## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (**http://bmjopen.bmj.com/site/about/resources/checklist.pdf**) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

## ARTICLE DETAILS

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| **TITLE (PROVISIONAL)** | What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire |
| **AUTHORS** | Brettell, Rachel; Fisher, Rebecca; Hunt, Helen; Garland, Sophie; Lasserson, Daniel; Hayward, Gail |

## VERSION 1 – REVIEW

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| **REVIEWER** | Eva Barallat Gimeno<br>Faculty of Nursing<br>University of Lleida<br>Spain |
| **REVIEW RETURNED** | 13-Nov-2017 |

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| **GENERAL COMMENTS** | The manuscript is interesting and in general is well written. Follow the required structure.<br>Allow me to give you some advice, mainly, because the manuscript is written as if the reader can only be Anglo-Saxon, since the terminology used is for use only in Anglo-Saxon countries. I think it should be adapted for an audience from all over the world, because it's interesting enough.<br>In the Keywords section, you should change the first word to Primary health care and also add health care administration. Both are Mesh Terms, and it is convenient to put Mesh Terms so that the article can be easily located in a simple search.<br>At the beginning of the manuscript there is talk of a 13-month study (between 1/12/14 to 11/30/2015), and until the end of the manuscript it is not understood why the date changes to 12/31/2015. I think that this clarification should be at the beginning, because it seems an error in the abstract.<br>Some statistical terms, such as PPV, IQR and OR, should appear with the full name Positive Predictive Value (PPV), Interquartile range (IQR), Odds Ratio (OR) the first time they appear in the text.<br>With reference to table 4, in the text that refers to you on page 7, line 26, you should change "due to cancer" to "due to malignancy" to facilitate reading.The term OOH GP should be explained more thoroughly, because, in all countries, this service does not exist specifically.<br>There are also terms that appear directly with the abbreviation, and are UK terms, they should appear as follows:<br>Point-of-care blood (POC blood), Care Quality Commission Call (CQC call) ....<br>The term CQC Call should also be explained, that is, explain what this type of call consists of.<br>In case you do not think it is convenient to make this type of suggested changes, you should add in the limitations that there are limitations for the reader, since the manuscript is mainly written for a |

| | health professional who knows the Anglo-Saxon health system well. The bibliographical references are correct, updated and convenient. |
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| **REVIEWER** | Grete Moth<br>Aarhus University |
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| **REVIEW RETURNED** | 29-Nov-2017 |

| **GENERAL COMMENTS** | An interesting study on the OOH primary care and focusing om palliative care. There are, however, some parts of the manuscript that could benefit from some revision/elaboration of the manuscript.<br>The following point refer to the list above:<br>1. 1. The aim of the study is not quite clear, as the authors aim to understand "…. The true extent of this workload, it's nature, and ….." – I find that the nature of the work of providing OOH care at the end of life is not addressed in this study. And what is meant precisely by "nature"?<br>2. The aim and conclusion differ from the manuscript<br>3. only partly as data originating from databases seldom provide in-depth information on e.g. "nature of workload"<br>4. 3. "appropriate subcutaneous medication" – This should be elaborated for readers and researchers to decide, if they agree in this choice an to be able to repeat the study<br>9. The aim about the "nature of the workload" is missing or at least not clearly addressed<br>10. Results that seem quite important in the study are not being shown, only reported in the text (page 6, the paragraph on comparison between palliative and non-palliative patients). This seems strange as a variety of other results that do not seem as central in the same way are shown in tables.<br>11. 1. An important aspect in the study concerns the method used to identify palliative patients (coded as such, referred to a hospice or received "appropriate subcutaneous medication"). However, nothing is mentioned in the manuscript about the validity of this method – that is, is it a well-known identification method used by others or has it been examined in a validation study by use of a gold standard? Moreover, the implications of this is mentioned only very shortly in the in the discussion section and the direction and extent of such possible information bias is not commented on.<br><br>Some comments on the contents of the manuscript beside the above mentioned:<br>- In the manuscript some of the abbreviations used have not been explained the first time they appear (e.g. PPV and CQC)<br>• The validity of clinical codes used by the OOH clinicians was examined and a PPV of 92.6% was found. As nothing is mentioned about, whether this is satisfactorily, one must conclude that the authors found it so. However, discussion this would be relevant.<br>• The results show large differences between palliative patients and non-palliative patients (Table 4) – is this not an indication that the coding of patients being palliative is actually working<br>• If the coding by the clinicians was ok, one could ask whether the overall aim of the study (the true extent of this workload) could not be met simply by using the clinical codes? Or is there an underlying assumption that palliative patients are not being coded correctly even though the PPV was ok?<br>• In the paragraph on implications in the discussion section it is mentioned that only a minority achieve to die at home and that |
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| | "enabling good deaths …is a key component of OOH primary care…". I find it very relevant to discuss whether it is a relevant task for the OOH primary care services to be responsible for or whether it is a task more suitable for the GP, with whom the patients in question are listed, as he/she knows the patients beforehand. |

