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Out of hours primary care contacts by patients at the end of life: a population based study.

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3 **Out of hours primary care contacts by patients at the end of life: a population based study.**
4

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28
29 **Abstract**
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31
32 **Objectives:** Out of hours (OOH) primary care services are a key element of community care at the
33 end of life, yet there have been no previous attempts to describe the scope of this activity. We
34 aimed to establish the proportion of Oxfordshire patients who were seen by the Out Of Hours
35 service within the last 30 days of life and whether they were documented as in a palliative phase of
36 care.
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41 **Design** Population based study linking a database of patient contacts with OOH primary care with
42 the register of all deaths within Oxfordshire (600000 population) during 13 months.
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46 **Setting** Oxfordshire
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49 **Participants** Between 1/12/14 and 30/11/2015 there were 102,877 OOH contacts made by 67,943
50 patients with the OOH service.
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53 **Main outcome measures** Proportion of patients dying in the Oxfordshire population who were seen
54 by the Out Of Hours service within the last 30 days of life. Demographic and clinical features of these
55 contacts.
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3 **Results** 29.5% of all population deaths were seen by the OOH service in the last 30 days of life.
4 Among the 1530 patients seen, patients whose palliative phase was documented (n=577, 36.4%)
5 were slightly younger (median age = 83.5 vs 85.2 years, p<0.001) and were seen closer to death
6 (median days to death = 2 v 8, p<0.001). More were assessed at home (59.8% vs 51.9%, p<0.001)
7 and less were admitted to hospital (2.7% vs 18.0%, p<0.001).
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12 **Conclusions** OOH services see around one third of all patients who die in a population. Most patients
13 at the end of life are not documented as palliative by OOH services and are less likely to receive
14 ongoing care at home.
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27 **Strengths and Limitations of this study**

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- 30 • This is the first study to use data linkage with death records to describe the true population
31 at the end of life who contact the OOH service.
- 32
- 33 • The study highlights both the importance of the OOH primary care service in end of life care
34 and the significant limitations of medical records studies which have used clinical coding of
35 palliative care as a proxy for end of life contacts
36
- 37 • Our understanding of the proportion of these deaths which were palliative and the causes of
38 death relied on the accuracy of clinical coding
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- 40 • Our study focused on a single area of the UK due to restriction in access to OOH provider
41 medical records
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Introduction

The provision of primary care services outside core contracted hours is fundamental to the operation of the NHS.¹ In 2013-14, out of hours GP services (OOH) in England handled approximately 5.8 million cases, 3.3 million of which were face to face consultations, including 800,000 home visits.² For the majority of patients OOH primary care is provided by a clinician who does not know them, often with limited access to their medical record.³

In January 2015 the top research priority identified by the Palliative and end of life care Priority Setting Partnership was the provision of palliative care outside of working hours to help patients stay in their place of choice by managing crises.⁴ Given that the majority of people with terminal illness do not wish to die in a hospital⁵, OOH primary care services must be viewed as an integral part of end of life care provision.

Our current understanding of the true extent of end of life care provided by the OOH service is limited. OOH services do not routinely receive feedback on patient deaths following contact with the service. We previously analysed an OOH service database⁶ and learned that patients whose needs were coded as palliative contacted the OOH service predominantly during weekend daytime periods, and that over a third had multiple contacts with the service. However, the study was limited because we were not able to identify all patients who had died and had contacted the service, thus underestimating the true proportion of patients with end of life care needs.

In order to understand how OOH care can best be provided at the end of life we need to understand the true extent of this workload, its nature, and whether there are differences between patients who appear to be recognised as palliative by clinicians and those who are not. This study used data linkage to identify people who died in Oxfordshire over the course of a year who had contact with the OOH services in the 30 days before death and the clinical care that they received from the OOH service.

Methods

The Oxfordshire OOH service provides care to a population of over 600,000 people from 18:30pm – 08:00am on weekdays and 24 hour cover on weekends and bank holidays. Access to the service is via the NHS 111 telephone advice line, where trained call handlers use the NHS Pathways algorithm to direct patients to the most appropriate service for their needs. Patients directed by 111 to the OOH service will receive an initial telephone consultation with an OOH clinician which may then lead to a

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3 base visit (patient comes to the OOH surgery to be seen), home visit or the case being passed to
4 another care provider (such as 'hospital at home'). Patients can also be booked directly by 111 to an
5 OOH base visit.
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9 A database of all patient contacts with the Oxfordshire Out of Hours (OOH) service over 1 year from
10 01.12.14 to 30.11.2015 was created from the OOH Electronic Record System used by clinicians
11 (Adastra).
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14 Mortality data for Oxfordshire (population 600,000) over 13 months (1.12.14-31.12.15) was
15 obtained via NHS Digital/Office of National Statistics, with Section 251 approval from the
16 Confidentiality Advisory Group. This was linked by NHS number with Oxfordshire OOH service care
17 records and was used to identify people who had contact with the OOH service in the 30 days prior
18 to death. All patient identifiers were removed on entry to the database. Any contact without an
19 NHS number was removed from the database, as repeat visits could not be assessed, as were those
20 with a duplicate case ID. Contacts that were seen after death were also removed. Demographic data
21 consisted of age, sex and Index of Multiple Deprivation score (available for 79% of contacts).⁷ Service
22 data included final contact type, outcome, date, clinical codes assigned and prescriptions issued.
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24 Mortality data included the date of death and all assigned ICD-10⁸ causes of death.
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31 Timings of calls were classified as evening 18:30-23:59, overnight 00:00-07:59 and daytime (i.e.
32 weekends and bank holidays) 08:00-18:29. The number of days difference between contact and
33 death was calculated using calendar days beginning at midnight. Weekend period was classified as
34 18:30 Friday until 08:00 Monday.
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38 Those who died were also classified according to whether they had been documented by the service
39 as palliative or not. We defined palliative patients as those who, at any contact with the OOH service
40 in the study period, had been assigned a clinical code relating to palliative care, been referred to a
41 hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication.
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44 This group was compared with all other patients who died within 30d of contact.
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48 49 Validation

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52 In order to validate the clinical codes applied by the OOH clinicians we estimated, based on previous
53 coding validity studies⁹ that analysis of 230 records would be required to establish the coding validity
54 with a confidence level of 90% and 5% margin of error. A random selection of 230 records was
55 obtained using SPSS, and the clinical code was compared by two authors (SG, HH) to the conclusion
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3 drawn by the clinician in the medical notes. The PPV of the clinical code for medical diagnosis or
4 conclusion was 92.6%.
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9 10 Statistical analysis

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12 Demographic details and details concerning the cause of death were compared at a patient level, so
13 that each patient was only considered once in the analysis. By contrast, the OOH contact and
14 outcome were compared at an OOH contact level. Statistical analysis was performed using SPSS
15 Version 22. T tests were used when comparing means, z tests when comparing proportions and
16 Mann Witney U test when comparing medians. Logistic regression was performed to test
17 associations for binary outcomes. This study had Research Ethics approval (REC number
18 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).
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29 30 Results

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32 Between 1/12/2014 -30/11/2015 there were 102,877 contacts, by 67,943 patients, with the
33 Oxfordshire OOH service. In the 13 month period between 1/12/14 – 31/12/15, 5193 people died in
34 Oxfordshire. Of the people who died, 1530 (29.5%) had contact with the OOH service in the 30 days
35 prior to their death. These patients made 2661 contacts with the OOH service in the 30d prior to
36 their death, accounting for 2.57% of all contacts to the service over the 12 month study period. A
37 further 791 contacts (with 752 patients) occurred *after* death, equating to 14.5% of all deaths and
38 0.76% of all contacts to the service. Contacts after death were excluded from further analyses.
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44 Of those patients who had contact with the OOH service in the 30d prior to death, 381 (24.9%) made
45 a contact in the last day of life (Figure 1). There was a median of 5 (IQR 1.75 – 13) days between final
46 OOH contact and death and the median number of contacts with the OOH service in the 30d prior to
47 death was 1 (IQR 1 – 2). A similar proportion of deaths occurred on each day of the week (figure 2)
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51 Tables 1 and 2 compare patients and patient contact features of those who died within 30 days of
52 death with those who were alive at 30 days after initial OOH consultation. Patients who died were
53 were older, less deprived and more likely to be male. Patient contacts were more frequently in their
54 own home and more likely to have their care escalated to an alternative provider (hospital, hospice,
55 community care provider).
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3 For those patients who died within 30 days the most commonly assigned clinical codes were
4 palliative (27.3% of all codes assigned), advice (8.8%), medication requests (7.1%), lower respiratory
5 tract infection (LRTI) (5.5%) or urinary tract infection (UTI) (4.2%) codes. By comparison, Ear, Nose
6 and Throat disorder (ENT) (13.5%), UTI (6.0%), musculoskeletal disease (MSK) (5.3%), upper
7 respiratory tract infection (URTI) (4.9%), and medication requests (4.2%) were the commonest codes
8 in those alive at 30 days after index assessment (supplementary tables 1 and 2)
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13 Acute events were the cause of death in 25% of patients. The commonest codes were types of
14 cancer (45.6%) followed by cardiac disease (34.8%), LRTI (25.2%), dementia (23.9%), age related
15 debility and other respiratory disease (both 15.2%) (see table 4 for full list).
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22 **Comparison between palliative patients and patients dying within 30 days not documented as** 23 **palliative.** 24

25 Patients who had contact with the OOH service in the 30 days prior to death were categorised into
26 those who had been documented by the service as palliative (any palliative code assigned to record,
27 hospice referral, or appropriate subcutaneous medication prescribed at any time), and those who
28 had not.
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32 557 patients (36.4%) were documented as palliative, and had 1310 contacts with the OOH service in
33 the 30 days prior to death. By contrast, 973 patients (63.6%) were not documented as palliative,
34 accounting for 1351 contacts.
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38 Patients documented as palliative were younger than those not documented (median 83.5 years
39 (IQR 74.1 – 89.6) vs 85.2years (IQR 78.3 – 91.1) ($p<0.001$, $z=4.45$), an association which was
40 maintained after adjusting for sex and deprivation in multivariable logistic regression (OR 0.98,
41 $p<0.001$, 95% CI 0.97-0.99).
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45 There were clear differences in the patterns of service use, depending on documentation of
46 palliative phase of care. Patients documented as palliative were seen more frequently in the 30d
47 prior to death (median 3 contacts, IQR 2-4, v median 2 contacts, IQR 1-3 $z = -12.813$ $p<0.001$), and
48 their final contact with the service was closer to the point of death (median number of days between
49 final contact and death 2 (IQR 1-6), days v 8 (IQR 3-17) days $z = -15.335$ ($p<0.001$), with 42.2% (v
50 15.1%) being seen on the day of death or day prior to death.
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55 Patients documented as palliative presented less frequently at the weekend (67.2% v 70.4%; $z=-1.79$,
56 $p=0.037$), and more frequently overnight (27%, vs 18.3%, $z=5.391$, $p<0.001$). They were more likely to
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3 be assessed at a home visit (59.8% v 51.9%; $z=4.094$, $p<0.001$) and less likely to be managed solely
4 through telephone contact (43.2% vs 36.6%, $z=-3.508$, $p=0.002$).
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6

7 The two groups of patients differed in the outcomes of contacts with the OOH service. Patients
8 documented as palliative were less likely to be admitted to hospital following their assessment (2.7%
9 vs 18.0% respectively, $z=-8.091$, $p<0.001$), but more likely to be referred for community input (12.7%
10 vs 2.3%, $z=10.221$, $p<0.001$) or require no further follow up (40.8% vs 35.7%, $z=2.7$, $p=0.0035$) (Table
11 3).
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15 In addition to palliative codes, the most common clinical codes assigned in those patients
16 documented as palliative were medication related (7.4%), advice (6.35%), LRTI (2.8%), nausea and
17 vomiting (2.0%) and catheter care (1.6%). In those patients not documented as palliative, a wider
18 range of clinical codes were applied, the commonest were advice (10.8%), LRTI (8.4%), UTI (6.9%),
19 medication related (6.2%) and shortness of breath (4.2%) (supplementary tables 3 and 4).
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25 Causes of death in both groups are detailed in table 4. The highest proportion of deaths was due to
26 cancer in the group documented as palliative (70.7%); over twice that in those not documented as
27 palliative (31.2%). There were similar proportions of patients with dementia as cause of death.
28 Conversely, infections, myocardial infarction, pulmonary embolism, gastroenterological and
29 endocrinological diseases were over twice as frequently assigned to patients in the group not
30 documented as palliative. Causes of death which would be considered acute events (acute kidney
31 injury, myocardial infarction, pulmonary embolism, fracture, fall, trauma, stroke and sepsis) were
32 applied to 18.1% of patients documented as palliative and 29.3% of those not documented as
33 palliative.
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45 Discussion

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47 OOH GP services provide end of life care to almost a third of people who die in a population,
48 frequently very close to death. This places OOH GP services at the forefront of end of life care
49 provision. Patients at the end of life are more likely to contact the service overnight, likely in part
50 due to the reduction in availability of other services at these times. Death administration contributes
51 significantly to the workload of the OOH service, being required for 14.5% of all deaths. Just 0.4% of
52 all contacts occurring within the 30 days prior to death result in a hospice admission.
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3 Only 36.4% of patients contacting the service at the end of life were documented as palliative, hence
4 studies relying on clinical coding of patient contacts as palliative will significantly under report the
5 burden on the service. A large number of contacts in the 30 days prior to death result in a home visit
6 irrespective of documentation of a palliative phase of care, reflecting significant frailty within this
7 patient group. Patients not documented as palliative had a much higher rate of acute hospital
8 admission, suggesting that initial management strategy is based on addressing an acute presenting
9 illness syndrome with hospital based care in this group.
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16 The only study which has used a similar methodology to explore OOH service use at the end of life
17 reported a similarly high proportion (25%) of deceased patients contacting a Norwegian OOH service
18 in the 4 weeks before death, with a much higher proportion (37%) referred to hospital at their OOH
19 contact.¹⁰
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22 23 **Strengths and Limitations**

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25 This is the first study to accurately report the proportion of patients who die shortly after contact
26 with OOH primary care by linking UK OOH records with mortality data. However, there are several
27 limitations to our analysis. By excluding deaths of patients living outside Oxfordshire we may have
28 underestimated demands on the service. Our analysis was also limited to contacts within 30 days of
29 death, however the majority of contacts were within 7 days of death, suggesting that this has not
30 significantly limited our conclusions
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36 In order to explore whether the service recognised the patient contact as palliative we relied on
37 OOH clinicians assigning a palliative code to the patients record or a documenting an action only
38 relevant to palliative care (prescribing subcutaneous medication or hospice referral). Some patients
39 who were recognised by the service as needing end of life care may have been misclassified in this
40 analysis. Similarly we relied on the accuracy of cause of death as recorded by either the regular
41 general practitioner or hospital clinician. It is possible that acute events could be under reported in
42 death certificates if active malignancy is present.
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50 51 **Implications**

