**Recognition of the need for palliative care among non-cancer conditions in primary care: a time trend analysis in the United Kingdom (2009-2014)**

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## Abstract (250 words)

**Objectives**

Whilst guidelines recommend palliative care in non-cancer conditions, this has not been widely implemented. We examined whether the recording of a palliative care approach and the numbers of hospital deaths for deceased patients with heart failure, dementia, chronic obstructive pulmonary disease (COPD) and cancer have changed since the UK End of Life Care Strategy was introduced.

**Methods**

We conducted sequential cross-sectional studies of decedents within the UK’s Clinical Practice Research Datalink and Hospital Episode Statistics. All adults with a primary care record of COPD (N=5,426), dementia (N=7,339), heart failure (N=6,409) or cancer (N=18,668) who died during three one-year periods (April 2009-March 2014) were included. Evidence of a palliative care approach was identified from primary care records, and death in hospital from secondary care data.

**Results**

From 2009 to 2014, proportions with a primary care record of palliative care increased for COPD from 13.6% to 21.2%; dementia from 20.9% to 40.7%; and heart failure from 12.6% to 21.2%; but remained substantially lower than for cancer (57.6% to 61.9%). Median days before death of recording improved for COPD (145 to 224) and dementia (44 to 209); but not for heart failure (168.5 to 153) and cancer (123 to 114). Trends in hospital deaths were not consistently downward, although the proportions of patients dying in hospital were lower in the last period compared to the first.

**Conclusions**

Recording of a palliative care approach for non-cancer conditions has increased since the introduction of the UK End of Life Care Strategy, but remains inadequate.

## Introduction

A palliative approach to care is important not only in cancer but in non-malignant conditions where patients have palliative care needs comparable to those of cancer patients [1]. Among the most common conditions identified by the World Health Organisation as diseases that would benefit from palliative care are heart failure (HF), dementia and chronic obstructive pulmonary disease (COPD) [2]. Such conditions carry a similar symptom burden and poor quality of life for patients and their families and friends, but there is evidence from the United States [3,4], and the United Kingdom (UK) [5] that these needs are less likely to be met.

In the UK, the introduction of a national End-of-Life Care Strategy in 2008 [6] represented a major policy shift to extend specialist palliative care *regardless of diagnosis*, to be delivered primarily by generalists, with access to specialist palliative care services for persistent or complex problems. Although the role of primary care is central to providing palliative care to those nearing the end of life, information on whether the need is being met in the UK is sparse, despite maintenance of a palliative care register by general practitioners being incentivised as part of the Quality and Outcomes Framework (QOF) since 2006 [7]. Using general practice-based registers of palliative care, one study conducted shortly after the Strategy’s introduction, found patients with HF were poorly represented on the register, and when recorded, registration was often within a week of death [8]. Using the same electronic datasource, Bloom and colleagues showed that whilst the proportion of people dying from COPD and receiving palliative care increased between 2005 and 2015, this remained disproportionately low in those dying with COPD only (16.5%) compared with those dying with COPD and cancer (56.5%) [9]. Although from simple observation, the rate of change appears to increase from 2011.

With the aim of exploring whether recording of palliative care in primary care has changed for non-cancer conditions since 2008, patients who died with HF, dementia, or COPD, and for comparison, patients who died with cancer, in three different years were identified in UK’s Clinical Practice Research Datalink (CPRD) [10]. Using information in their healthcare records, potential changes in palliative care recording as well as the prevalence of hospital deaths were explored.

## Materials and Methods

Patients aged 18 or over with at least one clinical record of COPD; dementia; heart failure; or cancer (excluding non-melanoma skin cancer) who died in the periods 1 April 2009 to 31 March 2010; 1 April 2011 to 31 March 2012; or 1 April 2013 to 31 March 2014, were identified in CPRD using Read codes described in the NHS’s Quality and Outcomes Framework (QOF) (QOF version 29, June 2014) [11]. The CPRD is a database of contemporaneous medical records from UK primary care and is demographically representative, covering around c.7% of the UK population [10]; the QOF is a voluntary incentive scheme for general practitioners in the UK [7]. Fact and date of death recorded in primary care records, which have shown a high level of agreement with national death certification, were used to identify patients who had died [12]. Focus was primarily on patients who had only one of these conditions; where two or more were recorded, patients were considered in two additional groups based on whether or not they had cancer. Patients were included if they had at least one year of records and met CPRD acceptability criteria for data quality; for sensitivity analyses, subgroups of patients were established based on whether conditions were recorded either within five years of, or in the year before, death.

