**PEER REVIEW HISTORY**

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

**ARTICLE DETAILS**

| | |
|---|---|
| **TITLE (PROVISIONAL)** | Healthcare access for children and families on the move and migrants |
| **AUTHORS** | Murphy, Lisa; Broad, Jonathan; Hopkinshaw, Bryony; Boutros, Sarah; Russell, Neal; Firth, Alison; McKeown, Rachael; Steele, Alison |

**VERSION 1 – REVIEW**

| | |
|---|---|
| **REVIEWER** | Reviewer name: Ayesha Kadir<br>Institution and Country: Nykøbing Falster Hospital<br>Competing interests: I have no competing interests. |
| **REVIEW RETURNED** | 31-Oct-2019 |

| | |
|---|---|
| **GENERAL COMMENTS** | Thank you for the opportunity to review this paper. The paper gives important insight into how health professionals understand childrens' and pregnant women's right to care, observations on care outcomes directly related to the health regulations, and reflections on the ethics of restrictive health care policies for migrants. The paper sheds light on the human cost of restrictive health policies, the ways in which these policies violate the rights of non-caucasian and migrant children and women in the United Kingdom, and the disempowerment of paediatric and child health workers to advocate for these children. The study is particularly important because it provides evidence that contradicts the UK Department of Health and Social Care statement about the impact of the charging regulations on health.<br><br>Comments:<br><br>Abstract<br>The methods should very briefly state what the survey was about<br><br>Background<br>Another useful reference for this section is the 2016 MOCHA report on primary health care access for asylum seekers, refugees and undocumented children in Europe.<br>http://www.childhealthservicemodels.eu/wp-content/uploads/2015/09/20160831_Deliverable-D3-D7.1_Migrant-children-in-Europe.pdf<br>The MOCHA report cites that children are required to have an NHS number in order to access primary care. The report goes on to describe barriers in access to care for unregistered children because of this requirement.<br><br>Results<br>Figure 1 and Tables 1-2 are helpful to visualize the data. It may be more effective, though, to show how few stated any degree of confidence in the questions for Tables 1-2.<br><br>Also, were the respondents who stated that they agreed or strongly agreed to the survey questions all the same 5-12 people? What |

| | |
|---|---|
| | made these people different from the other 188 respondents??<br><br>Table 1, question 2 (How to advocate for patients) – this is an important statistic, shows that 80% of the respondents are disempowered in their ability to advocate for migrants. This is an important finding and should be highlighted<br><br>Page 8, line 18 – there appears to be an error in the statistic on the number of respondents who had received training (N=178 or 12.4%.... but there were only 200 respondents).<br><br>Some suggestions to make the qualitative results clearer:<br>Page 8 line 28-31: This sentence would be clearer if it were simplified. One suggestion: “Seven key themes were identified from the free text answers (Appendix 4)”<br><br>Page 8, line 33: Theme 1. The subheading should specify who has fear. E.g. “Patients fear the consequences of engagement in health care”. Or alternatively, “Patients fear the consequences of accessing health care”.<br><br>Page 8 line 48: Theme 2. Suggest clarifying subtitle to: “Deterrence from accessing health care”<br><br>Page 9 Theme 3. Quotes should not be included in a list. The quote in lines 26-30 provides a useful example. Please revise the wording of the sentence so that the importance of the example and the other scenarios are made clear.<br><br>Page 10, theme 5 “Current charging regulations unworkable”. This theme seems quite broad in scope, encompassing what appears to be a number of different sub-themes:<br>a) lack of clarity about the regulations (and therefore questions about eligibility for exemption),<br>b) problems with coordination between clinical and nonclinical staff, inappropriate billing (and therefore barriers in accessing care or continuing care),<br>c) failure to recognize a trafficked patient,<br>d) a cruel practice of bringing bills to patients while they are admitted to hospital.<br>There is a lot of information packed into this lumping of themes, making it unwieldy and difficult to interpret. It should be unpacked a bit into smaller and more focused themes.<br><br>The reporting on the themes covers a broad range of problems and drawbacks to the UK health policy for immigrants. Did any respondents report positive outcomes or voice support for the increased restrictions? This has important implications both for implementation of the restrictions (and subsequent rights violations) and also for issues around advocacy for these vulnerable patient groups. Finally, the range of responses and presence or lack of supportive responses for the policies may also provide insight into the respondent population and some potential biases in your survey results…<br><br>Discussion<br>Why was the response rate so low? This should be addressed. It also would be helpful to have a breakdown of what parts of the UK are represented by the survey. It would have been very interesting to see survey results from nonclinical staff working at patient |