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53 The OOH service is making a significant contribution to end of life care. Despite a majority of
54 patients with terminal illness wishing to die at home, only a minority currently achieve this.¹¹
55 Enabling good deaths in the community is therefore a key component of OOH primary care
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3 provision. Ensuring that the OOH service is fit for this purpose in terms of staff skill mix and resource
4 is imperative.
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8 Two thirds of patients who died within 30 days of OOH contact were not documented as being in a
9 palliative phase of care. There will be patients for whom an acute life threatening syndrome has led
10 to an OOH contact. The percentage of deaths which were due to acute events was 25% overall, in
11 line with national estimates¹², and relatively higher in the group not documented as palliative
12 (29.3%). In addition, clinicians may recognise patients to be at the end of life, but choose to use
13 more immediately relevant clinical codes for the contact or be reluctant to use palliative codes for
14 patients who do not have cancer. Furthermore, there may be patients at the end of life where it is
15 simply not recognised in the setting of multiple morbidity and frailty.
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23 A greater number of acute, gastrointestinal, infection and cardiac codes were applied to patients
24 who were not documented as palliative. Gastrointestinal conditions in particular have been
25 highlighted previously as challenging to diagnose in prehospital urgent care settings.^{13,14} Evolving
26 OOH care services to include a greater range of POC blood and imaging diagnostics and tailored risk
27 scores could offer clinicians support in triaging and managing these difficult presentations.
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33 Reviews of deaths are standard practice in acute trusts and are viewed as integral to learning and
34 service improvement and in hours GPs are routinely informed of deaths of patients in their care.
35 However, there is no routine mechanism to feedback to clinicians working in OOH services when
36 deaths occur after contact. This deprives clinicians of the opportunity for valuable reflection and
37 learning and services of the opportunity for improvement.¹⁵ It is particularly relevant in light of the
38 recent CQC call¹⁶ to end missed opportunities to learn from patient deaths. Following the Mazars
39 report¹⁷, there is an increased focus on more robust systems to learn from deaths of patients
40 following contact with NHS trust services. This study may help OOH services prioritise deaths for
41 mortality review to maximise learning.
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51 **Conclusion**

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54 The contribution of OOH primary care services to patients at the end of life has previously been
55 under-researched and underestimated. This study demonstrates that almost a third of people who
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3 die have contact with an OOH service in the preceding 30 days. Further work to understand the how
4 OOH primary care can best meet the needs of patients at the end of life is required.
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8 **Acknowledgements**

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10
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15 of the NIHR, the Department of Health, or the NHS.
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21
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23 1176)
24
25
26

27 **Data sharing**

28
29 No additional data available
30
31
32

33 **Authors' contributions.**

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35
36 GH and DL conceived the study. RF developed the protocol, gained study permissions and developed
37 the databases. RB DL and GH analysed the data. HH and SG validated the dataset. RB and GH drafted
38 the manuscript and all authors contributed to interpretation of results and critical revision of the
39 manuscript.
40
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42

43 **Competing interest statements**

44
45 All authors have completed the *Unified Competing Interest form* (available on request from the
46 corresponding author) and declare: no support from any organisation for the submitted work [or
47 describe if any]; no financial relationships with any organisations that might have an interest in the
48 submitted work in the previous three years, no other relationships or activities that could appear to
49 have influenced the submitted work.
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53 **Ethics committee approval**

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56 This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory
57 Group Approval (15/CAG/0211).
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Figures

Figure 1 Number of days between final OOH contact and death expressed as cumulative percentage

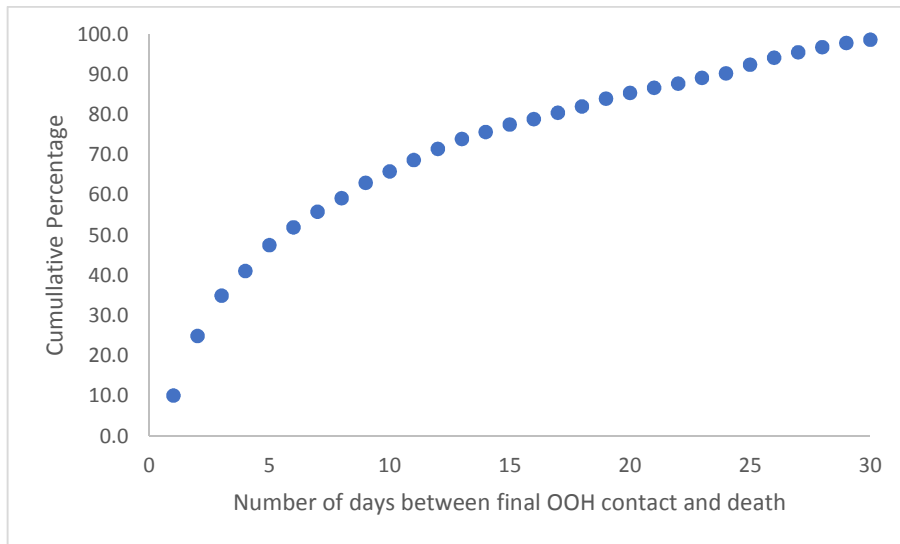
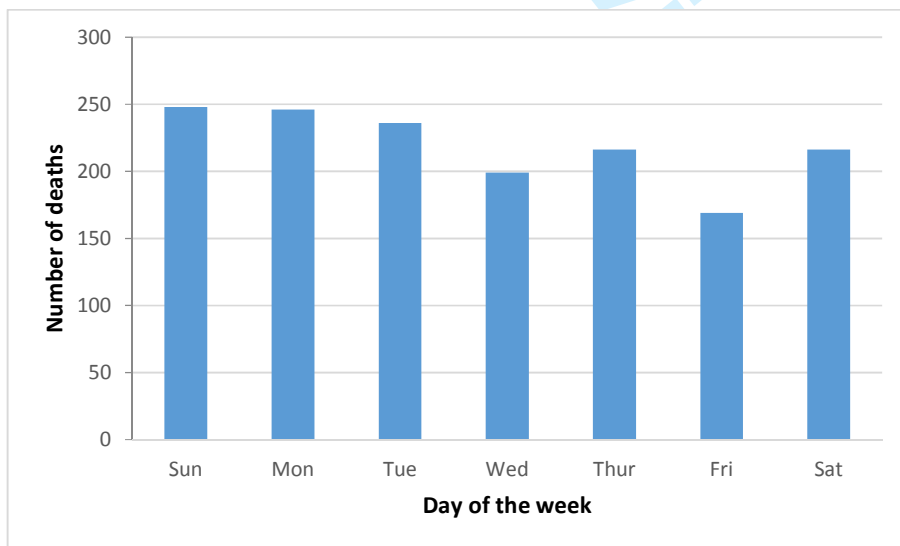


Figure 2 Number of deaths occurring on each day of the week



Tables

Table 1: Characteristics of patients contacting the service within 30 days of death compared to all other patients

| | Patients within 30d of death (n = 1530) | Patients not within 30d of death (n = 66413) |
|----------------------------|--|---|
| Age (median, IQR) | 84.9 (77.0 – 90.6) yrs | 33.3 (12.2-- 59.2) yrs |
| Gender (percentage, 95%CI) | 44.3% (41.8 – 46.8) | 41.6% (41.2 – 42.0) |
| IMD* score (mean, sd) | 12.00 (9.30) | 13.13 (9.67) |

*Index of multiple deprivation

Table 2: Characteristics of patient contacts with the service within 30 days of death compared to all other contacts

| | Contacts within 30d of death (n = 2661) | Contacts not within 30d of death (n = 100216) |
|---|--|--|
| Contact type (percentage (95%CI)) | | |
| Home visit | 55.8% (53.9 – 57.7) | 9.7% (9.5 – 9.9) |
| Base assessment | 4.2% (3.4 – 5.0) | 55.8% (55.5 – 56.1) |
| Telephone contact only | 39.9% (38.0 – 41.8) | 34.3% (34.0 – 34.6) |
| Time of contact (percentage (95%CI)) | | |
| Overnight 00:00-07:59 | 22.6% (21.0 – 24.2) | 15.5% (15.3 – 15.7) |
| Evening 18:30-23:59 | 29.4% (27.7 – 31.1) | 37.8% (37.5 – 38.1) |
| Daytime 08:00-18:29 | 48.0% (46.1 – 49.9) | 46.7% (46.4 – 47.0) |
| Outcome of the contact (percentage (95%CI)) | | |
| Acute admission (hospital, A&E, Emergency Multidisciplinary Unit) | 10.5% (9.3 – 11.7) | 7.43% (7.3 – 3.6) |
| Admission to hospice | 0.4% (0.1 – 0.6) | 0.03% (0.03 – 0.03) |
| Community input (Hospital at home, community nursing, social services, minor injury unit, mental health team) | 7.4% (6.4 – 8.4) | 1.2% (1.1 – 1.3) |
| Did not attend/unable to contact/left before treatment | 0.3% (0.1 – 0.6) | 1.4% (1.3 – 1.5) |
| GP Follow-up | 38.2% (36.3 – 40.0) | 36.8% (36.5 – 37.1) |
| No Follow-up | 38.3% (36.3 – 40.0) | 49.3% (49.0 – 49.6) |
| Other | 5.1% (4.3 – 5.9) | 3.8% (3.7 – 4.0) |

Table 3: Outcomes of contacts with patients documented palliative v those not documented palliative

| Outcome of contact | Documented as palliative | | Not documented as palliative | |
|---|--------------------------|------------------------|------------------------------|------------------------|
| | Frequency | Percentage of contacts | Frequency | Percentage of contacts |
| Acute admission (hospital, A&E, EMU) | 35 | 2.7% | 243 | 18.0% |
| Admission to hospice | 10 | 0.8% | 0 | 0.0% |
| Community input (H@H, comm nursing, SS, MIU) | 166 | 12.7% | 31 | 2.3% |
| Unable to contact | 2 | 0.2% | 7 | 0.5% |
| GP FU | 493 | 37.6% | 522 | 38.6% |
| No FU | 534 | 40.8% | 482 | 35.7% |
| Other (OP clinic, passed to another provider) | 68 | 5.2% | 63 | 4.7% |
| Outcome missing | 2 | 0.2% | 3 | 0.2% |
| Total | 1310 | 100.0% | 1351 | 100.0% |

Table 4: All assigned Causes of death by documented palliative / not and total

| | Documented as palliative | | Not documented as palliative | | Total | |
|---|--------------------------|------------------------|------------------------------|------------------------|-----------|------------------------|
| | frequency | percentage of patients | frequency | percentage of patients | frequency | percentage of patients |
| Malignancy | 394 | 70.7 | 304 | 31.2 | 698 | 45.6 |
| Cardiac disease excluding myocardial infarction | 137 | 24.6 | 396 | 40.7 | 533 | 34.8 |
| Acute lower respiratory infection | 87 | 15.6 | 298 | 30.6 | 385 | 25.2 |
| Dementia | 121 | 21.7 | 244 | 25.1 | 365 | 23.9 |
| Age-related physical debility | 96 | 17.2 | 136 | 14.0 | 232 | 15.2 |
| Respiratory disease | 57 | 10.2 | 175 | 18.0 | 232 | 15.2 |
| Stroke (haemorrhage or infarction) | 56 | 10.1 | 124 | 12.7 | 180 | 11.8 |
| Gastrointestinal disease | 20 | 3.6 | 128 | 13.2 | 148 | 9.7 |
| Type 2 diabetes mellitus without complications | 39 | 7.0 | 105 | 10.8 | 144 | 9.4 |
| Hypertension | 37 | 6.6 | 104 | 10.7 | 141 | 9.2 |
| Kidney disease | 40 | 7.2 | 99 | 10.2 | 139 | 9.1 |
| Peripheral vascular disease | 21 | 3.8 | 51 | 5.2 | 72 | 4.7 |
| Neurological disease | 21 | 3.8 | 44 | 4.5 | 65 | 4.2 |
| Urinary tract infection | 6 | 1.1 | 53 | 5.4 | 59 | 3.9 |
| Rheumatological disease | 20 | 3.6 | 39 | 4.0 | 59 | 3.9 |
| Other | 13 | 2.3 | 40 | 4.1 | 53 | 3.5 |
| Complication of procedure / surgery | 14 | 2.5 | 32 | 3.3 | 46 | 3.0 |
| Sepsis | 8 | 1.4 | 37 | 3.8 | 45 | 2.9 |
| Endocrinological disease | 6 | 1.1 | 35 | 3.6 | 41 | 2.7 |
| Parkinson's disease | 12 | 2.2 | 28 | 2.9 | 40 | 2.6 |
| Acute kidney failure | 6 | 1.1 | 34 | 3.5 | 40 | 2.6 |
| Acute myocardial infarction | 8 | 1.4 | 31 | 3.2 | 39 | 2.5 |
| Fracture | 14 | 2.5 | 25 | 2.6 | 39 | 2.5 |
| Pulmonary embolism | 6 | 1.1 | 24 | 2.5 | 30 | 2.0 |
| Infection (excluding LRTI & UTI) | 4 | 0.7 | 25 | 2.6 | 29 | 1.9 |
| Psychiatric | 6 | 1.1 | 14 | 1.4 | 20 | 1.3 |
| Non-malignant haematological | 4 | 0.7 | 12 | 1.2 | 16 | 1.0 |
| Traumatic | 2 | 0.4 | 6 | 0.6 | 8 | 0.5 |
| Fall | 2 | 0.4 | 2 | 0.2 | 4 | 0.3 |
| Drug related | 0 | 0.0 | 4 | 0.4 | 4 | 0.3 |

Supplementary tables

Table 1: most commonly assigned clinical codes (>1%) to contacts in 30d prior to death

| Clinical Code (grouped) | Frequency | % of all codes assigned. |
|--------------------------------------|-----------|--------------------------|
| Palliative | 957 | 27.27% |
| Advice/reassurance | 307 | 8.75% |
| Medication request/prescribed | 248 | 7.07% |
| LRTI | 194 | 5.53% |
| UTI | 148 | 4.22% |
| SOB | 95 | 2.71% |
| N&V | 79 | 2.25% |
| Procedure | 73 | 2.08% |
| Other Respiratory illness or symptom | 73 | 2.08% |
| Catheter care | 66 | 1.88% |
| Confusion/reduced GCS | 55 | 1.57% |
| Pain | 53 | 1.51% |
| Abdominal Pain | 47 | 1.34% |
| Other | 47 | 1.34% |
| Condition or symptom NOS | 46 | 1.31% |
| Abnormal bloods | 45 | 1.28% |
| Wound care | 44 | 1.25% |
| Collapse or Fall | 39 | 1.11% |
| Emergency treatment | 36 | 1.03% |
| Agitation | 35 | 1.00% |
| Cancer | 35 | 1.00% |