The palliative care register that has been part of QOF since 2006 covers clinical terms relating to palliative care services; advance care directives, recording of preferred place of death, indication of terminal illness and similar care near the end of life are not covered. Therefore, a comprehensive list of Read codes that reflected recognition of the need for end of life care was developed (Supplementary Table 1). Patients were considered as recognised as needing palliative approach if any of these codes appeared in their primary care records; in addition, the time between the earliest recording of any palliative care code and their death was calculated. Where no palliative care codes were recorded, patients were considered as not being recognised as needing palliative approach.

Information on whether patients died in hospital was obtained from secondary care data, which was available for 81% of the cohorts who had consented for linkage of CPRD to HES. From their HES records, it was possible to determine whether a patient had died in hospital; otherwise, patients were assumed to have died outside hospital. Patients with no consent for linkage were excluded from the analysis of death in hospital.

Proportions recognised as requiring a palliative approach were calculated, and in order to be comparable to cancer patients, were standardised to the age- and sex-distribution of cancer patients who died in the first year of the study (April 2009-March 2010). Annual changes in proportions, with 95% confidence intervals (CI), were estimated using binomial regression; annual changes in proportions were assumed to be linear since all tests for departure from linearity were not statistically significant.. All analyses were conducted using Stata 14.2.

## Results

Figure 1 shows how the 47 473 patients included in the sequential cross-sectional studies were identified in CPRD, and Table 1, the expected between-disease differences in age and sex distributions. For all conditions except cancer, palliative care codes outside QOF were used as often as those in QOF, and hence the totality was used in all presented analyses.

In the first year of our study, around three in every 20 patients with COPD, HF or dementia were recorded with a code recognising a palliative approach, compared to 12 in every 20 cancer patients (Table 2). By the final period, April 2013 to March 2014, proportions had increased to four in every 20 patients with COPD; eight in every 20 with dementia; and five in every 20 with HF. Palliative care recording increased most for patients with dementia, growing by 6.4% per year (95%CI 5.8, 7.0%); followed by HF at 2.6% (95%CI 2.0, 3.1%); and COPD at 2.3% (95%CI 1.7, 2.9%). Over the same period, recording among cancer patients grew by 1.1% (95%CI 0.7, 1.5%). For patients with two or more conditions, those without cancer saw an increase from three to six in every 20 patients being recorded, and those with cancer from nine to 11 in every 20 (Supplementary Table 2). Repeating analyses with patients whose conditions were recorded within the 5-year or 1-year period before death gave marginally greater proportions, mostly due to a smaller number of patients contributing to the denominator, but the annual change over time remained the same (data available on request). As for the timing of recording, this changed over the study period (Figure 2). In the year 2009-10, 35.8% with dementia and palliative care noted, 22.0% with HF and 16.0% with COPD were recorded for the first time in the week before death. By 2013-14, this had reduced to 17.5%, 15.6% and 13.3% for dementia, HF and COPD respectively, becoming closer to the 8-10% of patients with cancer.

Palliative care recording generally increased among men and women; in all age groups; and across all deprivation categories (Supplemental Table 3). Overall, proportions with palliative care recorded were similar for men and women; however, for dementia, sex-specific proportions diverged such that by 2013-14, 43.9% of women compared to 36.2% of men had palliative care recorded. With regards to age, some of the largest increases occurred in those aged 90 or over, with annual change estimated at 2.4% (95%CI 0.3, 4.5%) for COPD, and ranging up to 7.2% (95%CI 6.2, 8.2%) for dementia. On the other hand, patients aged under 70 did not see an increase in recording, and for COPD in particular, where around a fifth of deaths occurred in the under 70-year olds, palliative care recording was lower than for those aged 70-79, at 16.9% compared to 24.8% in the last period. For those living in more deprived areas, proportions of palliative care recording tended to be lower than amongst those from the most affluent, but not always significantly so.

