



Public Health
England

Protecting and improving the nation's health

National End of Life Care Intelligence Network

Electronic Palliative Care Co-ordination Systems (EPaCCS) National Data Project

A study to assess the challenges and opportunities associated with collating information from different EPaCCS.

Version 1.0/ October 2016

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About this report

Disclaimer

This report has been compiled from survey data submitted by clinical commissioning groups (CCGs) in England. We are aware that the data is not complete and there may be inaccuracies in some of the data reported. We do not accept responsibility for any loss, damage or expense resulting from the use of this information.

Acknowledgements

Special thanks to all those in CCGs and other EPaCCS implementing organisations who responded to the survey.

This summary report was written and developed with input from the stakeholders who support the National End of Life Care Intelligence Network. Their contributions were invaluable in the development of the questionnaire and the compilation of this report.

The questionnaire was developed, tested and approved by the national EPaCCS team in the National End of Life Care Intelligence Network and NHS Improving Quality, with support from Stephen Burrows, Diana Howard, Mike Arnold, Jason Leathen, Mandy Smith, Martel Brown and Mila Petrova.

Feedback

We welcome feedback from survey respondents and other users of this report. Please send comments to neolcin@phe.gov.uk

We would also be grateful if EPaCCS leads could let us know if their contact details change so that we can keep our details up to date. Please send details to: neolcin@phe.gov.uk. Thank you.

The intelligence networks

Public Health England operates a number of intelligence networks which work with partners to develop world class population health intelligence to help improve local, national and international public health systems.

National Cardiovascular Intelligence Network

The National Cardiovascular Intelligence Network (NCVIN) analyses information and data and turns it into meaningful, timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

National Mental Health, Dementia and Neurology Intelligence Network

The National Mental Health Intelligence Networks (NMHDNIN) bring together the distinct National Mental Health Intelligence Network, the Dementia Intelligence Network and the Neurology Intelligence Network under a single programme. The networks work in partnership with key stakeholder organisations. The networks seek to put information and intelligence into the hands of decision makers to improve mental health and wellbeing, support the reduction of risk, improve the lives of people living with dementia and improve neurology services.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

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Executive summary

The aim of this study is to collate EPaCCS data to better understand the impact of EPaCCS nationally, look at geographical variations in EPaCCS data, understand the potential challenges/barriers and opportunities associated with collating EPaCCS data and better understand the effectiveness of EPaCCS in achieving people's preferences for care, supporting co-ordination of care.

A limited aggregate dataset (data template) was designed with data items to be collected by each EPaCCS implementer. The aggregate dataset was developed in consultation with stakeholders through a planning workshop and pilot audit. The final audit was sent to 70 EPaCCS implementers, of which 15 were able to provide data; a total of 39,953 records for patients registered at GP practices in 58 different CCGs. Each represented one person alive on an EPaCCS system prior to 31 March 2014 or added to a system between 1 April 2014 and 31 March 2015.

The results of the study data show that:

- more than one third of people on EPaCCS are aged 85 and over with a further 44% aged 65 to 74 years
- just over half (56.5%) are female
- cancer is the most common diagnosis for patients on EPaCCS. Patients often had multiple diagnoses
- one third of patients on EPaCCS died at home and under 20% died in hospital
- of patients expressing a preferred place of death, half preferred to die at home. Of these, 30% died in their preferred place of death (home)

Collating data from different providers has its challenges. Many participants were simply unable to provide data, constrained by issues around data confidentiality and ownership, the ability to access information from computer systems and having sufficient resources (people and time) to obtain information.

For those able to supply information, the completeness for any given item of information ranged from over 90% (patient age group, patient gender) to under 1% (for patients with an advance decision to refuse treatment). Data quality was also influenced by it being held on fragmented systems, information not being updated once a patient had died and areas concurrently operating more than one information system.

Benefits of data collation include:

- providing a platform for national reporting
- provide an epidemiological insight into the cohort of patients on EPaCCS
- facilitate the development of consistent and comparable data
- provide information on how the use of EPaCCS can support the quality of care at the end of life
- provide a framework of support for those collecting data or looking to begin the task of creating EPaCCS registers

Introduction

The national End of Life Care Strategy (2008)¹ identifies the need to improve the co-ordination of care, recognising that people at the end of life frequently receive care from a wide variety of teams and organisations. Locality registers (which became Electronic Palliative Care Co-ordination Systems (EPaCCS) were identified as a mechanism for enabling co-ordination. EPaCCS enable the recording and sharing of people's care preferences and key details about their care with those delivering care.