Table 2: Most commonly assigned clinical codes (>1%) to contacts alive at 30 days after OOH contact

| Clinical code (grouped) | Frequency | % of all codes assigned |
|---|-----------|-------------------------|
| ENT symptom or condition | 10507 | 13.49% |
| UTI | 7305 | 6.00% |
| MSK disease | 6443 | 5.30% |
| URTI | 5909 | 4.86% |
| Medication request/prescribed | 5141 | 4.23% |
| Advice/reassurance | 4866 | 4.00% |
| Abdominal pain | 4845 | 3.98% |
| Viral illness | 4658 | 3.83% |
| Other respiratory symptoms or illness | 4324 | 3.55% |
| Diagnosis not made | 3733 | 3.07% |
| Skin infection | 3470 | 2.85% |
| LRTI | 3260 | 2.68% |
| Skin condition | 3043 | 2.50% |
| Wound care | 2708 | 2.23% |
| Gastroenteritis | 2634 | 2.16% |
| Fever | 2564 | 2.11% |
| Failed encounter/DNA | 2405 | 1.98% |
| Mental health symptom/condition | 2278 | 1.87% |
| N&V | 2271 | 1.87% |
| Neurological condition | 2158 | 1.77% |
| Accidental injury | 2105 | 1.73% |
| GI disease or symptom | 1995 | 1.64% |
| Catheter care | 1950 | 1.60% |
| Eye problem | 1876 | 1.54% |
| Oral disease | 1752 | 1.44% |
| Urological disorder | 1673 | 1.38% |
| Pregnancy, antenatal care or pregnancy complication | 1376 | 1.13% |
| Diarrhoea | 1314 | 1.08% |
| Chest pain/IHD | 1281 | 1.05% |

Table 3: Clinical codes most commonly assigned to contacts with patients not documented as palliative (codes accounting for >1% of all codes assigned.)

| Clinical code (grouped) | Frequency | % of all codes |
|-------------------------------|-----------|----------------|
| Advice | 191 | 10.82% |
| LRTI | 148 | 8.39% |
| UTI | 121 | 6.86% |
| Medication request/prescribed | 110 | 6.23% |
| SOB | 74 | 4.19% |
| N&V | 48 | 2.72% |
| Pain | 39 | 2.21% |
| Catheter care | 38 | 2.15% |
| Abdominal Pain | 37 | 2.10% |
| Procedure | 37 | 2.10% |
| Confusion | 36 | 2.04% |
| Abnormal bloods | 35 | 1.98% |
| Respiratory illness | 32 | 1.81% |
| MSK disease | 32 | 1.81% |
| Other | 31 | 1.76% |
| Wound care | 29 | 1.64% |
| Ill defined condition | 27 | 1.53% |
| COPD | 26 | 1.47% |
| Emergency treatment | 25 | 1.42% |
| Fall | 24 | 1.36% |
| Chest pain | 22 | 1.25% |
| CVA | 22 | 1.25% |
| Failed encounter | 21 | 1.19% |
| Referral | 20 | 1.13% |
| Dehydration | 19 | 1.08% |
| Skin infection | 19 | 1.08% |
| Unwell | 18 | 1.02% |
| Sepsis | 18 | 1.02% |
| GI bleed | 18 | 1.02% |

Table 4: Clinical codes (grouped) most commonly assigned to contacts with patients coded as palliative (i.e. codes accounting for >1% of all codes assigned.)

| Documented as palliative | | |
|-------------------------------|-----------|-------------------------|
| Clinical code (grouped) | Frequency | % of all codes assigned |
| Palliative | 1134 | 54.15% |
| Medication request/prescribed | 155 | 7.40% |
| Advice | 133 | 6.35% |
| LRTI | 59 | 2.82% |
| N&V | 42 | 2.01% |
| Catheter care | 34 | 1.62% |
| Cancer | 33 | 1.58% |
| UTI | 31 | 1.48% |
| Agitation | 29 | 1.38% |
| Procedure | 29 | 1.38% |
| SOB | 24 | 1.15% |

BMJ Open

What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire

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| | |

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3 1 **What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage**
4 2 **study in Oxfordshire.**

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6
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32 16 **Abstract**

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35 17 **Objectives:** Out of hours (OOH) primary care services are a key element of community care at the
36 18 end of life, yet there have been no previous attempts to describe the scope of this activity. We
37 19 aimed to establish the proportion of Oxfordshire patients who were seen by the Out Of Hours
38 20 service within the last 30 days of life, whether they were documented as in a palliative phase of care
39 21 and the demographic and clinical features of these groups

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44 22 **Design** Population based study linking a database of patient contacts with OOH primary care with
45 23 the register of all deaths within Oxfordshire (600000 population) during 13 months.

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48 24 **Setting** Oxfordshire

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51 25 **Participants** Between 1/12/14 and 30/11/2015 there were 102,877 OOH contacts made by 67,943
52 26 patients with the OOH service.
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3 27 **Main outcome measures** Proportion of patients dying in the Oxfordshire population who were seen
4 28 by the Out Of Hours service within the last 30 days of life. Demographic and clinical features of these
5 29 contacts.

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8 30 **Results** 29.5% of all population deaths were seen by the OOH service in the last 30 days of life.
9 31 Among the 1530 patients seen, patients whose palliative phase was documented (n=577, 36.4%)
10 32 were slightly younger (median age = 83.5 vs 85.2 years, p<0.001) and were seen closer to death
11 33 (median days to death = 2 v 8, p<0.001). More were assessed at home (59.8% vs 51.9%, p<0.001)
12 34 and less were admitted to hospital (2.7% vs 18.0%, p<0.001).

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17 35 **Conclusions** OOH services see around one third of all patients who die in a population. Most patients
18 36 at the end of life are not documented as palliative by OOH services and are less likely to receive
19 37 ongoing care at home.

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44 **Strengths and Limitations of this study**

- 46 • This is the first study to use data linkage with death records to describe the true population
47 at the end of life who contact the OOH service.
- 48 • The study highlights both the importance of the OOH primary care service in end of life care
49 and the significant limitations of medical records studies which have used clinical coding of
50 palliative care as a proxy for end of life contacts
- 51 • Our understanding of the proportion of these deaths which were palliative and the causes of
52 death relied on the accuracy of clinical coding
- 53 • Our study focused on a single area of the UK due to restriction in access to OOH provider
54 medical records

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62 Introduction

63 The provision of primary care services outside core contracted hours is fundamental to the
64 operation of the NHS.¹ In 2013-14, out of hours GP services (OOH) in England handled approximately
65 5.8 million cases, 3.3 million of which were face to face consultations, including 800,000 home
66 visits.² For the majority of patients OOH primary care is provided by a clinician who does not know
67 them, often with limited access to their medical record.³

68 In January 2015 the top research priority identified by the Palliative and end of life care Priority
69 Setting Partnership was the provision of palliative care outside of working hours to help patients stay
70 in their place of choice by managing crises.⁴ Given that the majority of people with terminal illness
71 do not wish to die in a hospital⁵, OOH primary care services must be viewed as an integral part of
72 end of life care provision.

73 Our current understanding of the true extent of end of life care provided by the OOH service is
74 limited. OOH services do not routinely receive feedback on patient deaths following contact with the
75 service. We previously analysed an OOH service database⁶ and learned that patients whose needs
76 were coded as palliative contacted the OOH service predominantly during weekend daytime periods,
77 and that over a third had multiple contacts with the service. However, the study was limited because
78 we were not able to identify all patients who had died and had contacted the service, thus
79 underestimating the true proportion of patients with end of life care needs.

80 In order to understand how OOH care can best be provided at the end of life we need to understand
81 the true extent of this workload and whether there are differences between patients who appear to
82 be recognised as palliative by clinicians and those who are not. This study used data linkage to
83 identify people who died in Oxfordshire over the course of a year who had contact with the OOH
84 services in the 30 days before death and the clinical care that they received from the OOH service.

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86 Methods

87 The Oxfordshire OOH service provides care to a population of over 600,000 people from 18:30pm –
88 08:00am on weekdays and 24 hour cover on weekends and bank holidays. Access to the service is via

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89 the NHS 111 telephone advice line, where trained call handlers use the NHS Pathways algorithm to
90 direct patients to the most appropriate service for their needs. Patients directed by 111 to the OOH
91 service will receive an initial telephone consultation with an OOH clinician which may then lead to a
92 base visit (patient comes to the OOH surgery to be seen), home visit or the case being passed to
93 another care provider (such as 'hospital at home'). Patients can also be booked directly by 111 to an
94 OOH base visit.

95 A database of all patient contacts with the Oxfordshire Out of Hours (OOH) service over 1 year from
96 01.12.14 to 30.11.2015 was created from the OOH Electronic Record System used by clinicians
97 (Adastra).

98 Mortality data for Oxfordshire (population 600,000) over 13 months (1.12.14-31.12.15, to capture
99 patients who died within 30 days of contact with the OOH service) was obtained via NHS
100 Digital/Office of National Statistics, with Section 251 approval from the Confidentiality Advisory
101 Group. This was linked by NHS number with Oxfordshire OOH service care records and was used to
102 identify people who had contact with the OOH service in the 30 days prior to death. All patient
103 identifiers were removed on entry to the database and data destruction was completed in
104 accordance with NHS Digital requirements. Any contact without an NHS number was removed from
105 the database, as repeat visits could not be assessed, as were those with a duplicate case ID. Contacts
106 that were seen after death were also removed. Demographic data consisted of age, sex and Index of
107 Multiple Deprivation score (available for 79% of contacts).⁷ Service data included final contact type,
108 outcome, date, clinical codes assigned and prescriptions issued. Mortality data included the date of
109 death and all assigned ICD-10⁸ causes of death. All assigned causes of death were included in the
110 analysis in recognition of the fact that the most important or relevant cause of death may not be the
111 first one listed on the certificate and therefore including only one cause would introduce significant
112 bias.

113 Timings of calls were classified as evening 18:30-23:59, overnight 00:00-07:59 and daytime (i.e.
114 weekends and bank holidays) 08:00-18:29. The number of days difference between contact and
115 death was calculated using calendar days beginning at midnight. Weekend period was classified as
116 18:30 Friday until 08:00 Monday.

117 Those who died were also classified according to whether they had been documented by the service
118 as palliative or not. We defined palliative patients as those who, at any contact with the OOH service
119 in the study period, had been assigned a clinical code specific to palliative care, been referred to a
120 hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication.

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3 121 Appropriate subcutaneous medications were defined as medications as specified in the British
4 122 National Formulary as being suitable for continuous subcutaneous infusion in palliative care. These
5 123 included medications used for bowel colic and excessive respiratory secretions, confusion and
6 124 restlessness, convulsions, nausea and vomiting and/or pain control.⁹ This group was compared with
7 125 all other patients who died within 30 days of contact. Further details regarding coding as supplied as
8 126 supplementary information.

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18 129 In order to validate the clinical codes applied by the OOH clinicians we estimated, based on previous
19 130 coding validity studies¹⁰ that analysis of 230 records would be required to establish the coding
20 131 validity with a confidence level of 90% and 5% margin of error. A random selection of 230 records
21 132 was obtained using SPSS, and the clinical code was compared by two authors (SG, HH) to the
22 133 conclusion drawn by the clinician in the medical notes. The positive predictive value (PPV) of the
23 134 clinical code for medical diagnosis or conclusion was 92.6%.

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33 137 Demographic details and details concerning the cause of death were compared at a patient level, so
34 138 that each patient was only considered once in the analysis. By contrast, the OOH contact and
35 139 outcome were compared at an OOH contact level. Statistical analysis was performed using SPSS
36 140 Version 22. T tests were used when comparing means, z tests when comparing proportions and
37 141 Mann Witney U test when comparing medians. Logistic regression was performed to test
38 142 associations for binary outcomes. This study had Research Ethics approval (REC number
39 143 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

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48 49 146 **Results**

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51 147 Between 1/12/2014 -30/11/2015 there were 102,877 contacts, by 67,943 patients, with the
52 148 Oxfordshire OOH service. In the 13 month period between 1/12/14 – 31/12/15, 5193 people died in
53 149 Oxfordshire. Of the people who died, 1530 (29.5%) had contact with the OOH service in the 30 days
54 150 prior to their death. These patients made 2661 contacts with the OOH service in the 30d prior to

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3 151 their death, accounting for 2.57% of all contacts to the service over the 12 month study period. A
4 152 further 791 contacts (with 752 patients) occurred *after* death, equating to 14.5% of all deaths and
5 153 0.76% of all contacts to the service. Contacts after death were excluded from further analyses.

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8 154 Of those patients who had contact with the OOH service in the 30d prior to death, 381 (24.9%) made
9 155 a contact in the last day of life (Figure 1). There was a median of 5 (Interquartile range (IQR) 1.75 –
10 156 13) days between final OOH contact and death and the median number of contacts with the OOH
11 157 service in the 30 days prior to death was 1 (IQR 1 – 2). A similar proportion of deaths occurred on
12 158 each day of the week (figure 2)

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17 159 Tables 1 and 2 compare patients and patient contact features of those who died within 30 days of
18 160 death with those who were alive at 30 days after initial OOH consultation. Patients who died were
19 161 older, less deprived and more likely to be male. Patient contacts were more frequently in their own
20 162 home and more likely to have their care escalated to an alternative provider (hospital, hospice,
21 163 community care provider).

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26 164 For those patients who died within 30 days the most commonly assigned clinical codes were
27 165 palliative (27.3% of all codes assigned), advice (8.8%), medication requests (7.1%), lower respiratory
28 166 tract infection (LRTI) (5.5%) or urinary tract infection (UTI) (4.2%) codes. By comparison, Ear, Nose
29 167 and Throat disorder (ENT) (13.5%), UTI (6.0%), musculoskeletal disease (MSK) (5.3%), upper
30 168 respiratory tract infection (URTI) (4.9%), and medication requests (4.2%) were the commonest codes
31 169 in those alive at 30 days after index assessment (supplementary tables 1 and 2)

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36 170 Acute events were the cause of death in 25% of patients. The commonest codes were types of
37 171 cancer (45.6%) followed by cardiac disease (34.8%), LRTI (25.2%), dementia (23.9%), age related
38 172 debility and other respiratory disease (both 15.2%) (see table 4 for full list).

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44 174 **Comparison between palliative patients and patients dying within 30 days not documented as**
45 175 **palliative.**

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48 176 Patients who had contact with the OOH service in the 30 days prior to death were categorised into
49 177 those who had been documented by the service as palliative (any palliative code assigned to record,
50 178 hospice referral, or appropriate subcutaneous medication prescribed at any time), and those who
51 179 had not.

180 557 patients (36.4%) were documented as palliative, and had 1310 contacts with the OOH service in
181 the 30 days prior to death. By contrast, 973 patients (63.6%) were not documented as palliative,
182 accounting for 1351 contacts.