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| **REVIEWER** | Alessandra Buja<br>University of Padua |
| **REVIEW RETURNED** | 11-Dec-2017 |

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| **GENERAL COMMENTS** | Abstract<br>The aims of study declared in the abstract are not strictly the same of those declared in the main text.<br>The main outcomes described in the abstract not exhaustively respond to the aim declared above in the abstract<br><br>Methods<br>To describe the kind of contact and different kind of services provision among OOH patients who dies in the last 30 days of life I will subdivide patients for major cause of death. I will consider only three major cause accounting for more than 75% of dead patients.<br><br>Results<br>To verify the stated aim "if patients who dies in the last 30 days of life were documented as in a palliative phase of care" and to verify the validity of this report, you should verified also how many patients do not dying in the 30 days subsequent were coded during an OOH the visit as "palliative" and to calculate positive and negative predictive value. However to be referred to an hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication, could be exhaustively collect all patients really need a palliative care defined as a multidisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing people with relief from the symptoms, pain, physical stress, and mental stress of the terminal diagnosis. This manner to operativize this variable jet excluded a lot of people needing palliative care in his definition.<br><br>Table 1 please report male and not only gender as modality of the variable<br>Table 2 please report in methods the difference between acute admission (hospital) and admission to hospital that in this table appear as different outcomes<br><br>Table 4 please the sum of the relative frequencies give percentage more than 100, probably you use not only principle diagnosis of death but also secondary causes of death. It should be explained, however to be more consistent I will use only the first cause of death to categorized death causes. |

## VERSION 1 – AUTHOR RESPONSE

Editors comments:

Along with your revised manuscript, please include a copy of the RECORD checklist indicating the page/line numbers of your manuscript where the relevant information can be found (http://www.record-statement.org/).

Response: Completed and included.

Please revise the title of your manuscript to include the research question, study design and setting. This is the preferred format of the journal.

Response: We have amended the title to "What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire" (lines 1-2).

Reviewer(s)' Comments to Author:

Reviewer: 1
Reviewer Name: Eva Barallat Gimeno

The manuscript is interesting and in general is well written. Follow the required structure.
Allow me to give you some advice, mainly, because the manuscript is written as if the reader can only be Anglo-Saxon, since the terminology used is for use only in Anglo-Saxon countries. I think it should be adapted for an audience from all over the world, because it's interesting enough.
In the Keywords section, you should change the first word to Primary health care and also add health care administration. Both are Mesh Terms, and it is convenient to put Mesh Terms so that the article can be easily located in a simple search.

Response: We have used the keywords available from the list which most closely approximate those suggested above

At the beginning of the manuscript there is talk of a 13-month study (between 1/12/14 to 11/30/2015), and until the end of the manuscript it is not understood why the date changes to 12/31/2015. I think that this clarification should be at the beginning, because it seems an error in the abstract (lines 98-99).

Response: The discrepancy reflects the correct method for the data linkage (to capture patients who died a month after contact with the OOH service the 'window' for deaths has to be one month longer than the 'window' for OOH contacts. We agree that this can appear confusing and have made this clarification earlier in the manuscript.

Some statistical terms, such as PPV, IQR and OR, should appear with the full name Positive Predictive Value (PPV), Interquartile range (IQR), Odds Ratio (OR) the first time they appear in the text.

Response: We have made these changes (lines 133, 155, 186-86)

With reference to table 4, in the text that refers to you on page 7, line 26, you should change "due to cancer" to "due to malignancy" to facilitate reading.

Response: We have made this change (line 208).

The term OOH GP should be explained more thoroughly, because, in all countries, this service does not exist specifically.

Response: We have described the OOH GP role in both the first paragraph of the introduction and in greater detail in the first paragraph of the methods section (lines 62-66 and 87-94).

There are also terms that appear directly with the abbreviation, and are UK terms, they should appear as follows: Point-of-care blood (POC blood), Care Quality Commission Call (CQC call) ....
The term CQC Call should also be explained, that is, explain what this type of call consists of.

Response: We have made all the suggested amendments (line 285)

In case you do not think it is convenient to make this type of suggested changes, you should add in the limitations that there are limitations for the reader, since the manuscript is mainly written for a health professional who knows the Anglo-Saxon health system well. The bibliographical references are correct, updated and convenient.

