Author's response to reviews

Title: What is known about the patient’s experience of medical tourism? A scoping review

Authors:

Valorie A Crooks (crooks@sfu.ca)
Paul Kingsbury (kingsbury@sfu.ca)
Jeremy Snyder (jeremycsnyder@sfu.ca)
Rory Johnston (rrj1@sfu.ca)

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

Thank you for the thorough review of our manuscript. Please find attached a revised version of the paper “What is known about the patient’s experience of medical tourism? A scoping review?”. We ask that you please consider our revised manuscript for publication in *BMC Health Services Research*.

We are very thankful to the reviewers for having invested their time to compile such thoughtful reports. We have carefully reviewed the reports, and in addressing the suggestions, we believe this paper has been strengthened significantly. Below we have outlined in detail the changes made to the paper, with our responses indicated by red text.

Thank you again for your time. We look forward to learning of your decision.

With best regards,
Valorie Crooks (on behalf of my co-authors)

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**Reviewer 1**

The topic of medical tourism is a fascinating one. Clearly there is developing research interest around this topic. The paper is rigorous in its scoping of the literature – it details very clearly the steps that it has gone through in terms of identifying, retrieving and assessing sources. It is logical, comprehensive and rigorous.

Thank you.

My main difficulty with this paper – and it is surmountable with a little readjusting of the papers focus/writing – concerns the status of the materials that are retrieved. In the abstract there is reference to “data” and themes being identified from the “data”. However, in many ways to bundle all the sources retrieved as “data” strikes me as problematic. The authors acknowledge that there are only 5 empirical papers. Now, I am not saying that only robust empirical papers are data. But the difficulty is that some of the conceptual and newspaper pieces are problematic to see as data. This is said given my familiarity with some of the these sources – they typically circular reference and are full of qualifiers: “perhaps”, “maybe”, “potential”, “can” etc.

In the original version of the paper we defined data as “information points contributing to answering the scoping question”. We were using the term specifically in relation to the points gathered in the scoping review database, where each point is a piece of data. We were not using it to signal an empirical fact. Seeing your comment, though, made us realize that data was likely not the best term to use in the case of the present review. Instead we now use the term ‘informational point’, which is defined as “discrete pieces of
information found within sources that contributed to answering the scoping question”. Thus, an informational point is a piece of information extracted from one of the sources included in the review.

My preference would be to ease the writing and to have it talk about potentially emerging issues and developments – and to drop the talk of data. It would also be good to recognise some of the weaknesses of some sources (newspaper coverage, some conceptual pieces). In short, there is a distinction between 1) what is known 2) what is written. There should be more acknowledgement of this (including within the conclusion).

This is a very useful revision. Upon re-reading the manuscript we agree that it is not sufficient to flag quality concerns with the sources only in the limitations section. We have added a new paragraph at the outset of the findings section. It reads:

Only a small minority of sources included in the scoping review were reporting on empirical studies that involved the collection of primary data (n=5) [20-24]. Instead, they were mostly conceptual pieces, discussion papers, law reviews, commentaries, editorials, reviews, magazine and newspaper articles, reports, and business briefs published in a range of venues. The breadth of sources included in the review has allowed for perspectives from a number of sectors, including industry, health professionals, health service administrators, tourism operators, and academia, to be captured in the review. At the same time, most of the sources are heavily speculative or anecdotal in nature, relying on opinion instead of empirical facts. Because of the emerging nature of medical tourism, however, and the lag time involved in gathering and publishing empirical evidence, grey literature and media reports that offer preliminary glimpses were not excluded because they provide some of the only insights into the patient’s perspective. Instead, caution was exercised in interpreting themes from the informational points extracted from the sources and a tentative tone is adopted below in sharing what was gleaned.

We have also changed the conclusion in response to this suggestion and those made by other reviewers.

Page 4 – if you are interested in what is “known” and are willing to rely on newspaper articles and magazines then why not also include evidence from consumer-rating sites. Would this not tell you more about what is “known”. This links to my point above – reframe how the discussion is presented.