183 Patients documented as palliative were younger than those not documented (median 83.5 years
184 (IQR 74.1 – 89.6) vs 85.2 years (IQR 78.3 – 91.1) ($p < 0.001$, $z = 4.45$), an association which was
185 maintained after adjusting for sex and deprivation in multivariable logistic regression (Odds Ratio
186 (OR) 0.98, $p < 0.001$, 95% CI 0.97-0.99).

187 There were clear differences in the patterns of service use, depending on documentation of
188 palliative phase of care. Patients documented as palliative were seen more frequently in the 30d
189 prior to death (median 3 contacts, IQR 2-4, v median 2 contacts, IQR 1-3 $z = -12.813$ $p < 0.001$), and
190 their final contact with the service was closer to the point of death (median number of days between
191 final contact and death (IQR 1-6), days v 8 (IQR 3-17) days $z = -15.335$ ($p < 0.001$), with 42.2% (v
192 15.1%) being seen on the day of death or day prior to death.

193 Patients documented as palliative presented less frequently at the weekend (67.2% v 70.4%; $z = -1.79$,
194 $p = 0.037$), and more frequently overnight (27%, vs 18.3%, $z = 5.391$, $p < 0.001$). They were more likely
195 to be assessed at a home visit (59.8% v 51.9%; $z = 4.094$, $p < 0.001$) and less likely to be managed solely
196 through telephone contact (43.2% vs 36.6%, $z = -3.508$, $p = 0.002$).

197 The two groups of patients differed in the outcomes of contacts with the OOH service. Patients
198 documented as palliative were less likely to be admitted to hospital following their assessment (2.7%
199 vs 18.0% respectively, $z = -8.091$, $p < 0.001$), but more likely to be referred for community input (12.7%
200 vs 2.3%, $z = 10.221$, $p < 0.001$) or require no further follow up (40.8% vs 35.7%, $z = 2.7$, $p = 0.0035$) (Table
201 3).

202 In addition to palliative codes, the most common clinical codes assigned in those patients
203 documented as palliative were medication related (7.4%), advice (6.35%), LRTI (2.8%), nausea and
204 vomiting (2.0%) and catheter care (1.6%). In those patients not documented as palliative, a wider
205 range of clinical codes were applied, the commonest were advice (10.8%), LRTI (8.4%), UTI (6.9%),
206 medication related (6.2%) and shortness of breath (4.2%) (supplementary tables 3 and 4).

207 Causes of death in both groups are detailed in table 4. The highest proportion of deaths was due to
208 malignancy in the group documented as palliative (70.7%); over twice that in those not documented
209 as palliative (31.2%). There were similar proportions of patients with dementia as cause of death.
210 Conversely, infections, myocardial infarction, pulmonary embolism, gastroenterological and
211 endocrinological diseases were over twice as frequently assigned to patients in the group not

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3 212 documented as palliative. Causes of death which would be considered acute events (acute kidney
4 213 injury, myocardial infarction, pulmonary embolism, fracture, fall, trauma, stroke and sepsis) were
5 214 applied to 18.1% of patients documented as palliative and 29.3% of those not documented as
6 215 palliative.
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11 217 **Discussion**

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14 218 OOH GP services provide end of life care to almost a third of people who die in a population,
15 219 frequently very close to death. This places OOH GP services at the forefront of end of life care
16 220 provision. Patients at the end of life are more likely to contact the service overnight, likely in part
17 221 due to the reduction in availability of other services at these times. Death administration contributes
18 222 significantly to the workload of the OOH service, being required for 14.5% of all deaths. Just 0.4% of
19 223 all contacts occurring within the 30 days prior to death result in a hospice admission.
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24 224 Only 36.4% of patients contacting the service at the end of life were documented as palliative, hence
25 225 studies relying on clinical coding of patient contacts as palliative will significantly under report the
26 226 burden on the service. A large number of contacts in the 30 days prior to death result in a home visit
27 227 irrespective of documentation of a palliative phase of care, reflecting significant frailty within this
28 228 patient group. Patients not documented as palliative had a much higher rate of acute hospital
29 229 admission, suggesting that initial management strategy is based on addressing an acute presenting
30 230 illness syndrome with hospital based care in this group.
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37 231 The only study which has used a similar methodology to explore OOH service use at the end of life
38 232 reported a similarly high proportion (25%) of deceased patients contacting a Norwegian OOH service
39 233 in the 4 weeks before death, with a much higher proportion (37%) referred to hospital at their OOH
40 234 contact.¹¹
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44 235 **Strengths and Limitations**

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46 236 This is the first study to accurately report the proportion of patients who die shortly after contact
47 237 with OOH primary care by linking UK OOH records with mortality data. However, there are several
48 238 limitations to our analysis. Our study is based in the English NHS, and we cannot comment on
49 239 whether our results would extrapolate to other models of out of hours healthcare provision. By
50 240 excluding deaths of patients living outside Oxfordshire we may have underestimated demands on
51 241 the service. Our analysis was also limited to contacts within 30 days of death, however the majority
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3 242 of contacts were within 7 days of death, suggesting that this has not significantly limited our
4 243 conclusions.
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7 244 In order to explore whether the service recognised the patient contact as palliative we relied on
8 245 OOH clinicians assigning a palliative code to the patients record or a documenting an action only
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10 246 relevant to palliative care (prescribing subcutaneous medication or hospice referral). Since no other
11 247 studies have attempted this form of classification we could not use a validated approach. It is likely
12 248 that some patients who were recognised by the service as needing end of life care may have been
13 249 misclassified in this analysis. However, the PPV of the clinical code for medical diagnosis or
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15 250 conclusion was higher than the average PPV found in a systematic review of studies using primary
16 251 care medical records.¹⁰ Similarly we relied on the accuracy of cause of death as recorded by either
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18 252 the regular general practitioner or hospital clinician. It is possible that acute events could be under
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20 253 reported in death certificates if active malignancy is present.
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255 **Implications**

256 The OOH service is making a significant contribution to end of life care. Despite a majority of
257 258 patients with terminal illness wishing to die at home, only a minority currently achieve this.¹²
259 Enabling good deaths in the community is therefore a key component of OOH primary care
260 261 provision. There is scope for debate on how best to provide a service to this patient group. One
262 263 component of this must be improving planning and communication from the in hours GP to avoid
264 265 OOH demands, and another might be the creation of dedicated palliative teams, operating in the
266 267 OOH period. However, both of these measures will only support the third of patients at the end of
268 269 life who are documented as palliative, and additional measures are needed to ensure that the OOH
270 271 service is fit for managing all patients at the end of life, in terms of recognition of end of life, staff
272 273 skill mix and resources.

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267 Two thirds of patients who died within 30 days of OOH contact were not documented as being in a
268 269 palliative phase of care. There will be patients for whom an acute life threatening syndrome has led
270 271 to an OOH contact. The percentage of deaths which were due to acute events was 25% overall, in
272 273 line with national estimates¹³, and relatively higher in the group not documented as palliative
274 275 (29.3%). In addition, clinicians may recognise patients to be at the end of life, but choose to use
276 277 more immediately relevant clinical codes for the contact or be reluctant to use palliative codes for

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3 273 patients who do not have cancer. Furthermore, there may be patients at the end of life where it is
4 274 simply not recognised in the setting of multiple morbidity and frailty.

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6 275 A greater number of acute, gastrointestinal, infection and cardiac codes were applied to patients
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8 276 who were not documented as palliative. Gastrointestinal conditions in particular have been
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10 277 highlighted previously as challenging to diagnose in prehospital urgent care settings.^{14,15} Evolving
11 278 OOH care services to include a greater range of POC blood and imaging diagnostics and tailored risk
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13 279 scores could offer clinicians support in triaging and managing these difficult presentations.
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15 280 Reviews of deaths are standard practice in acute trusts and are viewed as integral to learning and
16 281 service improvement and in hours GPs are routinely informed of deaths of patients in their care.
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18 282 However, there is no routine mechanism to feedback to clinicians working in OOH services when
19 283 deaths occur after contact. This deprives clinicians of the opportunity for valuable reflection and
20 284 learning and services of the opportunity for improvement.¹⁶ It is particularly relevant in light of the
21 285 recent Care Quality Commission call¹⁷ to end missed opportunities to learn from patient deaths.
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23 286 Following the Mazars report¹⁸, there is an increased focus on more robust systems to learn from
24 287 deaths of patients following contact with NHS trust services. This study may help OOH services
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26 288 prioritise deaths for mortality review to maximise learning.
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32 291 **Conclusion**

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35 293 The contribution of OOH primary care services to patients at the end of life has previously been
36 294 under-researched and underestimated. This study demonstrates that almost a third of people who
37
38 295 die have contact with an OOH service in the preceding 30 days. Further work to understand how
39
40 296 OOH primary care can best meet the needs of patients at the end of life is required.
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45
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4 307 1176)

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7 309 **Data sharing**

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9 310 No additional data available

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16 313 **Authors' contributions.**

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18 314 GH and DL conceived the study. RF developed the protocol, gained study permissions and developed
19 315 the databases. RB DL and GH analysed the data. HH and SG validated the dataset. RB and GH drafted
20 316 the manuscript and all authors contributed to interpretation of results and critical revision of the
21 317 manuscript.

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25 319 **Competing interest statements**

26
27 320 All authors have completed the *Unified Competing Interest form* (available on request from the
28 321 corresponding author) and declare: no support from any organisation for the submitted work [or
29 322 describe if any]; no financial relationships with any organisations that might have an interest in the
30 323 submitted work in the previous three years, no other relationships or activities that could appear to
31 324 have influenced the submitted work.

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35 326 **Ethics committee approval**

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37 327 This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory
38 328 Group Approval (15/CAG/0211).

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42 330 **References**

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3 386 **Figure Legends**

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5 387 Figure 1 Number of days between final OOH contact and death expressed as cumulative percentage

6
7 388 Figure 2 Number of deaths occurring on each day of the week

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23 396 **Tables**

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26 398 **Table 1: Characteristics of patients contacting the service within 30 days of death compared to all**
27 **other patients**
28 399

| | Patients within 30d of death (n = 1530) | Patients not within 30d of death (n = 66413) |
|--------------------------|--|---|
| Age (median, IQR) | 84.9 (77.0 – 90.6) yrs | 33.3 (12.2-- 59.2) yrs |
| Male (percentage, 95%CI) | 44.3% (41.8 – 46.8) | 41.6% (41.2 – 42.0) |
| IMD* score (mean, sd) | 12.00 (9.30) | 13.13 (9.67) |

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410 **Table 2: Characteristics of patient contacts with the service within 30 days of death compared to**
 411 **all other contacts**

| | Contacts within 30d of death (n = 2661) | Contacts not within 30d of death (n = 100216) |
|---|--|--|
| Contact type (percentage (95%CI)) | | |
| Home visit | 55.8% (53.9 – 57.7) | 9.7% (9.5 – 9.9) |
| Base assessment | 4.2% (3.4 – 5.0) | 55.8% (55.5 – 56.1) |
| Telephone contact only | 39.9% (38.0 – 41.8) | 34.3% (34.0 – 34.6) |
| Time of contact (percentage (95%CI)) | | |
| Overnight 00:00-07:59 | 22.6% (21.0 – 24.2) | 15.5% (15.3 – 15.7) |
| Evening 18:30-23:59 | 29.4% (27.7 – 31.1) | 37.8% (37.5 – 38.1) |
| Daytime 08:00-18:29 | 48.0% (46.1 – 49.9) | 46.7% (46.4 – 47.0) |
| Outcome of the contact (percentage (95%CI)) | | |
| Acute admission (hospital, A&E, ambulatory care unit) | 10.5% (9.3 – 11.7) | 7.43% (7.3 – 3.6) |
| Admission to hospice | 0.4% (0.1 – 0.6) | 0.03% (0.03 – 0.03) |
| Community input (Hospital at home, community nursing, social services, minor injury unit, mental health team) | 7.4% (6.4 – 8.4) | 1.2% (1.1 – 1.3) |
| Did not attend/unable to contact/left before treatment | 0.3% (0.1 – 0.6) | 1.4% (1.3 – 1.5) |
| GP Follow-up | 38.2% (36.3 – 40.0) | 36.8% (36.5 – 37.1) |
| No Follow-up | 38.3% (36.3 – 40.0) | 49.3% (49.0 – 49.6) |
| Other | 5.1% (4.3 – 5.9) | 3.8% (3.7 – 4.0) |

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417 **Table 3: Outcomes of contacts with patients documented palliative v those not documented**
 418 **palliative**

| Outcome of contact | Documented as palliative | | Not documented as palliative | |
|---|--------------------------|------------------------|------------------------------|------------------------|
| | Frequency | Percentage of contacts | Frequency | Percentage of contacts |
| Acute admission (hospital, A&E, EMU) | 35 | 2.7% | 243 | 18.0% |
| Admission to hospice | 10 | 0.8% | 0 | 0.0% |
| Community input (H@H, comm nursing, SS, MIU) | 166 | 12.7% | 31 | 2.3% |
| Unable to contact | 2 | 0.2% | 7 | 0.5% |
| GP FU | 493 | 37.6% | 522 | 38.6% |
| No FU | 534 | 40.8% | 482 | 35.7% |
| Other (OP clinic, passed to another provider) | 68 | 5.2% | 63 | 4.7% |
| Outcome missing | 2 | 0.2% | 3 | 0.2% |
| Total | 1310 | 100.0% | 1351 | 100.0% |