Response: We agree that the results of this study may be most applicable in the UK system, or others' which use a similar model of primary care provision. We have added a sentence to the limitations to reflect this (line 238-239).

Reviewer: 2
Reviewer Name: Grete Moth

An interesting study on the OOH primary care and focusing om palliative care. There are, however, some parts of the manuscript that could benefit from some revision/elaboration of the manuscript.

The following point refer to the list above:
1. 1. The aim of the study is not quite clear, as the authors aim to understand "…. The true extent of this workload, it's nature, and ….." – I find that the nature of the work of providing OOH care at the end of life is not addressed in this study. And what is meant precisely by "nature"?

Response: We agree that this is not a well-defined term and have deleted it (line 80).

2. The aim and conclusion differ from the manuscript 3. only partly as data originating from databases seldom provide in-depth information on e.g. "nature of workload"

Response: We have deleted 'nature of workload' from the manuscript, recognising this reviewer's insight that it reduces the clarity of our rationale.

4. 3. "appropriate subcutaneous medication" – This should be elaborated for readers and researchers to decide, if they agree in this choice an to be able to repeat the study

Response: Further information has been added, including supplementary coding information (lines 121-124 and supplementary material)

9. The aim about the "nature of the workload" is missing or at least not clearly addressed

Response: This has been addressed above

10. Results that seem quite important in the study are not being shown, only reported in the text (page 6, the paragraph on comparison between palliative and non-palliative patients). This seems strange as a variety of other results that do not seem as central in the same way are shown in tables.

Response: We have adhered to the BMJ limit on tables and figures and believe that these important results are in fact highlighted by their inclusion in the main text of the article.

11. 1. An important aspect in the study concerns the method used to identify palliative patients (coded as such, referred to a hospice or received “appropriate subcutaneous medication”). However, nothing is mentioned in the manuscript about the validity of this method – that is, is it a well-known identification method used by others or has it been examined in a validation study by use of a gold standard? Moreover, the implications of this is mentioned only very shortly in the in the discussion section and the direction and extent of such possible information bias is not commented on.

Response: As far as we know this is the first study to explore the group of patients who contact OOH services within thirty days of death and to attempt to classify them as documented as palliative. Therefore it was not possible to use a validated measure. As the reviewer notes, we have mentioned this limitation in our discussion, and have now expanded upon this in line with their comments (lines 246-249).

Some comments on the contents of the manuscript beside the above mentioned:
- In the manuscript some of the abbreviations used have not been explained the first time they appear (e.g. PPV and CQC)

Response: This has been addressed in response to comments from reviewer 1

• The validity of clinical codes used by the OOH clinicians was examined and a PPV of 92.6% was found. As nothing is mentioned about, whether this is satisfactorily, one must conclude that the authors found it so. However, discussion this would be relevant.

Response: Given the wide range of potential codes this is a high PPV for a routine data study - the average PPVs in a systematic review of coding within routine primary care records was 76.7%. This has now been included in the strengths and limitations section of the discussion (lines 249-251).

• The results show large differences between palliative patients and non-palliative patients (Table 4) – is this not an indication that the coding of patients being palliative is actually working

Response: This is a table reporting the cause of death of all patients who died within 30 days of contacting the OOH service. Therefore all of these patients were at the end of life. The differences might reflect accurate coding but there are other possible explanations for the differences, which we have explored in our discussion.

• If the coding by the clinicians was ok, one could ask whether the overall aim of the study (the true extent of this workload) could not be met simply by using the clinical codes? Or is there an underlying assumption that palliative patients are not being coded correctly even though the PPV was ok?

Response: This paper shows that only 36.4% of patients at the end of life were documented as palliative by the service. We believe that this argues strongly against previous assumptions that palliative care coding can be used to judge palliative workload.

• In the paragraph on implications in the discussion section it is mentioned that only a minority achieve to die at home and that "enabling good deaths …is a key component of OOH primary care…". I find it very relevant to discuss whether it is a relevant task for the OOH primary care services to be responsible for or whether it is a task more suitable for the GP, with whom the patients in question are listed, as he/she knows the patients beforehand.

Response: We agree that this merits further discussion and have expanded our discussion section to mention these elements (lines 259-263).

Reviewer: 3
Reviewer Name: Alessandra Buja

Abstract The aims of study declared in the abstract are not strictly the same of those declared in the main text. The main outcomes described in the abstract not exhaustively respond to the aim declared above in the abstract

Response: We have altered the aims in the main text in lines with the comments from reviewer 2 so that they match more clearly those in the abstract, and expanded slightly on the objectives of the abstract to make them clearer (line 20).