Proportions of patients dying in hospital increased initially before falling in 2013-14, being significantly lower in the last year than in the first for cancer, COPD, and dementia but not HF (Table 3). When considering whether patients had a primary care record of palliative care, fewer with a record died in hospital than those who did not. Over the course of the study, the only condition apart from cancer where the proportions with palliative care who died in hospital decreased was dementia. Repeating the analysis restricted to QOF palliative care register codes, or where patients whose first record of palliative care was in the week before death were removed, gave similar findings (data not shown).

## Discussion

### Summary of main findings

It is encouraging that the recognition of the need for palliative care approach has increased in those with non-cancer diseases since the introduction of the UK End of Life Care Strategy. Not only have the proportions increased, but the timeliness of recording has also changed, with fewer patients registered in the week before death. Despite the improvements, significant inequalities remain; most notably that decedents with these conditions remain less likely to be recorded as having palliative care needs than those with cancer. With regards to dying in hospital, the data suggest that the numbers have decreased, particularly among those with palliative care, but a longer trajectory is needed to confirm these observations.

Registration on the palliative care QOF is a proxy measure for clinical recognition of the need for a palliative approach to care. Since the introduction of this indicator in 2006, over 99% of practices use a palliative care register [7]. Despite clear guidance, there may be a perception that the palliative care QOF is for cancer patients. Interestingly though, not only did the use of QOF palliative care codes in the non-malignant conditions increase, but also other non-QOF codes relating to end of life care such as advanced care directives were used as often throughout the data. Some of the biggest increases in recording were among patients aged 90 or older. Socioeconomic differences in palliative care were present to a degree, with more deprived patients less likely to have a record of palliative care than those who were more affluent; however, among the factors we were able to examine, age and GP practice may have been more influential on the recording.

### Comparison with literature

A realist evaluation of 16 GP Practices showed improvement over time in recognition of palliative care in non-cancer conditions following the introduction of a palliative care pathway but, as found here, the inequity of lower recognition of palliative care in non-cancer conditions compared to cancer remained [13]. Our findings are consistent with the other CPRD study showing that recognition of a palliative care approach was driven by a lung cancer diagnosis rather than COPD itself [9]. Our slightly higher proportion categorised as palliative care may be because of our use of palliative care registration rather than Read codes only. Other studies have shown a reduction in hospital deaths, in both cancer and non-cancer conditions [14–16]. The reasons for these changes are likely to be multifactorial: the Strategy and its wider policy influence; public health initiatives; increased clinical education and more publications and awareness regarding palliative care for non-cancer conditions. For reduced hospital deaths in dementia, factors such as economic incentives to reduce hospital admissions and stays have been suggested as a factor in the UK, other European countries and the US and have resulted in more deaths in care homes [16]. This study did not explore death outside of hospital but a study of hospice deaths from 1993–2012 demonstrated an increase in non-cancer conditions among hospice decedents although absolute numbers remain small [17].

### Strengths and limitations

This study benefits not only from being population-based in a large primary care dataset, but also from having as its basis the contemporaneous recording of conditions and care by general practitioners and health care professionals. We were able to identify decedents who had a record of the conditions of interest in their primary care notes, rather than relying on causes of death on the death certificates which are known to be inaccurate [18]. Moreover, the conditions of interest- cancer, heart failure, dementia and COPD - are QOF indicators, whereby GPs are incentivised to maintain the disease registers and record diagnoses once confirmed using specific tests and assessments, and have proved reliable for population-based prevalence data [19]. One limitation is that since primary care notes were established across patients’ lifetimes, the disease may not have been relevant to the patient’s death, and our denominator may be overestimated. However, analyses including only those whose disease was recorded in the last five or final year of life, whilst finding slightly higher proportions of palliative care recording showed very similar patterns. A limitation of the cross-sectional design is that general practices contributing to CPRD can change over time; restricting the analyses to the 42618 decedents (89.8%) whose practices contributed to all three periods did not alter the findings (data not shown). Many of the general practices contributing to CPRD are located in the north west or south east of England, and of smaller practice size than the national average [20,21]; however, in terms of the patients, the 7% of the UK population in CPRD are generally representative of the total population [10].

Identification of a palliative care approach in this study is dependent on coding in the clinical record; whilst a broader range of codes was used than in some recent studies [8,9], it is likely that we have under-estimated true palliative care activity. However, systematic differences in this under-estimation by condition seem unlikely and hence the relative differences observed would remain robust.