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435 **Table 4: All assigned Causes of death by documented palliative / not and total**

| | Documented as palliative | | Not documented as palliative | | Total | |
|---|--------------------------|------------------------|------------------------------|------------------------|-----------|------------------------|
| | frequency | percentage of patients | frequency | percentage of patients | frequency | percentage of patients |
| Malignancy | 394 | 70.7 | 304 | 31.2 | 698 | 45.6 |
| Cardiac disease excluding myocardial infarction | 137 | 24.6 | 396 | 40.7 | 533 | 34.8 |
| Acute lower respiratory infection | 87 | 15.6 | 298 | 30.6 | 385 | 25.2 |
| Dementia | 121 | 21.7 | 244 | 25.1 | 365 | 23.9 |
| Age-related physical debility | 96 | 17.2 | 136 | 14.0 | 232 | 15.2 |
| Respiratory disease | 57 | 10.2 | 175 | 18.0 | 232 | 15.2 |
| Stroke (haemorrhage or infarction) | 56 | 10.1 | 124 | 12.7 | 180 | 11.8 |
| Gastrointestinal disease | 20 | 3.6 | 128 | 13.2 | 148 | 9.7 |
| Type 2 diabetes mellitus without complications | 39 | 7.0 | 105 | 10.8 | 144 | 9.4 |
| Hypertension | 37 | 6.6 | 104 | 10.7 | 141 | 9.2 |
| Kidney disease | 40 | 7.2 | 99 | 10.2 | 139 | 9.1 |
| Peripheral vascular disease | 21 | 3.8 | 51 | 5.2 | 72 | 4.7 |
| Neurological disease | 21 | 3.8 | 44 | 4.5 | 65 | 4.2 |
| Urinary tract infection | 6 | 1.1 | 53 | 5.4 | 59 | 3.9 |
| Rheumatological disease | 20 | 3.6 | 39 | 4.0 | 59 | 3.9 |
| Other | 13 | 2.3 | 40 | 4.1 | 53 | 3.5 |
| Complication of procedure / surgery | 14 | 2.5 | 32 | 3.3 | 46 | 3.0 |
| Sepsis | 8 | 1.4 | 37 | 3.8 | 45 | 2.9 |
| Endocrinological disease | 6 | 1.1 | 35 | 3.6 | 41 | 2.7 |
| Parkinson's disease | 12 | 2.2 | 28 | 2.9 | 40 | 2.6 |
| Acute kidney failure | 6 | 1.1 | 34 | 3.5 | 40 | 2.6 |
| Acute myocardial infarction | 8 | 1.4 | 31 | 3.2 | 39 | 2.5 |
| Fracture | 14 | 2.5 | 25 | 2.6 | 39 | 2.5 |
| Pulmonary embolism | 6 | 1.1 | 24 | 2.5 | 30 | 2.0 |
| Infection (excluding LRTI & UTI) | 4 | 0.7 | 25 | 2.6 | 29 | 1.9 |
| Psychiatric | 6 | 1.1 | 14 | 1.4 | 20 | 1.3 |
| Non-malignant haematological | 4 | 0.7 | 12 | 1.2 | 16 | 1.0 |
| Traumatic | 2 | 0.4 | 6 | 0.6 | 8 | 0.5 |
| Fall | 2 | 0.4 | 2 | 0.2 | 4 | 0.3 |
| Drug related | 0 | 0.0 | 4 | 0.4 | 4 | 0.3 |

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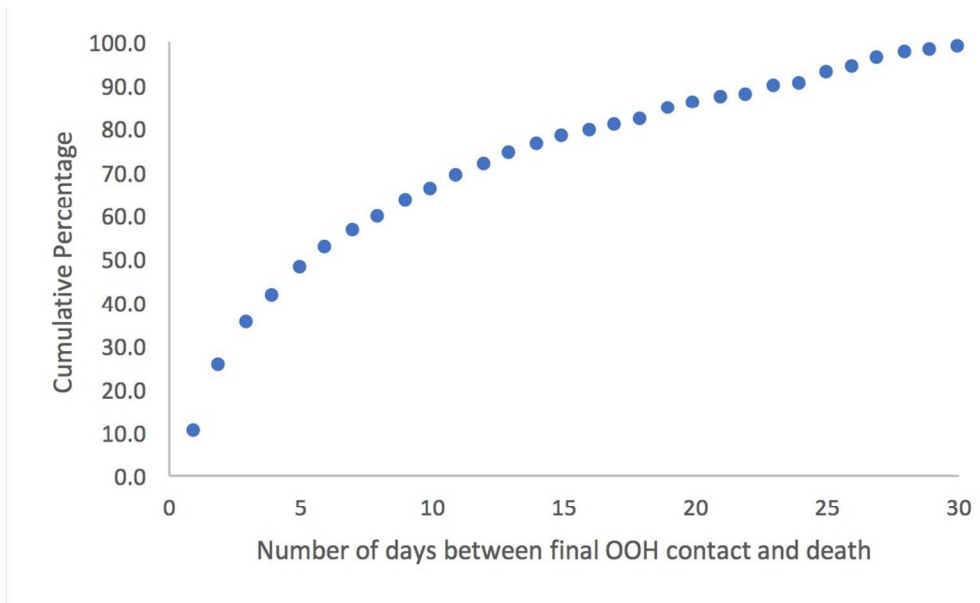


Figure 1: Number of days between final OOH contact and death expressed as cumulative percentage

106x63mm (300 x 300 DPI)

Review only

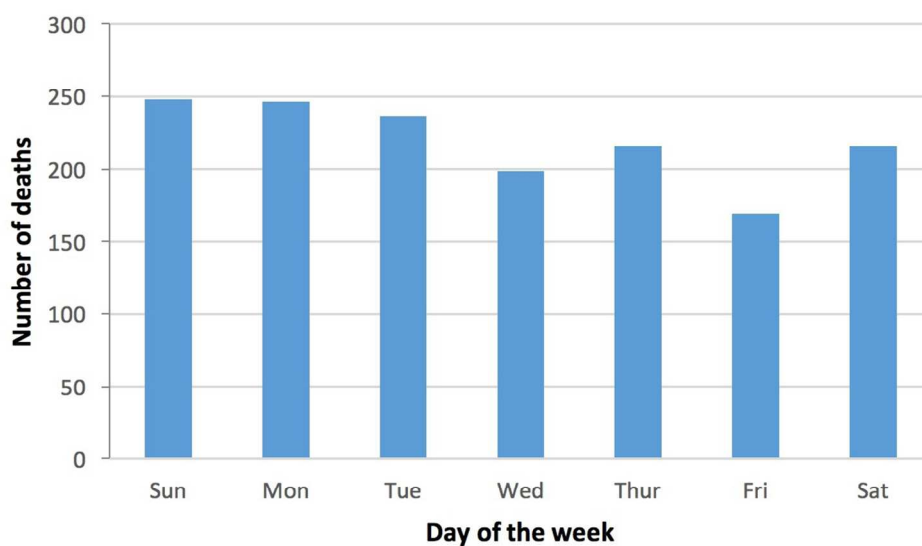


Figure 2: Number of deaths occurring on each day of the week

106x63mm (300 x 300 DPI)

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3 **1 Supplementary information**

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5 **2 Coding of palliative patients**

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7 **3 Palliative code**

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10 4 Patients were coded as palliative if they had any of the below palliative codes applied to their record
11 5 at any time, during any contact, within the entire study period.

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13 6 ZV57C [V]Palliative care

14
15 7 IZ0.. Terminal illness

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17 8 8BA2. Terminal Care

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21 **10 Subcutaneous medication**

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23 11 Patients were also coded as palliative if they had been prescribed an appropriate subcutaneous
24 12 medication at a contact within the 30 days prior to death.

25
26 13 This was determined via the hand searching of electronically recorded prescriptions, where the
27 14 prescription specified subcutaneous administration or 'via a syringe driver' of any of the following
28 15 medications as defined in the British National Formulary as being suitable for continuous
29 16 subcutaneous infusion in palliative care.

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31
32 17 Hyoscine hydrobromide Hyoscine butylbromide

33
34 18 Glycopyrronium bromide Haloperidol

35
36 19 Levomepromazine Midazolam

37
38 20 Cyclizine Metoclopramide

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40 21 Octreotide Morphine

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42 22 Diamorphine hydrochloride.

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46 **24 Hospice referral**

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48 25 Patients were also coded as palliative if they had been admitted to a hospice as a result of a contact
49 26 in the 30days prior to death.

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51 27 This was therefore defined as any patients who had 'admission to hospice' as the documented
52 28 contact outcome

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32 **Tables**

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34 **Table 1: most commonly assigned clinical codes (>1%) to contacts in 30d prior to death**

| Clinical Code (grouped) | Frequency | % of all codes assigned. |
|--------------------------------------|-----------|--------------------------|
| Palliative | 957 | 27.27% |
| Advice/reassurance | 307 | 8.75% |
| Medication request/prescribed | 248 | 7.07% |
| LRTI | 194 | 5.53% |
| UTI | 148 | 4.22% |
| SOB | 95 | 2.71% |
| N&V | 79 | 2.25% |
| Procedure | 73 | 2.08% |
| Other Respiratory illness or symptom | 73 | 2.08% |
| Catheter care | 66 | 1.88% |
| Confusion/reduced GCS | 55 | 1.57% |
| Pain | 53 | 1.51% |
| Abdominal Pain | 47 | 1.34% |
| Other | 47 | 1.34% |
| Condition or symptom NOS | 46 | 1.31% |
| Abnormal bloods | 45 | 1.28% |
| Wound care | 44 | 1.25% |
| Collapse or Fall | 39 | 1.11% |
| Emergency treatment | 36 | 1.03% |
| Agitation | 35 | 1.00% |
| Cancer | 35 | 1.00% |

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47 **Table 2: Most commonly assigned clinical codes (>1%) to contacts alive at 30 days after OOH**
 48 **contact**

| Clinical code (grouped) | Frequency | % of all codes assigned |
|---|-----------|-------------------------|
| ENT symptom or condition | 10507 | 13.49% |
| UTI | 7305 | 6.00% |
| MSK disease | 6443 | 5.30% |
| URTI | 5909 | 4.86% |
| Medication request/prescribed | 5141 | 4.23% |
| Advice/reassurance | 4866 | 4.00% |
| Abdominal pain | 4845 | 3.98% |
| Viral illness | 4658 | 3.83% |
| Other respiratory symptoms or illness | 4324 | 3.55% |
| Diagnosis not made | 3733 | 3.07% |
| Skin infection | 3470 | 2.85% |
| LRTI | 3260 | 2.68% |
| Skin condition | 3043 | 2.50% |
| Wound care | 2708 | 2.23% |
| Gastroenteritis | 2634 | 2.16% |
| Fever | 2564 | 2.11% |
| Failed encounter/DNA | 2405 | 1.98% |
| Mental health symptom/condition | 2278 | 1.87% |
| N&V | 2271 | 1.87% |
| Neurological condition | 2158 | 1.77% |
| Accidental injury | 2105 | 1.73% |
| GI disease or symptom | 1995 | 1.64% |
| Catheter care | 1950 | 1.60% |
| Eye problem | 1876 | 1.54% |
| Oral disease | 1752 | 1.44% |
| Urological disorder | 1673 | 1.38% |
| Pregnancy, antenatal care or pregnancy complication | 1376 | 1.13% |
| Diarrhoea | 1314 | 1.08% |
| Chest pain/IHD | 1281 | 1.05% |

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Table 3: Clinical codes most commonly assigned to contacts with patients not documented as palliative (codes accounting for >1% of all codes assigned.)

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| Clinical code (grouped) | Frequency | % of all codes |
|-------------------------------|-----------|----------------|
| Advice | 191 | 10.82% |
| LRTI | 148 | 8.39% |
| UTI | 121 | 6.86% |
| Medication request/prescribed | 110 | 6.23% |
| SOB | 74 | 4.19% |
| N&V | 48 | 2.72% |
| Pain | 39 | 2.21% |
| Catheter care | 38 | 2.15% |
| Abdominal Pain | 37 | 2.10% |
| Procedure | 37 | 2.10% |
| Confusion | 36 | 2.04% |
| Abnormal bloods | 35 | 1.98% |
| Respiratory illness | 32 | 1.81% |
| MSK disease | 32 | 1.81% |
| Other | 31 | 1.76% |
| Wound care | 29 | 1.64% |
| Ill defined condition | 27 | 1.53% |
| COPD | 26 | 1.47% |
| Emergency treatment | 25 | 1.42% |
| Fall | 24 | 1.36% |
| Chest pain | 22 | 1.25% |
| CVA | 22 | 1.25% |
| Failed encounter | 21 | 1.19% |
| Referral | 20 | 1.13% |
| Dehydration | 19 | 1.08% |
| Skin infection | 19 | 1.08% |
| Unwell | 18 | 1.02% |
| Sepsis | 18 | 1.02% |
| GI bleed | 18 | 1.02% |

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64 **Table 4: Clinical codes (grouped) most commonly assigned to contacts with patients coded as**
 65 **palliative (i.e. codes accounting for >1% of all codes assigned.)**

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| Documented as palliative | | |
|-------------------------------|-----------|-------------------------|
| Clinical code (grouped) | Frequency | % of all codes assigned |
| Palliative | 1134 | 54.15% |
| Medication request/prescribed | 155 | 7.40% |
| Advice | 133 | 6.35% |
| LRTI | 59 | 2.82% |
| N&V | 42 | 2.01% |
| Catheter care | 34 | 1.62% |
| Cancer | 33 | 1.58% |
| UTI | 31 | 1.48% |
| Agitation | 29 | 1.38% |
| Procedure | 29 | 1.38% |
| SOB | 24 | 1.15% |

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The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

| | Item No. | STROBE items | Location in manuscript where items are reported | RECORD items | Location in manuscript where items are reported |
|---------------------------|----------|--|---|---|---|
| Title and abstract | | | | | |
| | 1 | (a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found | | RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract. | Abstract, Page 1 |
| Introduction | | | | | |
| Background rationale | 2 | Explain the scientific background and rationale for the investigation being reported | | | Introduction, page 3 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | | | Abstract, Page 1 Introduction, page 3 |
| Methods | | | | | |
| Study Design | 4 | Present key elements of study design early in the paper | | | Methods, pages 3,4 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | | | Methods, pages 3,4 |

| | | | | | |
|--|----------|--|--|--|--|
| <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27</p> <p>Participants</p> | <p>6</p> | <p>(a) <i>Cohort study</i> - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p> | | <p>RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p> | <p>Methods, pages 3,4</p> <p>Methods, page 5</p> |
| <p>28 29 30 31 32 33 34</p> <p>Variables</p> | <p>7</p> | <p>Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.</p> | | <p>RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.</p> | <p>This is provided as supplementary material and is referred to in the methods section.</p> |
| <p>35 36 37 38 39 40 41 42</p> <p>Data sources/ measurement</p> | <p>8</p> | <p>For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group</p> | | | |

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|--|----------------------------------|----|--|---|---------------------------------------|
| 1 2 3 4 | Bias | 9 | Describe any efforts to address potential sources of bias | | |
| 5 6 7 8 9 | Study size | 10 | Explain how the study size was arrived at | | |
| 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 | Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why | | |
| 35 36 37 38 39 40 41 42 43 44 45 46 47 | Statistical methods | 12 | (a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses | | |
| | Data access and cleaning methods | | .. | RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. | Methods, page 4 Methods page 4 |

| | | | | | |
|------------------|----|---|--|--|-------------------|
| | | | | RECORD 12.2: Authors should provide information on the data cleaning methods used in the study. | |
| Linkage | | .. | | RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided. | Methods, page 4 |
| Results | | | | | |
| Participants | 13 | (a) Report the numbers of individuals at each stage of the study (<i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram | | RECORD 13.1: Describe in detail the selection of the persons included in the study (<i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram. | Methods, page 3,4 |
| Descriptive data | 14 | (a) Give characteristics of study participants (<i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time (<i>e.g.</i> , average and total amount) | | | |
| Outcome data | 15 | <i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure | | | |

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|-------------------|----|---|--|--|---------------------|
| | | category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or summary measures | | | |
| Main results | 16 | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | | | |
| Other analyses | 17 | Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses | | | |
| Discussion | | | | | |
| Key results | 18 | Summarise key results with reference to study objectives | | | |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | | RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported. | Discussion page 8,9 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, | | | |

| | | | | | |
|---|----|---|--|--|---|
| | | limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | | | |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | | | |
| Other Information | | | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | | | |
| Accessibility of protocol, raw data, and programming code | | .. | | RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code. | Page 10 – no additional data available. |

*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

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BMJ Open

What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage study in Oxfordshire

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3 1 **What proportion of patients at the end of life contact Out-of-hours primary care?: a data linkage**
4 2 **study in Oxfordshire.**

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7 3 **Brettell R^{1*}, Fisher R^{1*}, Hunt H², Garland S², Lasserson D³, Hayward G¹**

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32 16 **Abstract**

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35 17 **Objectives:** Out of hours (OOH) primary care services are a key element of community care at the
36 end of life, yet there have been no previous attempts to describe the scope of this activity. We
37 aimed to establish the proportion of Oxfordshire patients who were seen by the Out Of Hours
38 service within the last 30 days of life, whether they were documented as in a palliative phase of care
39 and the demographic and clinical features of these groups

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44 22 **Design** Population based study linking a database of patient contacts with OOH primary care with
45 the register of all deaths within Oxfordshire (600000 population) during 13 months.