The NHS Five Year Forward View (2014)² commits to the development of fully interoperable electronic health records that include social care information. One aim of the National Information Board is, by 2020, to provide care professionals and carers with access to all data information and knowledge that they need. Interoperable electronic systems are seen as the key to success.³

Despite the majority of EPaCCS systems having reporting functionality, there is no national reporting of EPaCCS data at this time. This report presents the findings of a study that collated data from different EPaCCS systems as a way of creating a national picture.

This report is the result of data acquired from participating EPaCCS sites all over England. Although the project was compressed into a short timescale, the response to the call for data resulted in access to some 40,000 records including analysis of more than 16,000 deaths. This has enabled the team to assess the impact of EPaCCS in a number of different areas, including:

- the EPaCCS cohort; the gender, age, diagnosis and preferences for people on EPaCCS registers
- information about the place of death and the preferred place of death
- data completeness: national data gathering can show us which fields are most consistently filled, and perhaps more interestingly, which fields are less likely to be filled. This can give us a unique look at how the EPaCCS system is being used and how it may be developed in future, which areas are obviously important – as defined by the level of use – and could therefore be enlarged or developed. Similarly, there may be redundant areas of the dataset which could be reduced in scale or even removed, with a view to simplifying the process wherever possible

Aim

PHE is aware that the majority of EPaCCS systems have reporting functionality and some areas are reporting on the impact of local implementation e.g. Co-ordinate My Care in London. However, there is no national reporting at this time. The aim was for PHE to lead an audit of local areas and collate EPaCCS data to:

- better understand the impact of EPaCCS nationally
- look at geographical variations in EPaCCS data
- understand the potential barriers to collating EPaCCS data nationally from local systems
- to better understand the effectiveness of EPaCCS in achieving people's preferences for care, supporting the co-ordination of care and reducing unnecessary medical intervention

Methodology

The approach was to design a limited aggregate dataset based on the national information standard, Palliative Care Co-ordination: Core content (SCCI1580), to be collected by each EPaCCS implementer. PHE coordinated the design of this dataset, the request for data and the compilation of the report.

Planning workshop

Held on 3 November 2015, this working event drafted an approach to the audit. It was decided to focus the audit on key items from the national information standard (see Appendix A). Also, to avoid the administrative overhead of dealing with patient level data, it was decided that local teams would submit aggregate data.

Pilot audit

Following the planning workshop, a draft audit specification was prepared, shared with stakeholders and updated following their comments.

Final audit

The request for data was sent to EPaCCS implementers across England in December 2015 with the request that returns be submitted by the end of January 2016.

A copy of the audit template is included in Appendix B.

Results

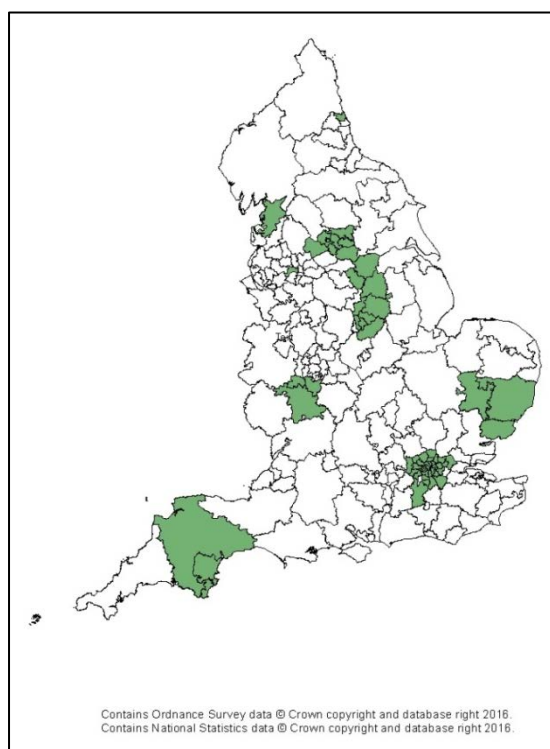
Response rates

Of the 70 implementers contacted with a request to contribute a dataset, there were a total of 15 respondents who were able to provide data (15 data providers). Not all providers were able to supply information on every data item that was asked for.