Information on place of death is not routinely available in primary care records in CPRD and was established from secondary care data. We were therefore only able to define whether patients died in hospital or not; information on deaths at home or hospice were unavailable. While we had only three alternate years of data available due to limitations of funding, this was sufficient to see an upward time trend in palliative care recording, described as linear growth but not of sufficient duration to assess alternative trend patterns; and when compounded by low palliative care recording, to determine clear patterns in hospital deaths. We also recognise that place of death in isolation should not be a quality marker of good care of the dying. Measures such as patient centred outcome measures (PCOMs) are increasingly seen as the gold standard for measuring quality of care but were not available and indeed are not widely used [22]. Although we relate our discussion to the UK End of Life Strategy of 2008, we are unable to assume causality in this observational study and data prior to 2008 were not analysed for comparison. Of interest, the rate of increase for COPD patients (2.3% per year) is similar to the rate of increase between 2008 to 2014 reported in Bloom et al, and which is approximately twice the rate of increase in their 2005 to 2008 data although they did not evaluate this [9].

### Implications for research, policy and practice

Although inequities seem to be improving for all disease further investigation of the reasons for and how to overcome the inequality are needed: for example, a case study approach of practices with low and high proportions of patients on the palliative care register. Also a study to explore more patient-centred outcomes of the result of being on a palliative care register especially as these become more widely used, for example the Integrated Palliative care Outcome Scale (IPOS), a

patient centred outcome measure developed and validated for use with people with advanced disease [22].

We would challenge the current UK strategy for identification of palliative care patients based on “*end* of life”. Although the UK policy definition does not intend an interpretation of “the last few days or weeks of life”, in practice, that is often the case. The use of the word “end” strongly implies a *time*-bound frame, and one which works backwards from the time of death. This risks delay in implementing a palliative approach, arising from the real challenges of accurately predicting the day of death, so called “prognostic paralysis” [23], a problem that is also well recognised as a barrier to hospice care for non-cancer diagnoses in the United States [24]. We welcome initiatives that promote supportive care and advance care planning earlier in the disease trajectory [25]. The more recent national framework for local implementation UK Ambitions of Care document uses the phrase “palliative and end-of-life” [26]. It will be interesting to see whether this clarifies or complicates clinical practice. We look to the WHO and Worldwide Palliative Care Alliance which do not mention either diagnosis, or prognosis, rather using the term life-limiting conditions and recommends identification of need for palliative care based on symptoms [2].

### Conclusions

To the best of our knowledge this is the first use of this data linkage in the palliative care population and allowed us to explore not only recognition of palliative care in primary care. Since the introduction of the UK End of Life Care Strategy recognition of the need for palliative care approach has increased in common life-limiting conditions, in a timelier manner. This may have in turn been related to a reduction in the number of patients dying in hospital but further study will be needed to confirm this.

## Contributors

All authors were responsible for the design and conduct of the study. AG and EK designed and created the database. EK and VA conducted the statistical analyses. AG, EK and VA drafted and revised the paper. SO, MJ and UM revised the draft paper. All authors have approved the final version for publication. AG is the guarantor.

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## Disclaimer

This study is based on data from the Clinical Practice Research Datalink obtained under license from the UK Medicines and Healthcare Products Regulatory Agency. However, the interpretation and conclusions contained in the study are those of the authors alone.

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## Competing Interests

None declared

## Ethical Approval

The CPRD Group has obtained ethics approval from a National Research Ethics Service Committee (NRES) for all purely observational research using anonymised CPRD data. This study was approved by the Independent Scientific Advisory Committee (ISAC) for Medicines and Healthcare products Regulatory Agency (MHRA) database research permission (Protocol number: 10\_168R). No further ethics approval was required for the analysis of the data.

## Data Sharing

No additional data available

## Transparency

The manuscript is an honest, accurate, and transparent account of the study being reported; that no aspects of the study have been omitted; and any discrepancies from the study as planned have been explained.

## Figure Legends

Figure 1: Flow diagram of identification of study subjects from CPRD GOLD.

Figure 2: Distribution of time before death when palliative care first recorded in primary care notes by disease and year.

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Table 1: Demographics of persons with cancer, chronic obstructive pulmonary disease (COPD), dementia, or heart failure in their general practice records who died in April 2009-March 2010, April 2011-March 2012 or April 2013-March 2014.