The search strategy created for this scoping review would have to be altered in order to allow us to include these sources. However, your point seems to be about the quality of the sources included and not to suggest that we actually review consumer sites, and so we expect that our above response carries forward for this point.

Page 4 – “general consensus that the industry will continue to grow” be careful here. There was some downturn talked about as a result of recent economic recession.

You are right, there has been some discussion of this in industry journals and websites. We have reworded the sentence to read: “Although estimates of the number of patients
engaging in medical tourism each year vary widely, ranging from millions to tens of thousands, there has been speculation that growth in the industry will continue in the coming years.”

Page 5 – “patients experience of this practice” and “current state of knowledge” statements. Perhaps simply be upfront – little is known. But there are a series of hunches, hypothesis and questions.

This sentence was cut through the editing process.

Page 8 – identifying exclusion criteria as you go is fine – but the point is that these sources are still fairly weak.

This has been addressed (see above).

Page 9 – top statement on data retrieval?

This is where we were defining how the term ‘data’ was being used in the context of the review. We have changed this sentence, and now use the term informational point (explained above).

Page 11 – Decision Making Section. Appears a little odd. Seems to say “There is no empirical data but if there were this is what it would say…”

This comment is likely about the first sentence in the original version, which has since been cut. We were trying to suggest that few of the sources were explicitly focused on decision-making.

Page 11-12. Remember, much of the work is simply opinions to date. Yet, the discussion presents hunches and unsubstantiated opinions as if they were something more. Also top, page 13.

Wording has been changed.

Page 14 – “Not surprisingly… motivation for participating in medical tourism”. This is not the case for the UK; medical tourists would not be reimbursed if they are pursuing treatments outside of EU or for treatments for which there is no local eligibility. The issues of EU cross-border treatment is something slightly different, whilst some see this as a part of medical tourism – I feel it confuses issues to do so.

This is correct. It was not our intention to suggest that UK patients would get reimbursed. Our wording was not effective in conveying the point we were trying to make, which is that some patients in systems with universal coverage may go abroad because they think they will receive reimbursement. We have changed the wording.
We also agree fully with you that cross-border care by arrangement is different from medical tourism. We have now clearly articulated the differences between the two in our introduction.

Page 14 - section on Risks - again presenting material as if it were in some way evidence rather than a framework.

Wording has been changed.

Page 16 – comment about patients carrying their records. Again, where does this come from in terms of substantiation.

We have referenced this speculative point, and have changed the tone in the sentence. (As a complete aside, though we are not discussing our own work in this paper we do know that this indeed happens from our own observations in hospitals treating international patients in India).

Page 16 – section on first-hand accounts. But what is the status of these quotes. Are they knowledge? If so, why not use consumer sites. My feeling is that this section is the weakest part of the discussion and should be cut. There are a number of difficulties with including it.

We believe strongly that this section needs to remain in the paper. It is the only one that provides an experiential perspective on medical tourism. Consumer sites are also likely to offer important experiential accounts, but were not included in our scoping review process. A different method would need to be used to effectively synthesize what is said on them.

Page 21- section on Implications for Health Service Providers. Why is the issue of potential emergency treatments in home countries not addressed in this section?

Good point. Though, we have actually cut this discussion in order to shorten the paper.

Page 22 – section on Knowledge Gaps. Given there is an acknowledgement of the “speculative”, idea-based nature of material then some earlier discussion needs to be fine-tuned.
But then it goes on to say “There is some certainty about specific aspects of patient experience”. Curious – what are they?

This sentence has been cut in the editing process. Certainty was the wrong word to use originally, though. We should’ve said ‘speculative consensus’, and we were referring to the points mentioned in the sentence (that cost savings is a motivating factor and that waiting lists push some patients abroad.

Reviewer 2
It is with great interest, that I have read the article on “What is known about the patient’s experience of medical tourism? A scoping review”.

