providers. It would have been helpful to address the three aims separately, as they might have their own specific barriers and facilitators. The authors could be more explicit about this.

-- Answer --
Indeed the aims of the booklet are 1. to educate patients, 2. to enhance the patients’ active role in the treatment course and 3. to improve communication with health care providers. It might be that these three aims have their own specific barriers and facilitators. However, in the results section we did not address these three aims separately as within qualitative research the themes emerge from the data analysis. This means that we did not specify the themes prior to the data analysis, but identified the themes during an iterative process of constant comparison of the data.
3. The study was part of the umbrella project BART. BART aims to implement the stepped-care strategy for hip and knee OA in primary care and to evaluate the implementation process. The authors refer to Heuts et al (2005) for more background information about this study. This paper, published in 2005, presents the results of trial. It’s unclear when the trial was performed (at least before 2005, which is 8 years ago) and when the data were collected for the qualitative study. There seems to be a time lag, that cannot be explained from the provided information. This should be clarified.

-- Answer --
Thank you very much for pointing this out. Unfortunately, we made a mistake in the reference list; we apologize for the confusion. Of course this should be clarified. The reference of Heuts et al. should be the study of Smink et al. (2011). “Beating osteoARThritis”: development of a stepped care strategy to optimize utilization and timing of non-surgical treatment modalities for patients with hip or knee osteoarthritis

We deleted the reference of the study of Heuts et al (2005) and included the reference of the study of Smink et al. (2011)

We added the period of the BART-project to the paragraph participants:
“In this broader project executed from August 2010 to March 2013, a cohort of 313 patients who visited their primary care general practices with a new episode of hip or knee complaints due to (symptomatic) hip or knee OA were included by their GP”.

4. In line with the previous comment, it’s surprisingly that patients experience so many barriers that relate to the BART-intervention. It feels as if the intervention was not implemented properly: doctors don’t agree with the cornerstones of self-management for patients with OA and don’t encourage the use of the booklet. How can the effectiveness of the intervention be evaluated, when the uptake is so poor? Apart from the Heuts et al (2005), I could not find any other publication on the BART-project. For the interpretation of the results, it is highly relevant how the context looked like, i.e. what measures were taken to facilitate the implementation of the BART-intervention? How did the booklet fit into this intervention?

-- Answer --
We apologize for the confusion. In the BART-project a regional implementation advisory board, consisting of a patient representative and 9 experts representing the main disciplines involved in OA care, was installed to agree on implementation activities aligned to patients as well as different health care providers. Those implementation activities are described in the following study that is under review: Smink AJ, Dekker J, Vliet Vlieland TPM, Swierstra BA, Kortland JH, Bijlsma JWJ, et al. Health care use of patients with osteoarthritis of the hip or knee after implementation of a stepped care strategy: an observational study.

The introduction of the booklet “Care for Osteoarthritis” is one of these implementation activities. It is beyond the scope of the current manuscript to describe all the implementation activities. However, we agree with the reviewer that for the interpretation of the results of our qualitative study, it is highly relevant to have access to information on the implementation activities of the BART-project.

The following line was added to the paragraph participants in the method section:
“To implement the stepped care strategy, several implementation activities aligned to patients as well as different health care providers were developed, performed and evaluated in the BART-project (Smink et al. Unpublished observations)”.

We also added a reference to another study that is part of the BART-project: Smink AJ, Bierma-Zeinstra SM, Dekker J, Vliet Vlieland TP, Bijlsma JW, Swierstra BA, Kortland JH, Voorn TB, van den Ende CH, Schers HJ. Agreement of general practitioners with the guideline-based stepped-care strategy for patients with osteoarthritis of the hip or knee: a cross-sectional study. *BMC.Fam.Pract.* 2013; 14: 33
5. In total 17 patients participated in the study, which was enough to achieve data saturation (page 9, last sentence of “data collection” section). How was data saturation confirmed? More information is needed, as 17 interviews is not very much, given the different perspectives that users, readers and non-users broad forward.

-- Answer --
See our reply on reviewer 1, suggestion 8.

6. For all three themes, that emerged from the analysis, the authors present a comparison between users, readers and non-users. This comparison should be included as a research objective.

-- Answer --
See our reply on reviewer 1, suggestion 1

To clarify that we also aimed to identify how patients used the booklet, we rephrased the objective of the study:
“The aim of this qualitative interview study was to evaluate the introduction of the booklet “Care for Osteoarthritis” by 1.) exploring how patients used the booklet and 2.) identifying patient reported barriers and facilitators to use het booklet”.

7. The I-change model was used to structure the interviews. This is a very extensive behavioural model, while the interview guide is rather comprehensive. Were elements in the model left out? If so, why?

-- Answer --
See our reply on reviewer 1, suggestion 4.