| | |
|---|---|
| | registration desks of A&E departments and in primary health care clinics.<br><br>Page 11, line 11 “hostile environment” should not be capitalized<br>Page 11 line 18-21 : confusing sentence (“That patients may be being impacted…”), please reword.<br><br>Page 11, paragraph 2, lines 26-37. The description of disagreement between clinical and nonclinical staff is also very important here in this paragraph. The decisions made by nonclinical staff based on inaccurate understanding of the regulations may be preventing patients from even reaching the clinicians. Further, disagreements among staff about the interpretation of the regulations may discourage clinical and nonclinical staff from advocating for vulnerable populations. Indeed, this is mentioned later in paragraph 4 of the same page.<br><br>Page 11, paragraph 3 – this point is very positive, and the examples given in the results section support it. However, Table 1 suggests that the vast majority are not confident in their skills to advocate for these patients. This should be addressed here in this paragraph.<br><br>Page 12, paragraph 4, section about health care entitlements in Europe. The MOCHA report provides some very good information about various health care entitlements for migrant children in Europe. |

| | |
|---|---|
| **REVIEWER** | Reviewer name: Karen Zwi<br>Institution and Country: SCHN and UNSW Sydney Australia<br>Competing interests: nil |
| **REVIEW RETURNED** | 05-Nov-2019 |

| | |
|---|---|
| **GENERAL COMMENTS** | This is an excellent, important and well written article about the limitations in access to healthcare placed on migrants by NHS charging regulations. It should be published and widely publicised will hopefully generate a change.<br>The only suggestions I have are:<br>1. more explanation early on in the article as to what the "charging regulations" actually are for those who are not familiar with them, and who is meant to enforce them<br>2. the interaction of immigration on healthcare charging policy is also not clear and need more explicit explanation.<br>3. sentence 1 in the Abstract Discussion is not clear - "due to fear of charging [whose fear?] or immigration enforcement [who is responsible for immigration enforcement and enforcement of what?]<br>Thanks for the opportunity to review. |

| | |
|---|---|
| **REVIEWER** | Reviewer name: Dr Laura C N Wood<br>Institution and Country: Lancaster University, England.<br>Competing interests: I have a voluntary work connection with one of the authors, Sarah Boutros, as a colleague in the emerging VITA Modern Slavery & Health Network for professionals and survivors invested in improving the health response to modern slavery. |
| **REVIEW RETURNED** | 07-Nov-2019 |

| | |
|---|---|
| **GENERAL COMMENTS** | Thank you for this well constructed and timely article on a very important topic.<br>Overall, the presentation of this research is excellent and demonstrates critical engagement with the data and the nuances of |

| | |
|---|---|
| | the current NHS and political climates.<br><br>I would like to offer a few suggestions to the authors, from the perspective that some readers may not be overtly familiar with the context of this piece, particularly given the potentially global audience.<br><br>1. 'undocumented children' definition is included in your Appendix, but I would suggest that a brief sentence is used within the introduction (or Appendix) that expands on a few reasons why children may be undocumented ie born in the UK to undocumented migrant parents, visa overstay, illegal entry and those with potential to regularise their status but unable to due to high fees. This again highlights to the reader the complexity of the migration landscape and not just 'illegal/legal/criminal' framework. Then, to keep the plumbline of undocumented migrants clear throughout, or clarify your work considers undocumented migrants, plus asylum seekers, refugees and economic migrants for example.<br><br>2. It might be helpful in the introduction to briefly clarify the official/mandated role and expectations of clinical staff in the UK with regards to the charging, as for a new reader it may not be clear what knowledge and decision making role health professionals are expected to have, in order to better interpret the data on their lack of knowledge (Table 1 pg7). This also has bearings on interpreting Table 2 data - confidence of indemnity/protection - the reader should be clear whether the doctor/health professional had the responsibility to make the charging decision and hence the protection need. Also, for this question, whether the need for indemnity/protection reflects the doctor making an erroneous charging decision (because of the confusions you detail) leading to harm, or a regulation-correct charging decision that led to harm.<br><br>3. In a similar vein, it may be worth briefly saying (in text or appendix) that urgent & immediate care decisions are primarily clinician led and not pre-defined (ie demonstrating that its not just that their are clear instructions but the staff don't know them but that defining needs in these categories is clinically (and ethically as you mention later) very challenging) in line with your discussion and conclusions that improved awareness alone is not the answer.<br><br>4. Page 8, please review if these stats are correct;<br><br>'12.4% of respondents had received training on this topic (n=178), whilst 72.3% (n=112) would like to receive further training'<br><br>5. pg 10 line 30 spelling ' congential' rather than congenital.<br><br>6. pg 13 line 24, consider changing 'UK border agency' to Home Office.<br><br>You may also like to consider a comment (should word count allow) on the health impact of high stress and fear itself on children, families, parents and parenting - Adverse Childhood Experiences, physical and mental health consequences of prolonged high grade stress etc. given fear is a powerful recurring theme in your findings.<br><br>Many thanks again for this valuable submission. |

## VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Comments:

Abstract

The methods should very briefly state what the survey was about

- Now included

Background

Another useful reference for this section is the 2016 MOCHA report on primary health care access for asylum seekers, refugees and undocumented children in Europe. http://www.childhealthservicemodels.eu/wp-content/uploads/2015/09/20160831_Deliverable-D3-D7.1_Migrant-children-in-Europe.pdf

The MOCHA report cites that children are required to have an NHS number in order to access primary care. The report goes on to describe barriers in access to care for unregistered children because of this requirement.

- We have now included details on the additional barriers faced by migrant children. However as children are not required by NHS policy or constitution to have an NHS number we have made it clear that this is actually administrative error often made by non-clinicians - rather than a need for high level policy change.

Results

Figure 1 and Tables 1-2 are helpful to visualize the data. It may be more effective, though, to show how few stated any degree of confidence in the questions for Tables 1-2.

- having reviewed this option it made the tables less clear in our view, and so they remain as they were previously.

Also, were the respondents who stated that they agreed or strongly agreed to the survey questions all the same 5-12 people? What made these people different from the other 188 respondents?? –

We have added in details on those who responded in this way.

Table 1, question 2 (How to advocate for patients) – this is an important statistic, shows that 80% of the respondents are disempowered in their ability to advocate for migrants. This is an important finding and should be highlighted

- included in our discussion

Page 8, line 18 – there appears to be an error in the statistic on the number of respondents who had received training (N=178 or 12.4%.... but there were only 200 respondents).

- we have made our use of ‘n’ clearer, as here it was intended to show 178 out of 200 respondents answer this question,

Some suggestions to make the qualitative results clearer:

Page 8 line 28-31: This sentence would be clearer if it were simplified. One suggestion: “Seven key themes were identified from the free text answers (Appendix 4)”

- agreed and change made

Page 8, line 33: Theme 1. The subheading should specify who has fear. E.g. “Patients fear the consequences of engagement in health care”. Or alternatively, “Patients fear the consequences of accessing health care”.

- agreed and change made

Page 8 line 48: Theme 2. Suggest clarifying subtitle to: “Deterrence from accessing health care”

- agreed and change made

Page 9 Theme 3. Quotes should not be included in a list. The quote in lines 26-30 provides a useful example. Please revise the wording of the sentence so that the importance of the example and the other scenarios are made clear.

- agreed and change made

Page 10, theme 5 “Current charging regulations unworkable”. This theme seems quite broad in scope, encompassing what appears to be a number of different sub-themes:

a) lack of clarity about the regulations (and therefore questions about eligibility for exemption),

b) problems with coordination between clinical and nonclinical staff, inappropriate billing (and therefore barriers in accessing care or continuing care),

c) failure to recognize a trafficked patient,

d) a cruel practice of bringing bills to patients while they are admitted to hospital.

There is a lot of information packed into this lumping of themes, making it unwieldy and difficult to interpret. It should be unpacked a bit into smaller and more focused themes.

- we have tried to make this theme clearer as a cohesive area bringing in different elements of impact on the health service, however we didn’t think splitting into sub themes added clarity (due to overlap) and thought it wasn’t technically methodologically sound to tweak our analysis framework retrospectively

The reporting on the themes covers a broad range of problems and drawbacks to the UK health policy for immigrants. Did any respondents report positive outcomes or voice support for the increased restrictions? This has important implications both for implementation of the restrictions (and subsequent rights violations) and also for issues around advocacy for these vulnerable patient groups. Finally, the range of responses and presence or lack of supportive responses for the policies may also provide insight into the respondent population and some potential biases in your survey results…

- we have included one case reported where a clinician found application to be appropriate, however we can't give any more detail on it without risking breaching confidentiality. This is included in the discussion as it didn't fit within the themes of our analysis framework. We have tried to address potential biases in our limitations section

Discussion

Why was the response rate so low? This should be addressed. It also would be helpful to have a breakdown of what parts of the UK are represented by the survey. It would have been very interesting to see survey results from nonclinical staff working at patient registration desks of A&E departments and in primary health care clinics.