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48 24 **Setting** Oxfordshire

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51 25 **Participants** Between 1/12/14 and 30/11/2015 there were 102,877 OOH contacts made by 67,943
52 patients with the OOH service.

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3 27 **Main outcome measures** Proportion of patients dying in the Oxfordshire population who were seen
4 28 by the Out Of Hours service within the last 30 days of life. Demographic and clinical features of these
5 29 contacts.

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8 30 **Results** 29.5% of all population deaths were seen by the OOH service in the last 30 days of life.
9 31 Among the 1530 patients seen, patients whose palliative phase was documented (n=577, 36.4%)
10 32 were slightly younger (median age = 83.5 vs 85.2 years, p<0.001) and were seen closer to death
11 33 (median days to death = 2 v 8, p<0.001). More were assessed at home (59.8% vs 51.9%, p<0.001)
12 34 and less were admitted to hospital (2.7% vs 18.0%, p<0.001).

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17 35 **Conclusions** OOH services see around one third of all patients who die in a population. Most patients
18 36 at the end of life are not documented as palliative by OOH services and are less likely to receive
19 37 ongoing care at home.

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44 **Strengths and Limitations of this study**

- 46 • This is the first study to use data linkage with death records to describe the true population
47 at the end of life who contact the OOH service.
- 48 • The study highlights both the importance of the OOH primary care service in end of life care
49 and the significant limitations of medical records studies which have used clinical coding of
50 palliative care as a proxy for end of life contacts
- 51 • Our understanding of the proportion of these deaths which were palliative and the causes of
52 death relied on the accuracy of clinical coding
- 53 • Our study focused on a single area of the UK due to restriction in access to OOH provider
54 medical records

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62 Introduction

63 The provision of primary care services outside core contracted hours is fundamental to the
64 operation of the NHS.¹ In 2013-14, out of hours GP services (OOH) in England handled approximately
65 5.8 million cases, 3.3 million of which were face to face consultations, including 800,000 home
66 visits.² For the majority of patients OOH primary care is provided by a clinician who does not know
67 them, often with limited access to their medical record.³

68 In January 2015 the top research priority identified by the Palliative and end of life care Priority
69 Setting Partnership was the provision of palliative care outside of working hours to help patients stay
70 in their place of choice by managing crises.⁴ Given that the majority of people in the UK with
71 terminal illness do not wish to die in a hospital⁵, OOH primary care services must be viewed as an
72 integral part of end of life care provision.

73 Our current understanding of the true extent of end of life care provided by the OOH service is
74 limited. OOH services do not routinely receive feedback on patient deaths following contact with the
75 service. We previously analysed an OOH service database⁶ and learned that patients whose needs
76 were coded as palliative contacted the OOH service predominantly during weekend daytime periods,
77 and that over a third had multiple contacts with the service. However, the study was limited because
78 we were not able to identify all patients who had died and had contacted the service, thus
79 underestimating the true proportion of patients with end of life care needs.

80 In order to understand how OOH care can best be provided at the end of life we need to understand
81 the true extent of this workload and whether there are differences between patients who appear to
82 be recognised as palliative by clinicians and those who are not. This study used data linkage to
83 identify people who died in Oxfordshire over the course of a year who had contact with the OOH
84 services in the 30 days before death and the clinical care that they received from the OOH service.

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86 Methods

87 The Oxfordshire OOH service provides care to a population of over 600,000 people from 18:30pm –
88 08:00am on weekdays and 24 hour cover on weekends and bank holidays. Access to the service is via

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3 89 the NHS 111 telephone advice line, where trained call handlers use the NHS Pathways algorithm to
4 90 direct patients to the most appropriate service for their needs. Patients directed by 111 to the OOH
5 91 service will receive an initial telephone consultation with an OOH clinician which may then lead to a
6 92 base visit (patient comes to the OOH surgery to be seen), home visit or the case being passed to
7 93 another care provider (such as 'hospital at home'). Patients can also be booked directly by 111 to an
8 94 OOH base visit.

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13 95 A database of all patient contacts with the Oxfordshire Out of Hours (OOH) service over 1 year from
14 96 01.12.14 to 30.11.2015 was created from the OOH Electronic Record System used by clinicians
15 97 (Adastra).

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18 98 Mortality data for Oxfordshire (population 600,000) over 13 months (1.12.14-31.12.15, to capture
19 99 patients who died within 30 days of contact with the OOH service) was obtained via NHS
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22 100 Digital/Office of National Statistics, with Section 251 approval from the Confidentiality Advisory
23 101 Group. This was linked by NHS number with Oxfordshire OOH service care records and was used to
24 102 identify people who had contact with the OOH service in the 30 days prior to death. All patient
25 103 identifiers were removed on entry to the database and data destruction was completed in
26 104 accordance with NHS Digital requirements. Any contact without an NHS number was removed from
27 105 the database, as repeat visits could not be assessed, as were those with a duplicate case ID. Contacts
28 106 that were seen after death were also removed. Demographic data consisted of age, sex and Index of
29 107 Multiple Deprivation score (available for 79% of contacts).⁷ Service data included final contact type,
30 108 outcome, date, clinical codes assigned and prescriptions issued. Mortality data included the date of
31 109 death and all assigned ICD-10⁸ causes of death. All assigned causes of death were included in the
32 110 analysis in recognition of the fact that the most important or relevant cause of death may not be the
33 111 first one listed on the certificate and therefore including only one cause would introduce significant
34 112 bias.

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43 113 Timings of calls were classified as evening 18:30-23:59, overnight 00:00-07:59 and daytime (i.e.
44 114 weekends and bank holidays) 08:00-18:29. The number of days difference between contact and
45 115 death was calculated using calendar days beginning at midnight. Weekend period was classified as
46 116 18:30 Friday until 08:00 Monday.

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50 117 Those who died were also classified according to whether they had been documented by the service
51 118 as palliative or not. We defined palliative patients as those who, at any contact with the OOH service
52 119 in the study period, had been assigned a clinical code specific to palliative care, been referred to a
53 120 hospice as a result of an OOH contact or been prescribed an appropriate subcutaneous medication.

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3 121 The clinical codes specific to palliative care were: ZV57C [V]Palliative care, 1Z0 Terminal illness, and
4 122 8BA2 Terminal Care.

5
6 123 Appropriate subcutaneous medications were defined as medications as specified in the British
7 124 National Formulary as being suitable for continuous subcutaneous infusion in palliative care. These
8 125 included medications used for bowel colic and excessive respiratory secretions, confusion and
9 126 restlessness, convulsions, nausea and vomiting and/or pain control.⁹ This group was compared with
10 127 all other patients who died within 30 days of contact. Further details regarding coding are supplied
11 128 as supplementary information.

129 130 Validation

131 In order to validate the clinical codes applied by the OOH clinicians we estimated, based on previous
132 coding validity studies¹⁰ that analysis of 230 records would be required to establish the coding
133 validity with a confidence level of 90% and 5% margin of error. A random selection of 230 records
134 was obtained using SPSS, and the clinical code was compared by two authors (SG, HH) to the
135 conclusion drawn by the clinician in the medical notes. The positive predictive value (PPV) of the
136 clinical code for medical diagnosis or conclusion was 92.6%.

137 138 Statistical analysis

139 Demographic details and details concerning the cause of death were compared at a patient level, so
140 that each patient was only considered once in the analysis. By contrast, the OOH contact and
141 outcome were compared at an OOH contact level. Statistical analysis was performed using SPSS
142 Version 22. T tests were used when comparing means, z tests when comparing proportions and
143 Mann Whitney U test when comparing medians. Logistic regression was performed to test
144 associations for binary outcomes. This study had Research Ethics approval (REC number
145 15/SC/0754) and Confidentiality Advisory Group Approval (15/CAG/0211).

146 147 Patient and Public Involvement

148 Patients were not involved in this study

149

150 Results

151 Between 1/12/2014 - 30/11/2015, 67,943 patients made 102,877 contacts, with the Oxfordshire
152 OOH service. In the 13 month period between 1/12/14 – 31/12/15, 5193 people died in Oxfordshire.
153 Of the people who died, 1530 (29.5%) had contact with the OOH service in the 30 days prior to their
154 death. These patients made 2661 contacts with the OOH service in the 30d prior to their death,
155 accounting for 2.57% of all contacts to the service over the 12 month study period. A further 791
156 contacts (with 752 patients) occurred *after* death, equating to 14.5% of all deaths and 0.76% of all
157 contacts to the service. Contacts after death were excluded from further analyses.

158 Of those patients who had contact with the OOH service in the 30d prior to death, 381 (24.9%) made
159 a contact in the last day of life (Figure 1). There was a median of 5 (Interquartile range (IQR) 1.75 –
160 13) days between final OOH contact and death and the median number of contacts with the OOH
161 service in the 30 days prior to death was 1 (IQR 1 – 2). A similar proportion of deaths occurred on
162 each day of the week (figure 2)

163 Tables 1 and 2 compare patients and patient contact features of those who died within 30 days of
164 death with those who were alive at 30 days after initial OOH consultation. Patients who died were
165 older, less deprived and more likely to be male. Patient contacts were more frequently in their own
166 home and more likely to have their care escalated to an alternative provider (hospital, hospice,
167 community care provider).

168 For those patients who died within 30 days the most commonly assigned clinical codes were
169 palliative (27.3% of all codes assigned), advice (8.8%), medication requests (7.1%), lower respiratory
170 tract infection (LRTI) (5.5%) or urinary tract infection (UTI) (4.2%) codes. By comparison, Ear, Nose
171 and Throat disorder (ENT) (13.5%), UTI (6.0%), musculoskeletal disease (MSK) (5.3%), upper
172 respiratory tract infection (URTI) (4.9%), and medication requests (4.2%) were the commonest codes
173 in those alive at 30 days after index assessment (supplementary tables 1 and 2)

174 Acute events were the cause of death in 25% of patients. The commonest codes were types of
175 cancer (45.6%) followed by cardiac disease (34.8%), LRTI (25.2%), dementia (23.9%), age related
176 debility and other respiratory disease (both 15.2%) (see table 3 for full list).

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178 **Comparison between palliative patients and patients dying within 30 days not documented as**
179 **palliative.**

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3 180 Patients who had contact with the OOH service in the 30 days prior to death were categorised into
4 181 those who had been documented by the service as palliative (any palliative code assigned to record,
5 182 hospice referral, or appropriate subcutaneous medication prescribed at any time), and those who
6 183 had not.

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10 184 557 patients (36.4%) were documented as palliative, and had 1310 contacts with the OOH service in
11 185 the 30 days prior to death. By contrast, 973 patients (63.6%) were not documented as palliative,
12 186 accounting for 1351 contacts.

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15 187 Patients documented as palliative were younger than those not documented (median 83.5 years
16 188 (IQR 74.1 – 89.6) vs 85.2 years (IQR 78.3 – 91.1) ($p < 0.001$, $z = 4.45$), an association which was
17 189 maintained after adjusting for sex and deprivation in multivariable logistic regression (Odds Ratio
18 190 (OR) 0.98, $p < 0.001$, 95% CI 0.97-0.99).

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22 191 There were clear differences in the patterns of service use, depending on documentation of
23 192 palliative phase of care. Patients documented as palliative were seen more frequently in the 30d
24 193 prior to death (median 3 contacts, IQR 2-4, v median 2 contacts, IQR 1-3 $z = -12.813$ $p < 0.001$), and
25 194 their final contact with the service was closer to the point of death (median number of days between
26 195 final contact and death (IQR 1-6), days v 8 (IQR 3-17) days $z = -15.335$ ($p < 0.001$), with 42.2% (v
27 196 15.1%) being seen on the day of death or day prior to death.

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32 197 Patients documented as palliative presented less frequently at the weekend (67.2% v 70.4%; $z = -1.79$,
33 198 $p = 0.037$), and more frequently overnight (27%, vs 18.3%, $z = 5.391$, $p < 0.001$). They were more likely
34 199 to be assessed at a home visit (59.8% v 51.9%; $z = 4.094$, $p < 0.001$) and less likely to be managed solely
35 200 through telephone contact (43.2% vs 36.6%, $z = -3.508$, $p = 0.002$).

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40 201 The two groups of patients differed in the outcomes of contacts with the OOH service. Patients
41 202 documented as palliative were less likely to be admitted to hospital following their assessment (2.7%
42 203 vs 18.0% respectively, $z = -8.091$, $p < 0.001$), but more likely to be referred for community input (12.7%
43 204 vs 2.3%, $z = 10.221$, $p < 0.001$) or require no further follow up (40.8% vs 35.7%, $z = 2.7$, $p = 0.0035$) (Table
44 205 4).

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48 206 In addition to palliative codes, the most common clinical codes assigned in those patients
49 207 documented as palliative were medication related (7.4%), advice (6.35%), LRTI (2.8%), nausea and
50 208 vomiting (2.0%) and catheter care (1.6%). In those patients not documented as palliative, a wider
51 209 range of clinical codes were applied, the commonest were advice (10.8%), LRTI (8.4%), UTI (6.9%),
52 210 medication related (6.2%) and shortness of breath (4.2%) (supplementary tables 3 and 4).