8. Page 5, last sentence of first paragraph: the authors state that “Increasing evidence shows ...”. Three references support this statement, one published in 2003, one in 2005 and one in 2012. The most important one, a meta-analysis, is the oldest, as it was published in 2003. What makes that the authors conclude that “evidence is emerging”?

-- Answer --
With this sentence we wanted to emphasize that studies on the effectiveness of self-management programs for OA are increasing. We agree with the reviewer that based on the three references “increasing evidence” is not the most suitable description.

As suggested by the author, we changed this line of the first paragraph of the introduction: “In the last decade, a growing number of studies have examined the effectiveness of self-management programs for OA, with some studies showing improvements in pain and disability”.

9. Page 5, second sentence of second paragraph (“the use of educational booklets is common practice”). The authors refer to a large research trial, from the UK, to support this statement. How does a research setting relate to “common practice”? Is this common practice in the UK, or in other countries as well? Please clarify.

-- Answer --
The use of educational booklets is common practice in clinical settings in the UK as stated by the trial. However, we decided to remove this sentence from the introduction as our study has been performed in the Netherlands.

10. This paper addressed the barriers and facilitators, as experiences by patients, are addressed. On page 5, in the third paragraph, the authors suggest that the patients perspective is the only one that needs to be clarified, for a successful introduction of the booklet. Of course, that is not true, as also pointed out in the discussion of the paper. It would be better to state in the background section more that the patients are just one piece of the implementation challenge.
We agree with the reviewer that for a successful introduction of the booklet, barriers and facilitators at different levels have to be identified: the level of the patient, the professional, the health care team and the health care organisation. As described in the paragraph on limitations in the discussion section, the current study restricted to the patients level. We agree with the reviewer that it would be better to state in the background section that barriers and facilitators at different stages in the health care system have to be acknowledged to improve implementation.

The following line was rephrased and moved to the second paragraph of the introduction. Hereby we postulate that various targets could influence the implementation process and we refer to the study of Grol et al. 2003 in which the different levels of the health care system are described that should be acknowledged for an effective implementation:

“To successfully introduce this booklet on a large scale, we should evaluate its implementation among the stakeholder group of end users, i.e. the patient”.

To emphasize that barriers and facilitators for booklet use could also act at other levels of the health care system, we rephrased the line of the limitation paragraph in the discussion section and referred to Grol et al. 2003:

“We did not cover the perceptions of health care providers about the booklet because this study was restricted to patient perceptions, while barriers and facilitators can also act at other levels of the healthcare system”.

11. Out of the 313 patients, participating in the BART-project, 26 (<10%) were invited for an interview. How was this sample drawn?

We used purposive sampling to identify potential participants for the current study. Based on the question “Do you use the booklet “Care for Osteoarthritis”? included in the questionnaire of the BART project we selected patients from all response categories to ensure diversity of the patients’ view about the booklet. In total, we randomly selected 26 participants of the BART project to participate in the qualitative study.

We added “randomly” to the following line of the paragraph participants in the method section

“We randomly selected participants based on their answer to the question included in the questionnaire of the BART-project one year after baseline: “Do you use the booklet “Care for Osteoarthritis”? (yes, regularly / yes, occasionally / yes, but not in the past six months / no, never)”.

12. It’s surprisingly to read that all patients that used the booklet regularly, all refused to participate in the study (page 8, last sentence of the “participants” section).

During this qualitative study, only one patient reported in the questionnaire of the BART-project to use the booklet regularly. Unfortunately this patient refused to participate in the current study as the patient believed not to be able to give any meaningful information.

We changed the last line of the participants section:

“We were not able to include patients in the category “yes, regularly” as only one patient selected that answer in the questionnaire but refused to participate in this qualitative study”.

We included the following lines in the limitation section of the discussion:

“Second, we did not include patients who reported in the questionnaire of the BART-project to use the booklet regularly. During this qualitative study, only one patient reported to use...”
the booklet regularly but refused to participate as the patient believed not being able to give meaningful information”.

13. What was the benefit of having both audio and video tapes of the interviews? Was the information coming from the video tapes used in the analysis?

--- Answer ---
The equipment we used to record the interviews provided both audio and video tapes. However, in this study we only used the audio tapes to interpret the data.

We changed the line “The interviews were both audio and video taped” into “The interviews were both audio and video taped, however for this study we only used the audio tapes to analyse the data”.

14. Audio and video tapes of one interview got lost, but field notes were used for the analysis. Field notes will not be a full representation of the interview: it is recommended to leave this interview out of the results.

--- Answer ---
We understand the concerns of the reviewer. However, immediately after this interview the two researchers studied the field notes that were made during the interview and wrote everything down they remembered from the interview independently. Subsequently the two researchers discussed their results until consensus was achieved, what resulted in a rich amount of interesting information. Therefore in our opinion it is legitimate to use this data.