Thank you.

1 Research question - The authors identify the research questions well, well stating its focus and scope: a review of existing literature on medical tourism.
2 Methodology - A straightforward and sound methodology builds on referenced proven research methods. However, the methodology section is very lengthy, where large descriptions do not add much value. Here the article could gain from shortening.

We have managed to cut some text from this section. Because the review took many stages, and because it is important for us to be transparent about each one, the section cannot be cut down beyond a certain point.

3 Sound data - there are no primary data, though it could have been of benefit to include some data / articles reflecting the extent of the problem of medical tourism. As the article focuses on Canada – it would have been interesting to get some idea on how many patients seek treatment abroad, maybe even comparing it to neighboring USA.

The focus of the article is not on Canada. Our media sources were Canadian, but the review itself is international. Unfortunately, reliable numbers of patient outflows are not available in most countries. This is because medical tourists are typically leaving their home systems when they go abroad and so there is no effective measure for tracking them. Estimates of patient flows vary dramatically and it is unclear as to which are most relatable. Because of this, no flow numbers are discussed.

4 Standards for reporting and data deposition - Not applicable – as this is a literature review.
5 Conclusions - Discussion and conclusions could be formulated more in terms of what the literature review really revealed – it is somehow surprising to read again a lengthy description of the starting point of the research, instead of statements reflecting the findings of the review.

We have edited the discussion and conclusion and have more closely aligned them to the findings. The discussion section is intended to use what is discussed in the findings section as a ‘launching point’ for identifying knowledge gaps in particular, which is commonly done in review papers.

6 Limitation stated - Limitations of the article and the research are stated but could have been described more explicitly , eg. industry and government reports from non–English speaking countries available in English are said to have been included but no examples are given. It is mentioned that the literature review is limited to Canada –some general reference are included, but some very relevant
are missing, particularly those who have already done a similar literature review in different settings (US, Europe).

We have included a reference example of an industry report from a non-English speaking country that was used in the review. Only the media review was limited to Canada; the remaining literature (law reviews, government reports, academic literature, business briefs etc.) were drawn from the international English language literature. Reviews that seem to have been missed may have been reviewed and excluded because of a focus on cross-border care or patient mobility in general, for example, which is not the focus of the review. Also, reports are very difficult to systematically gather. A number were identified in our searched databases using the keyword terms; however, those not included in the databases would not have been found.

7 Work built on - There is an impressive list of references, which seems to have been well reviewed following a sound methodology. However, the stated limitations have retained them to included important state of the art in the field. Here more of the relevant literature could have been included, such as work by HBS professor Regina Herzlinger (US), a reference for this debate in the US. Also one would have expected the inclusion of some of the related associations, such as the Medical Tourism and Travel Developers Group on LinkedIn (www.linkedin.com), the International Medical Travel Journal www.imtj.com, or the European Medical Travel Conference 2010 www.emtc2010.com.

We have included a number of US sources in the review. Herzlinger’s work on consumer-driven health care (which we are assuming is what is being referred to here) is off-topic for the review. EMTC is about cross-border care and not medical tourism specifically. As for medical tourism organizations, we’ve not listed their websites in the paper, but have included a number of industry and trade perspectives through our inclusion of business briefs.

8 Title and Abstract - The titles is fine, but the abstract could be more concise – really reflecting the findings from the article review, it merely reflects the (very good) framework of analysis but fails to state in a concise way what are the main findings from the exercise. It starts by mentioning the need for further research – but the knowledge base from the review exercise, on which further research could build - is not clearly stated.

We have edited the abstract down and have included specific examples of findings from the review.

9 Writing - Writing a bit lengthy and a few avoidable repetitions, the methodology is described in lengths in several places. Once is enough and could then be referred to in other places of the text. In general language could be more concise, otherwise good.
Reviewer 3

This is a very important and timely study of factors related to patients' decisions to pursue medical tourism. The authors have performed a very thoughtful, careful study of existing literature on this topic.