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3 211 Causes of death in both groups are detailed in table 3. The highest proportion of deaths was due to
4 212 malignancy in the group documented as palliative (70.7%); over twice that in those not documented
5 213 as palliative (31.2%). There were similar proportions of patients with dementia as cause of death.
6 214 Conversely, infections, myocardial infarction, pulmonary embolism, gastroenterological and
7 215 endocrinological diseases were over twice as frequently assigned to patients in the group not
8 216 documented as palliative. Causes of death which would be considered acute events (acute kidney
9 217 injury, myocardial infarction, pulmonary embolism, fracture, fall, trauma, stroke and sepsis) were
10 218 applied to 18.1% of patients documented as palliative and 29.3% of those not documented as
11 219 palliative.
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20 221 **Discussion**

22 222 OOH GP services provide end of life care to almost a third of people who die in a population,
23 223 frequently very close to death. This places OOH GP services at the forefront of end of life care
24 224 provision. Patients at the end of life are more likely to contact the service overnight, likely in part
25 225 due to the reduction in availability of other services at these times. Death administration contributes
26 226 significantly to the workload of the OOH service, being required for 14.5% of all deaths. Just 0.4% of
27 227 all contacts occurring within the 30 days prior to death result in a hospice admission.

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32 228 Only 36.4% of patients contacting the service at the end of life were documented as palliative, hence
33 229 studies relying on clinical coding of patient contacts as palliative will significantly under report the
34 230 burden on the service. A large number of contacts in the 30 days prior to death result in a home visit
35 231 irrespective of documentation of a palliative phase of care, reflecting significant frailty within this
36 232 patient group. Patients not documented as palliative had a much higher rate of acute hospital
37 233 admission, suggesting that initial management strategy is based on addressing an acute presenting
38 234 illness syndrome with hospital based care in this group.

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45 235 The only study which has used a similar methodology to explore OOH service use at the end of life
46 236 reported a similarly high proportion (25%) of deceased patients contacting a Norwegian OOH service
47 237 in the 4 weeks before death, with a much higher proportion (37%) referred to hospital at their OOH
48 238 contact.¹¹
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51 239 **Strengths and Limitations**

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54 240 This is the first study to accurately report the proportion of patients who die shortly after contact
55 241 with OOH primary care by linking UK OOH records with mortality data. However, there are several
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3 242 limitations to our analysis. Our study is based in the English NHS, and we cannot comment on
4 243 whether our results would extrapolate to other models of out of hours healthcare provision. By
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6 244 excluding deaths of patients living outside Oxfordshire we may have underestimated demands on
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8 245 the service. Our analysis was also limited to contacts within 30 days of death, however the majority
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10 246 of contacts were within 7 days of death, suggesting that this has not significantly limited our
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12 247 conclusions.

13 248 In order to explore whether the service recognised the patient contact as palliative we relied on
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15 249 OOH clinicians assigning a palliative code to the patients record or a documenting an action only
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17 250 relevant to palliative care (prescribing subcutaneous medication or hospice referral). Since no other
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19 251 studies have attempted this form of classification we could not use a validated approach. It is likely
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21 252 that some patients who were recognised by the service as needing end of life care may have been
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23 253 misclassified in this analysis. However, the PPV of the clinical code for medical diagnosis or
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25 254 conclusion was higher than the average PPV found in a systematic review of studies using primary
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27 255 care medical records.¹⁰ Similarly we relied on the accuracy of cause of death as recorded by either
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29 256 the regular general practitioner or hospital clinician. It is possible that acute events could be under
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31 257 reported in death certificates if active malignancy is present.

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33 259 **Implications**

34 260 The OOH service is making a significant contribution to end of life care. Despite a majority of
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36 261 patients with terminal illness wishing to die at home, only a minority currently achieve this.¹²
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38 262 Enabling good deaths in the community is therefore a key component of OOH primary care
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40 263 provision. There is scope for debate on how best to provide a service to this patient group. One
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42 264 component of this must be improving planning and communication from the in hours GP to avoid
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44 265 OOH demands, and another might be the creation of dedicated palliative teams, operating in the
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46 266 OOH period. However, both of these measures will only support the third of patients at the end of
47
48 267 life who are documented as palliative, and additional measures are needed to ensure that the OOH
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50 268 service is fit for managing all patients at the end of life, in terms of recognition of end of life, staff
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52 269 skill mix and resources.

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54 271 Two thirds of patients who died within 30 days of OOH contact were not documented as being in a
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56 272 palliative phase of care. There will be patients for whom an acute life threatening syndrome has led
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58 273 to an OOH contact. The percentage of deaths which were due to acute events was 25% overall, in

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3 274 line with national estimates¹³, and relatively higher in the group not documented as palliative
4 275 (29.3%). In addition, clinicians may recognise patients to be at the end of life, but choose to use
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6 276 more immediately relevant clinical codes for the contact or be reluctant to use palliative codes for
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8 277 patients who do not have cancer. Furthermore, there may be patients at the end of life where it is
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10 278 simply not recognised in the setting of multiple morbidity and frailty.

11 279 A greater number of acute, gastrointestinal, infection and cardiac codes were applied to patients
12 280 who were not documented as palliative. Gastrointestinal conditions in particular have been
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14 281 highlighted previously as challenging to diagnose in prehospital urgent care settings.^{14,15} Evolving
15 282 OOH care services to include a greater range of POC blood and imaging diagnostics and tailored risk
16 283 scores could offer clinicians support in triaging and managing these difficult presentations.
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18 284 Reviews of deaths are standard practice in acute trusts and are viewed as integral to learning and
19 285 service improvement and in hours GPs are routinely informed of deaths of patients in their care.
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21 286 However, there is no routine mechanism to feedback to clinicians working in OOH services when
22 287 deaths occur after contact. This deprives clinicians of the opportunity for valuable reflection and
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24 288 learning and services of the opportunity for improvement.¹⁶ It is particularly relevant in light of the
25 289 recent Care Quality Commission call¹⁷ to end missed opportunities to learn from patient deaths.
26
27 290 Following the Mazars report¹⁸, there is an increased focus on more robust systems to learn from
28 291 deaths of patients following contact with NHS trust services. This study may help OOH services
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30 292 prioritise deaths for mortality review to maximise learning.
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37 295 **Conclusion**

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40 297 The contribution of OOH primary care services to patients at the end of life has previously been
41 298 under-researched and underestimated. This study demonstrates that almost a third of people who
42 299 die have contact with an OOH service in the preceding 30 days. Further work to understand how
43 300 OOH primary care can best meet the needs of patients at the end of life is required.
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50
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6
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8 311 1176)
9

10 312

11 313 **Data sharing**

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13 314 No additional data available
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20 317 **Authors' contributions.**

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22 318 GH and DL conceived the study. RF developed the protocol, gained study permissions and developed
23 319 the databases. RB DL and GH analysed the data. HH and SG validated the dataset. RB and GH drafted
24 320 the manuscript and all authors contributed to interpretation of results and critical revision of the
25 321 manuscript.
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29 323 **Competing interest statements**

30
31 324 All authors have completed the *Unified Competing Interest form* (available on request from the
32 325 corresponding author) and declare: no support from any organisation for the submitted work [or
33 326 describe if any]; no financial relationships with any organisations that might have an interest in the
34 327 submitted work in the previous three years, no other relationships or activities that could appear to
35 328 have influenced the submitted work.
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40 330 **Ethics committee approval**

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42 331 This study had Research Ethics approval (REC number 15/SC/0754) and Confidentiality Advisory
43 332 Group Approval (15/CAG/0211).
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47 334 **References**

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4 343 [dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_111893.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_111893.pdf)
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390 **Figure Legends**

391 Figure 1 Number of days between final OOH contact and death expressed as cumulative percentage

392 Figure 2 Number of deaths occurring on each day of the week

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400 **Tables**

401

402 **Table 1: Characteristics of patients contacting the service within 30 days of death compared to all**
403 **other patients**

| | Patients within 30d of death (n = 1530) | Patients not within 30d of death (n = 66413) |
|--------------------------|--|---|
| Age (median, IQR) | 84.9 (77.0 – 90.6) yrs | 33.3 (12.2-- 59.2) yrs |
| Male (percentage, 95%CI) | 44.3% (41.8 – 46.8) | 41.6% (41.2 – 42.0) |
| IMD* score (mean, sd) | 12.00 (9.30) | 13.13 (9.67) |

404 *Index of multiple deprivation

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414 **Table 2: Characteristics of patient contacts with the service within 30 days of death compared to**
 415 **all other contacts**

| | Contacts within 30d of death (n = 2661) | Contacts not within 30d of death (n = 100216) |
|---|---|---|
| Contact type (percentage (95%CI)) | | |
| Home visit | 55.8% (53.9 – 57.7) | 9.7% (9.5 – 9.9) |
| Base assessment | 4.2% (3.4 – 5.0) | 55.8% (55.5 – 56.1) |
| Telephone contact only | 39.9% (38.0 – 41.8) | 34.3% (34.0 – 34.6) |
| Time of contact (percentage (95%CI)) | | |
| Overnight 00:00-07:59 | 22.6% (21.0 – 24.2) | 15.5% (15.3 – 15.7) |
| Evening 18:30-23:59 | 29.4% (27.7 – 31.1) | 37.8% (37.5 – 38.1) |
| Daytime 08:00-18:29 | 48.0% (46.1 – 49.9) | 46.7% (46.4 – 47.0) |
| Outcome of the contact (percentage (95%CI)) | | |
| Acute admission (hospital, emergency department (ED), ambulatory care unit) | 10.5% (9.3 – 11.7) | 7.43% (7.3 – 3.6) |
| Admission to hospice | 0.4% (0.1 – 0.6) | 0.03% (0.03 – 0.03) |
| Community input (Hospital at home, community nursing, social services, minor injury unit, mental health team) | 7.4% (6.4 – 8.4) | 1.2% (1.1 – 1.3) |
| Did not attend/unable to contact/left before treatment | 0.3% (0.1 – 0.6) | 1.4% (1.3 – 1.5) |
| GP Follow-up | 38.2% (36.3 – 40.0) | 36.8% (36.5 – 37.1) |
| No Follow-up | 38.3% (36.3 – 40.0) | 49.3% (49.0 – 49.6) |
| Other | 5.1% (4.3 – 5.9) | 3.8% (3.7 – 4.0) |

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422 **Table 3: All assigned Causes of death by documented palliative / not and total**

| | Documented as palliative | | Not documented as palliative | | Total | |
|---|--------------------------|------------------------|------------------------------|------------------------|-----------|------------------------|
| | frequency | percentage of patients | frequency | percentage of patients | frequency | percentage of patients |
| Malignancy | 394 | 70.7 | 304 | 31.2 | 698 | 45.6 |
| Cardiac disease excluding myocardial infarction | 137 | 24.6 | 396 | 40.7 | 533 | 34.8 |
| Acute lower respiratory infection | 87 | 15.6 | 298 | 30.6 | 385 | 25.2 |
| Dementia | 121 | 21.7 | 244 | 25.1 | 365 | 23.9 |
| Age-related physical debility | 96 | 17.2 | 136 | 14.0 | 232 | 15.2 |
| Respiratory disease | 57 | 10.2 | 175 | 18.0 | 232 | 15.2 |
| Stroke (haemorrhage or infarction) | 56 | 10.1 | 124 | 12.7 | 180 | 11.8 |
| Gastrointestinal disease | 20 | 3.6 | 128 | 13.2 | 148 | 9.7 |
| Type 2 diabetes mellitus without complications | 39 | 7.0 | 105 | 10.8 | 144 | 9.4 |
| Hypertension | 37 | 6.6 | 104 | 10.7 | 141 | 9.2 |
| Kidney disease | 40 | 7.2 | 99 | 10.2 | 139 | 9.1 |
| Peripheral vascular disease | 21 | 3.8 | 51 | 5.2 | 72 | 4.7 |
| Neurological disease | 21 | 3.8 | 44 | 4.5 | 65 | 4.2 |
| Urinary tract infection | 6 | 1.1 | 53 | 5.4 | 59 | 3.9 |
| Rheumatological disease | 20 | 3.6 | 39 | 4.0 | 59 | 3.9 |
| Other | 13 | 2.3 | 40 | 4.1 | 53 | 3.5 |
| Complication of procedure / surgery | 14 | 2.5 | 32 | 3.3 | 46 | 3.0 |
| Sepsis | 8 | 1.4 | 37 | 3.8 | 45 | 2.9 |
| Endocrinological disease | 6 | 1.1 | 35 | 3.6 | 41 | 2.7 |
| Parkinson's disease | 12 | 2.2 | 28 | 2.9 | 40 | 2.6 |
| Acute kidney failure | 6 | 1.1 | 34 | 3.5 | 40 | 2.6 |
| Acute myocardial infarction | 8 | 1.4 | 31 | 3.2 | 39 | 2.5 |
| Fracture | 14 | 2.5 | 25 | 2.6 | 39 | 2.5 |
| Pulmonary embolism | 6 | 1.1 | 24 | 2.5 | 30 | 2.0 |
| Infection (excluding LRTI & UTI) | 4 | 0.7 | 25 | 2.6 | 29 | 1.9 |
| Psychiatric | 6 | 1.1 | 14 | 1.4 | 20 | 1.3 |
| Non-malignant haematological | 4 | 0.7 | 12 | 1.2 | 16 | 1.0 |
| Traumatic | 2 | 0.4 | 6 | 0.6 | 8 | 0.5 |
| Fall | 2 | 0.4 | 2 | 0.2 | 4 | 0.3 |
| Drug related | 0 | 0.0 | 4 | 0.4 | 4 | 0.3 |

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425 **Table 4: Outcomes of contacts with patients documented palliative v those not documented**
 426 **palliative**

| Outcome of contact | Documented as palliative | | Not documented as palliative | |
|---|--------------------------|------------------------|------------------------------|------------------------|
| | Frequency | Percentage of contacts | Frequency | Percentage of contacts |
| Acute admission (hospital, A&E, EMU) | 35 | 2.7% | 243 | 18.0% |
| Admission to hospice | 10 | 0.8% | 0 | 0.0% |
| Community input (H@H, comm nursing, SS, MIU) | 166 | 12.7% | 31 | 2.3% |
| Unable to contact | 2 | 0.2% | 7 | 0.5% |
| GP FU | 493 | 37.6% | 522 | 38.6% |
| No FU | 534 | 40.8% | 482 | 35.7% |
| Other (OP clinic, passed to another provider) | 68 | 5.2% | 63 | 4.7% |
| Outcome missing | 2 | 0.2% | 3 | 0.2% |
| Total | 1310 | 100.0% | 1351 | 100.0% |