- we have added in detail RE: the response rate, there were no complete nonclinical staff data, with the only non clinical person submitting their role and location and not answering any other questions (and subsequently removed from analysis)

Page 11, line 11 "hostile environment" should not be capitalized –

- agreed and change made

Page 11 line 18-21 : confusing sentence ("That patients may be being impacted…"), please reword.

- agreed and change made

Page 11, paragraph 2, lines 26-37. The description of disagreement between clinical and nonclinical staff is also very important here in this paragraph. The decisions made by nonclinical staff based on inaccurate understanding of the regulations may be preventing patients from even reaching the clinicians. Further, disagreements among staff about the interpretation of the regulations may discourage clinical and nonclinical staff from advocating for vulnerable populations. Indeed, this is mentioned later in paragraph 4 of the same page.

- agreed and further detail added

Page 11, paragraph 3 – this point is very positive, and the examples given in the results section support it. However, Table 1 suggests that the vast majority are not confident in their skills to advocate for these patients. This should be addressed here in this paragraph.

- agreed and change made as above

Page 12, paragraph 4, section about health care entitlements in Europe. The MOCHA report provides some very good information about various health care entitlements for migrant children in Europe.

- we reviewed this but felt we couldn't add in sufficient detail without detracting from our own work or doing justice to this important issue of variance in healthcare across the continent

Reviewer: 2

The only suggestions I have are:

1. more explanation early on in the article as to what the "charging regulations" actually are for those who are not familiar with them, and who is meant to enforce them

- agreed and change made in introduction to show where the responsibilities lie

2. the interaction of immigration on healthcare charging policy is also not clear and need more explicit explanation.

- agreed and change made in abstract and introduction to show this intersection

3. sentence 1 in the Abstract Discussion is not clear - "due to fear of charging [whose fear?] or immigration enforcement [who is responsible for immigration enforcement and enforcement of what?]

- agreed and change made to show patients' fear and what enforcement entails

Reviewer: 3

I would like to offer a few suggestions to the authors, from the perspective that some readers may not be overtly familiar with the context of this piece, particularly given the potentially global audience.

1. 'undocumented children' definition is included in your Appendix, but I would suggest that a brief sentence is used within the introduction (or Appendix) that expands on a few reasons why children may be undocumented ie born in the UK to undocumented migrant parents, visa overstay, illegal entry and those with potential to regularise their status but unable to due to high fees. This again highlights to the reader the complexity of the migration landscape and not just 'illegal/legal/criminal' framework. Then, to keep the plumbline of undocumented migrants clear throughout, or clarify your work considers undocumented migrants, plus asylum seekers, refugees and economic migrants for example.

- agreed and detail added on routes to being an undocumented migrant, as well as being clear that we are dicussiong migrants more broadly

2. It might be helpful in the introduction to briefly clarify the official/mandated role and expectations of clinical staff in the UK with regards to the charging, as for a new reader it may not be clear what knowledge and decision making role health professionals are expected to have, in order to better interpret the data on their lack of knowledge (Table 1 pg7).

- agreed and change made to show clinician role expected in this

This also has bearings on interpreting Table 2 data - confidence of indemnity/protection - the reader should be clear whether the doctor/health professional had the responsibility to make the charging decision and hence the protection need.

- we didn't delineate this exactly for a specific case and were asking more generally, therefore hard to know specific levels of responsibility for each respondent in a theoretical case

Also, for this question, whether the need for indemnity/protection reflects the doctor making an erroneous charging decision (because of the confusions you detail) leading to harm, or a regulation-correct charging decision that led to harm.

- have changed to say that we didn't specify one interpretation so arguably could be either

3. In a similar vein, it may be worth briefly saying (in text or appendix) that urgent & immediate care decisions are primarily clinician led and not pre-defined (ie demonstrating that its not just that their are clear instructions but the staff don't know them but that defining needs in these categories is clinically (and ethically as you mention later) very challenging) in line with your discussion and conclusions that improved awareness alone is not the answer.

- agreed and change made

4. Page 8, please review if these stats are correct;

'12.4% of respondents had received training on this topic (n=178), whilst 72.3% (n=112) would like to receive further training'

- we have made this sentence, and our use of n numbers clearer

5. pg 10 line 30 spelling ' congential' rather than congenital.

- agreed and change made

6. pg 13 line 24, consider changing 'UK border agency' to Home Office.

- agreed and change made for consistency

You may also like to consider a comment (should word count allow) on the health impact of high stress and fear itself on children, families, parents and parenting - Adverse Childhood Experiences, physical and mental health consequences of prolonged high grade stress etc. given fear is a powerful recurring theme in your findings.

- have added in a line on this alongside our detail in discussion on the complexity of assessing the impact of these regulations

Many thanks again for this valuable submission.