Thank you.

The manuscript will have more impact if the authors can endeavour to simplify their writing style, and reduce the size of each section of the manuscript. While specific advice by the reviewer will not be given, the authors should focus on brevity, and distill the key findings of their study into the manuscript.

Finally, although Table 3 summarises the themes of the extracted data, it does not provide specifics. Could this be provided in a larger table, giving key examples for each theme? This would a very helpful data summary for the reader.

Reviewer 4

1. The paper is well written, the applied methodology is solid, rigorously applied and well explained. It provides a good overview about what is known, and what is not known on the issue. The discussion and conclusions are well balanced.

Thank you.

2. The scope of the article is on medical tourism, which has been defined as travel abroad with the express intention of obtaining non-emergency medical services. Expatriates who return home to access care and established cross-border care arrangements between proximal countries are not considered as forms of medical tourism. It is however not clarified why these two categories have been excluded. Expatriates not only receive care at home when on visit, but often also intentionally return home for care. Patient mobility in border regions fits exactly in the definition as it has been formulated for medical tourism. This bias has an impact on the kind of listed motives: people going abroad because of proximity and familiarity are not mentioned. Please refine/clarify the definition or expand the scope of the study.

We have carefully revised this paragraph to better explain why expatriates receiving care in their nation or region of residence and also people accessing cross-border care by arrangement are not considered to be medical tourists. As reviewer 1 points out,
equating medical tourism with cross-border care very much confuses the issues at hand. We fully agree. The paragraph in which we define medical tourism now reads:

While there is no singular definition of medical tourism that has gained wide acceptance, in this article we place some widely acknowledged parameters on what it is understood to be in order to focus the scoping review. People who become ill or injured while traveling abroad and require hospital care are not thought to be medical tourists, nor are expatriates accessing care in the countries or regions in which they live. A survey run by the Thai government to assess the scope of its domestic medical tourism industry distinguished between international patients who were medical tourists, ill vacationers, and expatriates living in Thailand or a neighbouring country, which confirms the distinctions being used here [15]. Established cross-border care arrangements between proximal countries are not forms of medical tourism. This is because out-of-pocket payments for the accessed care are not typically made under such arrangements, as is the case for medical tourists, and because these arrangements typically require referrals to be given for care that is not available locally based on collaborative arrangements between hospitals or care systems, meanwhile medical tourists can choose to go abroad for care without the referral of a physician. These distinctions are made elsewhere. For example, a World Health Organization report on cross-border care within Europe distinguishes between patients travelling independently (i.e., without referral) for care internationally, those who are sent abroad by their home systems in order to access specialized care that is not available locally, and those who live in border regions with traditions of sharing care across borders [16]. Further, the pursuit of complementary and alternative care abroad is not medical tourism; instead, it falls under the even broader rubric of health tourism. When taken together, these parameters result in achieving a focused understanding of medical tourism, whereby it occurs when patients intentionally leave their country of residence in pursuit of non-emergency medical interventions (namely surgeries) abroad that are commonly paid for out-of-pocket. This typically includes staying abroad for at least part of the recovery period, whereby such post-discharge time can be spent at tourist resorts that cater to international patients [17-19].

3. The authors state that only 5 sources reported on empirical studies involved the collection of primary data. However, nowhere it is made clear which these 5 are, nor which part of the analysis is based on these reports. No clear distinction is made between sources of a different quality (media vs academic research). As a consequence, it is not always clear whether the findings are empirical or speculative (e.g. travel related risks: are these potential risks or actually experienced risks)? Please clarify.

We have now indicated which reference numbers are for the empirical studies cited in the review. As noted above (see comments for reviewer 1), we have also added a paragraph at the outset of the findings explaining the speculative nature of many of the sources and that the source types varied in quality.
4. Rather surprisingly, the search strategy did not include keywords such as patient mobility and cross border care. As a consequence, some documents, for instance the documents below, providing an overview of studies on the patient perspective were not found:

Could you clarify/justify selection of research terms or expand them?