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Cancer | | | COPD | | | Dementia | | | Heart Failure | | |
|  | 2009-10 | 2011-12 | 2013-14 | 2009-10 | 2011-12 | 2013-14 | 2009-10 | 2011-12 | 2013-14 | 2009-10 | 2011-12 | 2013-14 |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| *Annual Deaths* | 6799 | 6386 | 5483 | 1924 | 1872 | 1630 | 2433 | 2474 | 2432 | 2429 | 2152 | 1828 |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| *Sex*- Male(%) | 51.0% | 51.3% | 50.4% | 53.8% | 55.7% | 54.4% | 32.3% | 32.1% | 32.0% | 47.3% | 47.6% | 50.2% |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| *Age*- Mean(sd) | 74.1(12.8) | 74.4(13.1) | 74.6(12.8) | 77.7(10.1) | 78.2(10.1) | 77.7(10.5) | 86.4(7.6) | 86.9(7.5) | 86.9(7.7) | 83.4(10.5) | 84.2(10.3) | 83.6(10.9) |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| *Index of Multiple Deprivation* |  |  |  |  |  |  |  |  |  |  |  |  |
| 1- least deprived | 22.8% | 22.8% | 21.8% | 14.8% | 15.1% | 15.0% | 23.6% | 22.5% | 22.0% | 20.0% | 18.8% | 19.6% |
| 2 | 25.9% | 24.0% | 24.9% | 21.2% | 21.1% | 19.0% | 25.0% | 23.7% | 23.0% | 24.0% | 24.7% | 25.4% |
| 3 | 20.8% | 21.9% | 20.2% | 17.7% | 19.5% | 19.6% | 21.9% | 22.5% | 23.1% | 22.0% | 22.1% | 22.8% |
| 4 | 17.3% | 17.8% | 18.7% | 22.8% | 21.7% | 23.0% | 16.8% | 17.1% | 16.4% | 18.6% | 19.1% | 17.6% |
| 5-most deprived | 13.1% | 13.5% | 14.3% | 23.3% | 22.5% | 23.3% | 12.6% | 14.2% | 15.4% | 15.4% | 15.3% | 14.6% |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| *Palliative Care*- Yes(%) | 57.6% | 60.2% | 61.7% | 13.4% | 17.3% | 22.6% | 16.1% | 30.5% | 41.4% | 13.0% | 16.8% | 24.2% |
| QOF Codes | 50.1% | 52.1% | 52.1% | 8.4% | 11.0% | 14.3% | 9.7% | 17.3% | 22.7% | 7.1% | 9.8% | 13.9% |
| Other Codes | 7.5% | 8.1% | 9.6% | 4.9% | 6.4% | 8.3% | 6.4% | 13.2% | 18.8% | 5.9% | 7.0% | 10.3% |
|  |  |  |  |  |  |  |  |  |  |  |  |  |
| *Death in Hospital-* Yes(%) | 34.7% | 35.4% | 28.9% | 47.1% | 51.9% | 40.8% | 23.7% | 25.6% | 20.5% | 42.8% | 48.5% | 41.0% |
|  |  |  |  |  |  |  |  |  |  |  |  |  |

Index of Multiple Deprivation and place of death were available for 81% of deaths.