15. A point is missing, at the end of the first paragraph of the “Barriers and facilitators for booklet use” section.

--- Answer ---
Thank you, we corrected this

16. Page 16, last sentence of the second paragraph: please add the context of reference [23]. For example, “... of the booklet what prevented diabetes patients from discussion a diabetes self-management booklet”.

--- Answer ---
As suggested by the reviewer we added the context of reference 23:
“Another explanation might be that patients have low expectations regarding the GP’s encouragement of the booklet what prevented patients from discussing the booklet as has been shown in a study on the implementation of a diabetes passport”.

17. Discussion: the limitations of the study are presented at the end of the discussion. It reads better when the limitations are put upfront in the discussion section and end the discussion more positive.

--- Answer ---
We agree with this suggestion of the reviewer.

We moved the paragraph regarding the study limitations to the second paragraph of the discussion. We also rephrased some lines resulting in the following paragraph:
“Before discussing the results, some limitations need to be addressed. First, it is important to recognize that the patients’ perceptions might not coincide with their own or their health care providers actual behaviour. We did not cover the health care providers’ perceptions about the booklet because this study was restricted to patients, while barriers and facilitators can also act at other levels of the health care system. Second, we did not include patients who reported to use the booklet regularly in the questionnaire of the BART-project. During the current study, only one patient reported to use the booklet regularly but refused to participate as the patient believed not being able of giving meaningful
information. Moreover, the patients answers to the question “do you use the booklet” were inconsistent between the questionnaires and interviews. We categorized booklet use based on the interviews as we considered these answers most valid because in the interviews we were able to explore in more detail how patients used the booklet. Although this could have resulted in missing relevant barriers or facilitators, we believed this was not very likely as the data collection was continued until analytical saturation was achieved. Another limitation might be recall bias, particularly in the non-users as patients were interviewed 12 to 18 months after receiving the booklet. Finally, the identified themes present some of the reasons for patients with OA to make use of a self-management booklet in their treatment course. Other themes could emerge due to differences in ethnic background, culture or health care systems”.

18. One of the finds is the influence of the professionals’ attitude on patients activation. The authors are encouraged to link this to other studies, like “Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G Authoritarian physicians and patients’ fear of being labeled “difficult” among key obstacles to shared decision making. Health Affairs. 2012;31(5):1030-8.”

-- Answer --
We thank the reviewer for this suggestion. This very interesting article of Frosch et al. shows that attitudes of health care providers remain a major barrier for patients to collaborate with their health care providers when making important clinical decisions. Patients are reluctant to do so for fear of being categorized as difficult and less worthy of attention and high quality care. Participants did not feel they could rely on their health care providers to help them become aware of and understand treatment options.

We added the following line to the discussion section and referred to the study of Frosch et al. 2012:
“Recently it has been shown that attitudes of health care providers remain a major barrier for patients to be more actively involved in their treatment course (Frosch et al 2012)”

19. The reference list contains many typo’s, mainly in the authors names. For example:
   a. reference 8: the second author is not “de BR”, the last author is not “van SO”.
   b. reference 32: the first author is “de Vries H” instead of “Vries H”.
   c. reference 47: volume and page numbers are missing

-- Answer --
We thank the reviewer for this critical view on the references. We studied the reference list critically and made multiple adjustments.

20. It would be helpful to summarize the results in some sort of a model for effective usage

-- Answer --
We thank the reviewer for this interesting suggestion. We decided to summarize the results by using a table. For each theme the barriers and facilitators are presented in this table. In this way we provide the readers with an overview of the identified barriers and facilitators.

In the paragraph “Barriers and facilitators for booklet use” in the results section we referred to Table 3 and we added this table to the manuscript:
Table 3. Overview of the patient reported barriers and facilitators to use the self-management booklet

**Theme 1: the role of health care providers**

*Barriers*
- Lack of clear information about how to use the booklet given by the health care providers
- Lack of encouragement from health care providers to use the booklet in the treatment course of OA
- Patients’ doubts concerning the health care providers’ endorsement of non-surgical treatment modalities for OA

*Facilitator*
- Encouragement from health care providers to use the booklet in the treatment course of OA.

**Theme 2: the patient’s perceptions about OA and its manageability**

*Barriers*
- Patients’ perceptions of OA as inevitable or not curable
- Patients’ perceptions that the complaints due to OA are not severe enough
- Thinking that being pro-active during the treatment course is not an effective strategy to control the disease course

*Facilitator*
- Being convinced of the importance of an active participation in the treatment course of OA

**Theme 3: the patient’s perceptions about the usefulness of the booklet and patient’s information needs**

*Barriers*
- Patients’ perceptions that the booklet is not a useful tool to manage their OA or being not aware of the aims of the booklet
- Having already sufficient knowledge about OA or sufficient support from health care providers.
- Not willing to know everything about OA or an indifferent attitude towards OA

*Facilitators*
- Lack of knowledge about OA or being interested in having more information
- Patients’ perceptions that the booklet is a useful tool to manage their OA