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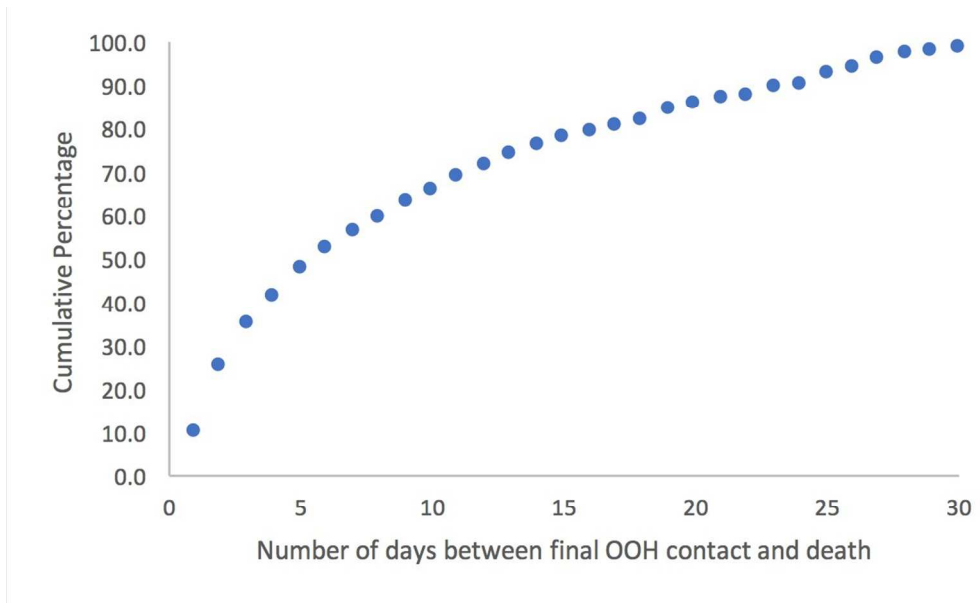


Figure 1: Number of days between final OOH contact and death expressed as cumulative percentage

106x63mm (300 x 300 DPI)

Review only

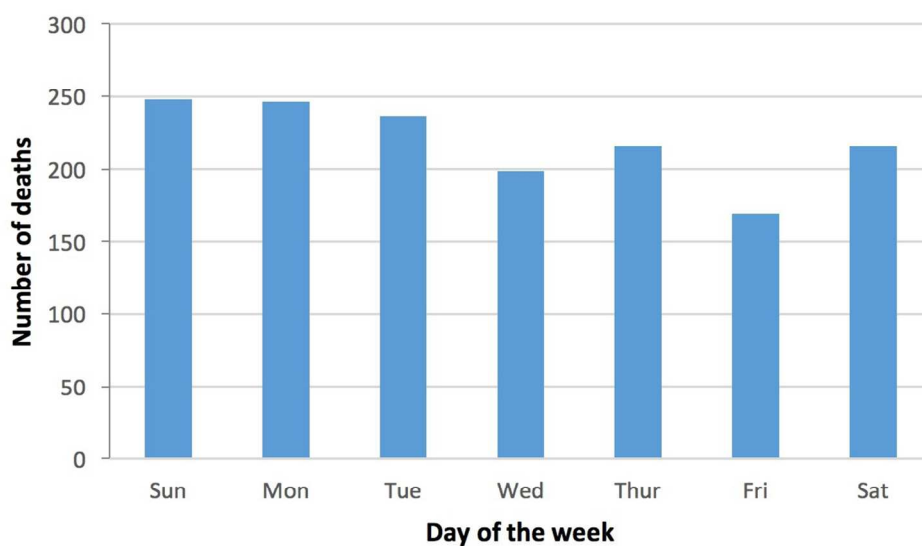


Figure 2: Number of deaths occurring on each day of the week

106x63mm (300 x 300 DPI)

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3 **1 Supplementary information**

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5 **2 Coding of palliative patients**

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7 **3 Palliative code**

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10 4 Patients were coded as palliative if they had any of the below palliative codes applied to their record
11 5 at any time, during any contact, within the entire study period.

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13 6 ZV57C [V]Palliative care

14
15 7 1Z0.. Terminal illness

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17 8 8BA2. Terminal Care

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21 **10 Subcutaneous medication**

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23 11 Patients were also coded as palliative if they had been prescribed an appropriate subcutaneous
24 12 medication at a contact within the 30 days prior to death.

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26 13 This was determined via the hand searching of electronically recorded prescriptions, where the
27 14 prescription specified subcutaneous administration or 'via a syringe driver' of any of the following
28 15 medications as defined in the British National Formulary as being suitable for continuous
29 16 subcutaneous infusion in palliative care.

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31
32 17 Hyoscine hydrobromide Hyoscine butylbromide

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34 18 Glycopyrronium bromide Haloperidol

35
36 19 Levomepromazine Midazolam

37
38 20 Cyclizine Metoclopramide

39
40 21 Octreotide Morphine

41
42 22 Diamorphine hydrochloride.

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46 **24 Hospice referral**

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48 25 Patients were also coded as palliative if they had been admitted to a hospice as a result of a contact
49 26 in the 30days prior to death.

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51 27 This was therefore defined as any patients who had 'admission to hospice' as the documented
52 28 contact outcome

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32 **Tables**

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34 **Table 1: most commonly assigned clinical codes (>1%) to contacts in 30d prior to death**

| Clinical Code (grouped) | Frequency | % of all codes assigned. |
|--------------------------------------|-----------|--------------------------|
| Palliative | 957 | 27.27% |
| Advice/reassurance | 307 | 8.75% |
| Medication request/prescribed | 248 | 7.07% |
| LRTI | 194 | 5.53% |
| UTI | 148 | 4.22% |
| SOB | 95 | 2.71% |
| N&V | 79 | 2.25% |
| Procedure | 73 | 2.08% |
| Other Respiratory illness or symptom | 73 | 2.08% |
| Catheter care | 66 | 1.88% |
| Confusion/reduced GCS | 55 | 1.57% |
| Pain | 53 | 1.51% |
| Abdominal Pain | 47 | 1.34% |
| Other | 47 | 1.34% |
| Condition or symptom NOS | 46 | 1.31% |
| Abnormal bloods | 45 | 1.28% |
| Wound care | 44 | 1.25% |
| Collapse or Fall | 39 | 1.11% |
| Emergency treatment | 36 | 1.03% |
| Agitation | 35 | 1.00% |
| Cancer | 35 | 1.00% |

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47 **Table 2: Most commonly assigned clinical codes (>1%) to contacts alive at 30 days after OOH**
 48 **contact**

| Clinical code (grouped) | Frequency | % of all codes assigned |
|---|-----------|-------------------------|
| ENT symptom or condition | 10507 | 13.49% |
| UTI | 7305 | 6.00% |
| MSK disease | 6443 | 5.30% |
| URTI | 5909 | 4.86% |
| Medication request/prescribed | 5141 | 4.23% |
| Advice/reassurance | 4866 | 4.00% |
| Abdominal pain | 4845 | 3.98% |
| Viral illness | 4658 | 3.83% |
| Other respiratory symptoms or illness | 4324 | 3.55% |
| Diagnosis not made | 3733 | 3.07% |
| Skin infection | 3470 | 2.85% |
| LRTI | 3260 | 2.68% |
| Skin condition | 3043 | 2.50% |
| Wound care | 2708 | 2.23% |
| Gastroenteritis | 2634 | 2.16% |
| Fever | 2564 | 2.11% |
| Failed encounter/DNA | 2405 | 1.98% |
| Mental health symptom/condition | 2278 | 1.87% |
| N&V | 2271 | 1.87% |
| Neurological condition | 2158 | 1.77% |
| Accidental injury | 2105 | 1.73% |
| GI disease or symptom | 1995 | 1.64% |
| Catheter care | 1950 | 1.60% |
| Eye problem | 1876 | 1.54% |
| Oral disease | 1752 | 1.44% |
| Urological disorder | 1673 | 1.38% |
| Pregnancy, antenatal care or pregnancy complication | 1376 | 1.13% |
| Diarrhoea | 1314 | 1.08% |
| Chest pain/IHD | 1281 | 1.05% |

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Table 3: Clinical codes most commonly assigned to contacts with patients not documented as palliative (codes accounting for >1% of all codes assigned.)

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| Clinical code (grouped) | Frequency | % of all codes |
|-------------------------------|-----------|----------------|
| Advice | 191 | 10.82% |
| LRTI | 148 | 8.39% |
| UTI | 121 | 6.86% |
| Medication request/prescribed | 110 | 6.23% |
| SOB | 74 | 4.19% |
| N&V | 48 | 2.72% |
| Pain | 39 | 2.21% |
| Catheter care | 38 | 2.15% |
| Abdominal Pain | 37 | 2.10% |
| Procedure | 37 | 2.10% |
| Confusion | 36 | 2.04% |
| Abnormal bloods | 35 | 1.98% |
| Respiratory illness | 32 | 1.81% |
| MSK disease | 32 | 1.81% |
| Other | 31 | 1.76% |
| Wound care | 29 | 1.64% |
| Ill defined condition | 27 | 1.53% |
| COPD | 26 | 1.47% |
| Emergency treatment | 25 | 1.42% |
| Fall | 24 | 1.36% |
| Chest pain | 22 | 1.25% |
| CVA | 22 | 1.25% |
| Failed encounter | 21 | 1.19% |
| Referral | 20 | 1.13% |
| Dehydration | 19 | 1.08% |
| Skin infection | 19 | 1.08% |
| Unwell | 18 | 1.02% |
| Sepsis | 18 | 1.02% |
| GI bleed | 18 | 1.02% |

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64 **Table 4: Clinical codes (grouped) most commonly assigned to contacts with patients coded as**
 65 **palliative (i.e. codes accounting for >1% of all codes assigned.)**

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| Documented as palliative | | |
|-------------------------------|-----------|-------------------------|
| Clinical code (grouped) | Frequency | % of all codes assigned |
| Palliative | 1134 | 54.15% |
| Medication request/prescribed | 155 | 7.40% |
| Advice | 133 | 6.35% |
| LRTI | 59 | 2.82% |
| N&V | 42 | 2.01% |
| Catheter care | 34 | 1.62% |
| Cancer | 33 | 1.58% |
| UTI | 31 | 1.48% |
| Agitation | 29 | 1.38% |
| Procedure | 29 | 1.38% |
| SOB | 24 | 1.15% |

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The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

| | Item No. | STROBE items | Location in manuscript where items are reported | RECORD items | Location in manuscript where items are reported |
|---------------------------|----------|--|---|---|---|
| Title and abstract | | | | | |
| | 1 | (a) Indicate the study's design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found | | RECORD 1.1: The type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included. RECORD 1.2: If applicable, the geographic region and timeframe within which the study took place should be reported in the title or abstract. RECORD 1.3: If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract. | Abstract, Page 1 |
| Introduction | | | | | |
| Background rationale | 2 | Explain the scientific background and rationale for the investigation being reported | | | Introduction, page 3 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | | | Abstract, Page 1 Introduction, page 3 |
| Methods | | | | | |
| Study Design | 4 | Present key elements of study design early in the paper | | | Methods, pages 3,4 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | | | Methods, pages 3,4 |

| | | | | | |
|--|----------|--|--|--|--|
| <p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27</p> <p>Participants</p> | <p>6</p> | <p>(a) <i>Cohort study</i> - Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> - Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> - Give the eligibility criteria, and the sources and methods of selection of participants</p> <p>(b) <i>Cohort study</i> - For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> - For matched studies, give matching criteria and the number of controls per case</p> | | <p>RECORD 6.1: The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail. If this is not possible, an explanation should be provided.</p> <p>RECORD 6.2: Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere, detailed methods and results should be provided.</p> <p>RECORD 6.3: If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals with linked data at each stage.</p> | <p>Methods, pages 3,4</p> <p>Methods, page 5</p> |
| <p>28 29 30 31 32 33 34</p> <p>Variables</p> | <p>7</p> | <p>Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable.</p> | | <p>RECORD 7.1: A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.</p> | <p>This is provided as supplementary material and is referred to in the methods section.</p> |
| <p>35 36 37 38 39 40 41 42</p> <p>Data sources/ measurement</p> | <p>8</p> | <p>For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group</p> | | | |

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|--|----------------------------------|----|--|---|---------------------------------------|
| 1 2 3 4 | Bias | 9 | Describe any efforts to address potential sources of bias | | |
| 5 6 7 8 9 | Study size | 10 | Explain how the study size was arrived at | | |
| 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 | Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why | | |
| 35 36 37 38 39 40 41 42 43 44 45 46 47 | Statistical methods | 12 | (a) Describe all statistical methods, including those used to control for confounding (b) Describe any methods used to examine subgroups and interactions (c) Explain how missing data were addressed (d) <i>Cohort study</i> - If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> - If applicable, explain how matching of cases and controls was addressed <i>Cross-sectional study</i> - If applicable, describe analytical methods taking account of sampling strategy (e) Describe any sensitivity analyses | | |
| | Data access and cleaning methods | | .. | RECORD 12.1: Authors should describe the extent to which the investigators had access to the database population used to create the study population. | Methods, page 4 Methods page 4 |

| | | | | | |
|------------------|----|---|--|--|-------------------|
| | | | | RECORD 12.2: Authors should provide information on the data cleaning methods used in the study. | |
| Linkage | | .. | | RECORD 12.3: State whether the study included person-level, institutional-level, or other data linkage across two or more databases. The methods of linkage and methods of linkage quality evaluation should be provided. | Methods, page 4 |
| Results | | | | | |
| Participants | 13 | (a) Report the numbers of individuals at each stage of the study (<i>e.g.</i> , numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed) (b) Give reasons for non-participation at each stage. (c) Consider use of a flow diagram | | RECORD 13.1: Describe in detail the selection of the persons included in the study (<i>i.e.</i> , study population selection) including filtering based on data quality, data availability and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram. | Methods, page 3,4 |
| Descriptive data | 14 | (a) Give characteristics of study participants (<i>e.g.</i> , demographic, clinical, social) and information on exposures and potential confounders (b) Indicate the number of participants with missing data for each variable of interest (c) <i>Cohort study</i> - summarise follow-up time (<i>e.g.</i> , average and total amount) | | | |
| Outcome data | 15 | <i>Cohort study</i> - Report numbers of outcome events or summary measures over time <i>Case-control study</i> - Report numbers in each exposure | | | |

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|-------------------|----|---|--|--|---------------------|
| | | category, or summary measures of exposure <i>Cross-sectional study</i> - Report numbers of outcome events or summary measures | | | |
| Main results | 16 | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | | | |
| Other analyses | 17 | Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses | | | |
| Discussion | | | | | |
| Key results | 18 | Summarise key results with reference to study objectives | | | |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | | RECORD 19.1: Discuss the implications of using data that were not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to the study being reported. | Discussion page 8,9 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, | | | |

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|---|----|---|--|--|---|
| | | limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | | | |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | | | |
| Other Information | | | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | | | |
| Accessibility of protocol, raw data, and programming code | | .. | | RECORD 22.1: Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code. | Page 10 – no additional data available. |

*Reference: Benchimol EI, Smeeth L, Guttman A, Harron K, Moher D, Petersen I, Sørensen HT, von Elm E, Langan SM, the RECORD Working Committee. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine* 2015; in press.

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