Table 2: Proportions and changes in proportion of deaths recorded as needing palliative care approach in primary care since April 2009-March 2010.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Year | Total Deaths | Palliative Care Register | | | | |
|  | Total | Unadjusted Proportion | Adjusted Proportion (95%CI) | Changes in Proportion (95%CI) | |
|  |  |  |  |  |  | |
|  | *Cancer* | | | | |  |
|  |  |  |  |  |  | |
| 2009-10 | 6799 | 3913 | 57.6% | 57.6%(56.4,58.7%) | 0(ref) | |
| 2011-12 | 6386 | 3845 | 60.2% | 60.6%(59.5,61.8%) | 2.97%(1.33,4.62%) | |
| 2013-14 | 5483 | 3381 | 61.7% | 61.9%(60.6,63.2%) | 4.44%(2.74,6.14%) | |
| *Annual Change* |  |  |  |  | *1.12%(0.70,1.54%)* | |
|  |  |  |  |  |  | |
|  | *COPD* | | | | |  |
|  |  |  |  |  |  | |
| 2009-10 | 1924 | 257 | 13.4% | 13.6%(11.9,15.3%) | 0(ref) | |
| 2011-12 | 1872 | 324 | 17.3% | 17.5%(15.4,19.6%) | 4.08%(1.82,6.34%) | |
| 2013-14 | 1630 | 368 | 22.6% | 21.2%(19.2,23.3%) | 9.36%(6.85,11.9%) | |
| *Annual Change* |  |  |  |  | *2.31%(1.70,2.92%)* | |
|  |  |  |  |  |  | |
|  | *Dementia* | | | | |  |
|  |  |  |  |  |  | |
| 2009-10 | 2433 | 391 | 16.1% | 20.9%(17.8,23.9%) | 0(ref) | |
| 2011-12 | 2474 | 755 | 30.5% | 37.5%(33.8,41.1%) | 14.6%(12.3,16.9%) | |
| 2013-14 | 2432 | 1008 | 41.4% | 40.7%(37.2,44.2%) | 25.4%(22.9,27.8%) | |
| *Annual Change* |  |  |  |  | *6.43%(5.82,7.04%)* | |
|  |  |  |  |  |  | |
|  | *Heart Failure* | | | | |  |
|  |  |  |  |  |  | |
| 2009-10 | 2429 | 315 | 13.0% | 12.6%(10.7,14.4%) | 0(ref) | |
| 2011-12 | 2152 | 361 | 16.8% | 15.0%(12.8,17.2%) | 3.26%(1.20,5.32%) | |
| 2013-14 | 1828 | 443 | 24.2% | 21.2%(18.7,23.8%) | 10.7%(8.38,13.1%) | |
| *Annual Change* |  |  |  |  | *2.56%(1.99,3.12%)* | |
|  |  |  |  |  |  | |

Adjusted proportions were standardised to the age- and sex- distribution of persons with cancer who died between April 2009 and March 2010. Changes in proportions and 95% confidence intervals (95%CI) were estimated using binomial regression adjusted for age, sex and index of multiple deprivation.