Methods
To describe the kind of contact and different kind of services provision among OOH patients who dies in the last 30 days of life I will subdivide patients for major cause of death. I will consider only three major cause accounting for more than 75% of dead patients.

Response: We used all assigned causes of death, particularly because it can be difficult to determine a single cause in patients with multiple morbidity. Therefore, it would introduce bias if we used the approach suggested by this reviewer as choosing one cause can be an arbitrary process.

Results
To verify the stated aim "if patients who dies in the last 30 days of life were documented as in a palliative phase of care" and to verify the validity of this report, you should verified also how many patients do not dying in the 30 days subsequent were coded during an OOH the visit as "palliative" and to calculate positive and negative predictive value. However to be referred to an hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication, could be exhaustively collect all patients really need a palliative care defined as a multidisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing people with relief from the symptoms, pain, physical stress, and mental stress of the terminal

diagnosis. This manner to operativize this variable jet excluded a lot of people needing palliative care in his definition.

Response: Our definition of 'documented as palliative' included hospice referral in addition to all those where a palliative clinical code was applied. We agree that hospice referral alone would be unlikely to include the majority of patients needing palliative care and the results presented in the paper in fact show that this is the case.

PPVs and NPVs are measures used for diagnostic tests – the PPV reported earlier was to validate the diagnostic coding. Being coded as palliative and not dying within 30 days is not relevant to this analysis because we are using death within 30 days as the marker of end of life care.

Table 1 please report male and not only gender as modality of the variable Table 2 please report in methods the difference between acute admission (hospital) and admission to hospital that in this table appear as different outcomes

Response: Thank you for pointing this out. We agree and have added male to table 1 (line 408).
Table 2 has one line for acute admission to hospital and separate line for hospice admission – we think this distinction should be clear to the general readership.
Table 4 please the sum of the relative frequencies give percentage more than 100, probably you use not only principle diagnosis of death but also secondary causes of death. It should be explained, however to be more consistent I will use only the first cause of death to categorized death causes.

Response: As UK causes of death are not assigned in order of importance, we decided to include all causes of death in order to reduce bias as far as possible, and to include all potentially relevant causes of death. Comparison across groups is equally acceptable with multiple or single causes. We have included a justification for this decision in our methods section (lines 109-112).

## VERSION 2 – REVIEW

| REVIEWER | Eva Barallat-Gimeno<br>Universitat de Lleida. Faculty of nursing and physiotherapy.<br>Lleida<br>Spain |
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| REVIEW RETURNED | 22-Jan-2018 |

| GENERAL COMMENTS | It is an interesting study of OOH primary care and its relation with palliative care field. Strengths an limitations of this study are clear and clarifies some aspects of the paper. Minor revision is needed.<br>- In line 19 (page 3), in the sentence " Given that the majority of people with terminal illness do not wish to die in a hospital" , you have to add "in th UK" or add "accordint to the study....."<br>- It is needed to explain better the "clinical code relating to palliative care", because in the tables you are using patients "documented as palliative", and it refers to these codes. Although you have added a supplementary file to explain, it would be better to add into the main document. The best line to add could be in line 42 (page 4).<br>- In line 53 (page 5), there is a word left over "were".<br>- In Table 2, in section Outcome of the co |
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| REVIEWER | Grete Moth<br>The Research Unit for General Practice, Aarhus University, Denmark |
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| REVIEW RETURNED | 28-Jan-2018 |

| GENERAL COMMENTS | I find that the authors have made use of the points of criticism and accordingly have succeeded in improving the manuscript.<br>Hence, I have no further comments |
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**VERSION 2 – AUTHOR RESPONSE**

Reviewer: 1

Reviewer Name: Eva Barallat-Gimeno

- In line 19 (page 3), in the sentence " Given that the majority of people with terminal illness do not wish to die in a hospital" , you have to add "in th UK" or add "accordint to the study....."

Thank you. ‘In the UK’ has been added as suggested.

- It is needed to explain better the "clinical code relating to palliative care", because in the tables you are using patients "documented as palliative", and it refers to these codes. Although you have added a supplementary file to explain, it would be better to add into the main document. The best line to add could be in line 42 (page 4).

We have added in further detail to the main text as suggested.

- In line 53 (page 5), there is a word left over "were".

We have edited this line for clarity

- In Table 2, in section Outcome of the contact, in the first line, explain what is A&E, because nowhere is the explanation before.

We have now explained this as suggested

Reviewer: 2

Reviewer Name: Grete Moth

I find that the authors have made use of the points of criticism and accordingly have succeeded in improving the manuscript.

Hence, I have no further comments