The parameters of the search are justified above. Cross-border care by arrangement cannot be equated with medical tourism, and most reports on the issue do not address the specific issues of medical tourism.

5. In the decision making and motivations section it might be relevant to make a distinction between factors leading to the decision why to go abroad vs why choose a specific country/provider, and on the other hand facilitating factors (what made it possible to realise the wish to go abroad).

We do this by distinguishing between push and pull factors.

6. The section on implications for health service providers deals only with the domestic provider, not with the treating provider abroad. Could you please explain why or complement?

This sub-section was cut in order to shorten the article.

7. The discussions part on implications for patients could be better structured.

We have changed the paragraph structure.

8. About the title: wouldn’t it be more appropriate to speak about the patients’ perspective, rather than the patients’ experience, since almost nothing seems to be known about the patients’ experience?

There is also little empirical evidence about patients’ perceptions (i.e., more experiential accounts). As such, we have decided to not change the title as it does reflect the focus of the review.

Reviewer 5
The scoping process seems not so different from a systematic review at some points. The authors state that a main difference is the development of criteria to include or exclude articles. In scoping reviews this is done post hoc. The team identified bases for exclusion of articles, all based on the focus of the article. Although I can understand that these criteria were developed post hoc, I do not understand why there are no quality criteria. For systematic reviews quality of the studies included is important and it is obvious that this is also important in scoping reviews.

Development of exclusion criteria post-hoc is a main difference between the process of a systematic and scoping review. In terms of extraction of ‘data’ from the reviewed sources, while a quality assessment is included in a systematic review, it is not in a scoping review. The nature of the sources reviewed for the current paper varied widely and so there is no common basis for a quality assessment. If we were able to do a quality assessment then we would have done a systematic review and created exclusion/inclusion criteria at the outset. We have made some overall comments about the quality of the sources that were included at the outset of the findings section.

The scoping review includes different countries. However, the authors do not mention differences in rules and regulations for medical tourism or cross-border health care. In July 2008, the European Commission (EC) adopted a proposal concerning patients’ rights in cross-border health care. Aim of this proposal is to make clear who is responsible for quality and safe health care in cross-border settings. Furthermore, it underlines the importance of providing transparent information to make people aware of their rights and opportunities. Desired and expected impact is to achieve enhanced patient mobility and to realize effective cooperation and better sharing capacities between different European countries. Health insurers in European countries can contract health care providers in other countries. This is only an example of relevant information in an article on this topic and similar information should be provided for the US and Canada. More information on the context is necessary to understand the results.

As we have explained above, cross-border care by arrangement is not the same as medical tourism. Proposals about cross-border care are thus not pertinent to the scope of the review. There is a significant difference between resource sharing between countries and patients choosing to pay out-of-pocket to go to another country (often a developing nation) for care without a referral. Very few framework documents exist on medical tourism, and none were picked up through our review process. We do believe that our newly included discussion about the difference between medical tourism and cross-border care by arrangement helps to clarify this issue.

On page 7 the authors state that the rationale for choosing only Canada for their media search was that the identified sources would likely replicate media coverage of the patient’s experience of medical tourism in other countries. This can be questioned as rules and regulations differ. The authors should provide more information to describe to what extent their statement would be true, and
where results can not be generalized.

We have revised what has been said here. Again, there are very few rules or regulations that exist in patients’ home countries regarding medical tourism (unlike with cross-border care by arrangement).

The conclusions section is quite long. A lot of information is repeated again. This section should be reduced to one or two paragraphs.

We have cut back on both the discussion and conclusion.

Page 6. Eight types of rationale were identified for the why category. What were the types?

We have noted that they can be seen in Table 2.

Page 8. The authors state that the level of agreement between authors was high. What is the inter-rater reliability?

While a kappa score is typically generated for a systematic review, it is not for a scoping review. As such, we have not quantified our inter-rater reliability and have simply characterized it as high.