Table 3: Changes in proportion of deaths in hospital since April 2009-March 2010 among all patients, and among those not recorded or recorded as needing palliative care.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Year | Total | | | No Recording of Palliative Care | | | Recording of Palliative Care | | |
|  | Deaths: Hospital/ Total | Proportion | Change in Proportion  (95%CI) | Deaths: Hospital/ Total | Proportion | Change in Proportion  (95%CI) | Deaths: Hospital/ Total | Proportion | Change in Proportion  (95%CI) |
|  |  |  |  |  |  |  |  |  |  |
|  | *Cancer* | | | | | | | | |
| 2009-10 | 1929/5565 | 34.6% | 0(ref) | 1076/2371 | 45.4% | 0(ref) | 853/3194 | 26.7% | 0(ref) |
| 2011-12 | 1842/5200 | 35.4% | 0.69%(-1.11,2.49%) | 1033/2094 | 50.7% | 5.33%(2.41,8.26%) | 781/3106 | 25.1% | -1.47%(-3.63,0.69%) |
| 2013-14 | 1277/4426 | 28.9% | -5.69%(-7.73,-4.08%) | 727/1694 | 42.9% | -2.56%(-5.65,0.53%) | 550/2732 | 20.1% | -6.32%(-8.47,-4.18%) |
| *Annual Change* |  |  | *-1.43%(-1.90,-0.97%)* |  |  | *-0.45%(-1.23,0.32%)* |  |  | *-1.62%(-2.19,-1.05%)* |
|  |  |  |  |  |  |  |  |  |  |
|  | *COPD* | | | | | | | | |
| 2009-10 | 734/1557 | 47.1% | 0(ref) | 672/1364 | 49.3% | 0(ref) | 62/193 | 32.1% | 0(ref) |
| 2011-12 | 795/1531 | 51.9% | 4.75%(1.23,8.28%) | 711/1272 | 55.9% | 6.57%(2.76,10.4%) | 84/259 | 32.4% | 0.38%(-8.36,9.11%) |
| 2013-14 | 537/1315 | 40.8% | -6.25%(-9.88,-2.62%) | 456/1022 | 44.6% | -4.60%(-8.63,-0.56%) | 81/293 | 27.6% | -4.47%(-12.8,3.89%) |
| *Annual Change* |  |  | *-1.46%(-2.38,-0.55%)* |  |  | *-0.93%(-1.94,0.08%)* |  |  | *-1.24%(-3.34,0.86%)* |
|  |  |  |  |  |  |  |  |  |  |
|  | *Dementia* | | | | | | | | |
| 2009-10 | 463/1951 | 23.7% | 0(ref) | 426/1655 | 25.7% | 0(ref) | 37/296 | 12.5% | 0(ref) |
| 2011-12 | 519/2025 | 25.6% | 1.77%(-0.86,4.40%) | 463/1417 | 32.7% | 6.84%(3.63,10.1%) | 56/608 | 9.2% | -2.07%(-6.17,2.03%) |
| 2013-14 | 401/1953 | 20.5% | -2.99%(-5.54,-0.45%) | 340/1135 | 30.0% | 4.03%(0.66,7.40%) | 61/818 | 7.5% | -3.74%(-7.64,0.16%) |
| *Annual Change* |  |  | *-0.78%(-1.44,-0.12%)* |  |  | *1.21%(0.34,2.07%)* |  |  | *-0.90%(-1.74,-0.06%)* |
|  |  |  |  |  |  |  |  |  |  |
|  | *Heart Failure* | | | | | | | | |
| 2009-10 | 865/2022 | 42.8% | 0(ref) | 797/1759 | 45.3% | 0(ref) | 68/263 | 25.9% | 0(ref) |
| 2011-12 | 865/1783 | 48.5% | 5.89%(2.74,9.05%) | 779/1500 | 51.9% | 6.72%(3.30,10.1%) | 86/283 | 30.4% | 5.14%(-2.37,12.6%) |
| 2013-14 | 599/1462 | 41.0% | -1.26%(-4.55,2.03%) | 513/1127 | 45.5% | 0.71%(-2.99,4.40%) | 86/335 | 25.7% | 1.18%(-5.81,8.17%) |
| *Annual Change* |  |  | *-0.14%(-0.97,0.69%)* |  |  | *0.43%(-0.50,1.35%)* |  |  | *0.19%(-1.62,2.00%)* |
|  |  |  |  |  |  |  |  |  |  |

Change in proportions and 95% confidence intervals (95%CI) were estimated using binomial regression adjusted for age, sex and index of multiple deprivation.

Figure 1: Flow diagram of identification of study subjects from CPRD GOLD.

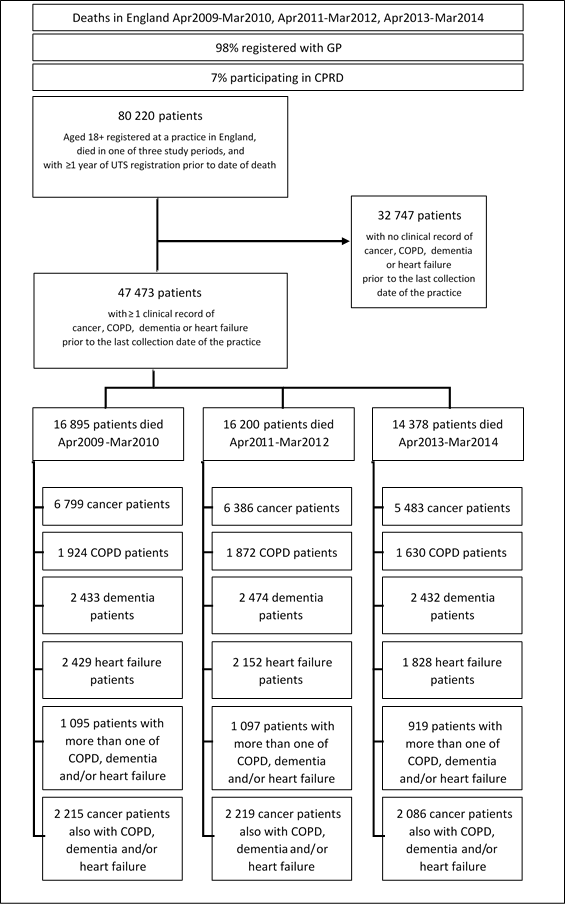


Figure 2: Distribution of time before death when palliative care first recorded in primary care notes by disease and year.