Geographic coverage

The 15 data providers represented a variety of organisations (hospices, commissioning support units and CCGs) across England. These provided data for patients registered at GP practices in 58 different CCGs. These included the 32 CCGs comprising Greater London, Nottingham City CCG, Nottingham North and East CCG, Nottingham West CCG, Rushcliffe CCG, Bassetlaw CCG, Mansfield and Ashfield CCG, Newark and Sherwood CCG, South Worcestershire CCG, Redditch and Bromsgrove CCG, Wyre Forest CCG, North East Essex CCG, Northern Eastern and Western Devon CCG, South Devon and Torbay CCG, North Tyneside CCG, Doncaster CCG, Ipswich and East Suffolk CCG, West Suffolk CCG, Leeds West CCG, Leeds North CCG and Leeds South and East CCG, Calderdale CCG, North Kirklees CCG, Wakefield CCG, Salford CCG, Lancashire North CCG and Bradford City CCG (Map 1).

Map 1. Geographical distribution of responses



A number of organisations were unable to submit data for a variety of reasons:

- unable to extract data because of coding and formatting issues
- data not collected for certain requested items
- no EPaCCS system, no money for investment
- fragmented local systems held by different organisations from which data has to be extracted manually and then collated
- the information required is more detailed than usually required and requires the development of a specific query
- the existing templates in Aadastra won't enable extraction of the information required
- no IT person to extract the data
- information governance prevents extraction of the information without the patients consent
- the systems that held data for that time period are no longer in place and the data is unavailable
- no access to patients date of death due to current restrictions on data confidentiality and security, unable to identify patients who have died within a particular time period

EPaCCS systems used by respondents

Respondents to the audit reported that EPaCCS data was held on a variety of different systems. Some areas stored data on two different systems concurrently. The systems listed included:

- Aadastra
- SystemOne
- EMIS Web
- EMIS Enterprise
- SRSS
- plus proprietary systems at Co-ordinate my Care (Greater London) and Worcestershire

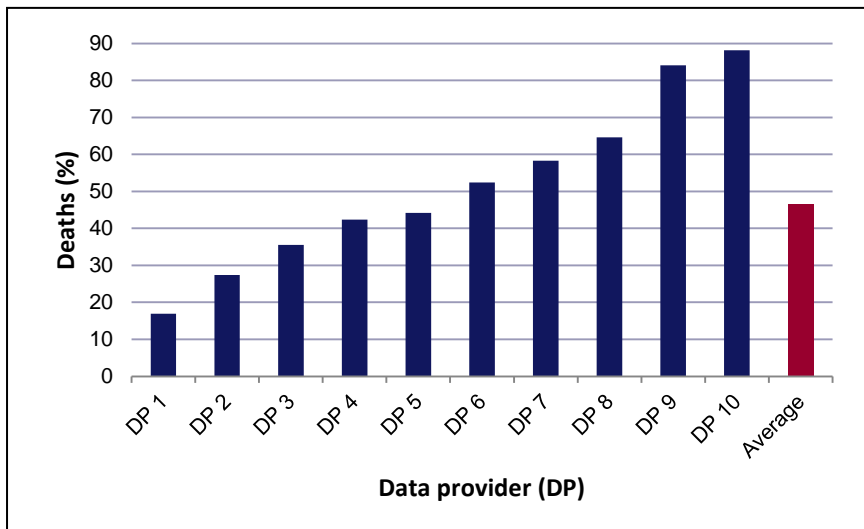
Summary of the data submitted

A total of 19,147 persons were reported on EPaCCS systems at 31 March 2014 (data recorded by 12 data providers). A further 20,806 persons were added to systems between 1 April 2014 and 31 March 2015 (data recorded by 13 data providers). A total of 39,953 people were already on an EPaCCS system at 31 March 2014 or were added during the 12 months from 1 April 2014.

Two data providers were unable to provide information within the given 12 month time period due to system setup and/or data confidentiality issues. Three data providers were unable to provide information prior to 1 April 2014.

46.5% of patients (15,962 people) on EPaCCS prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015 died (data reported by 10 data providers). The percentage of deaths for each data provider ranged from 17% to 88% (Figure 1).

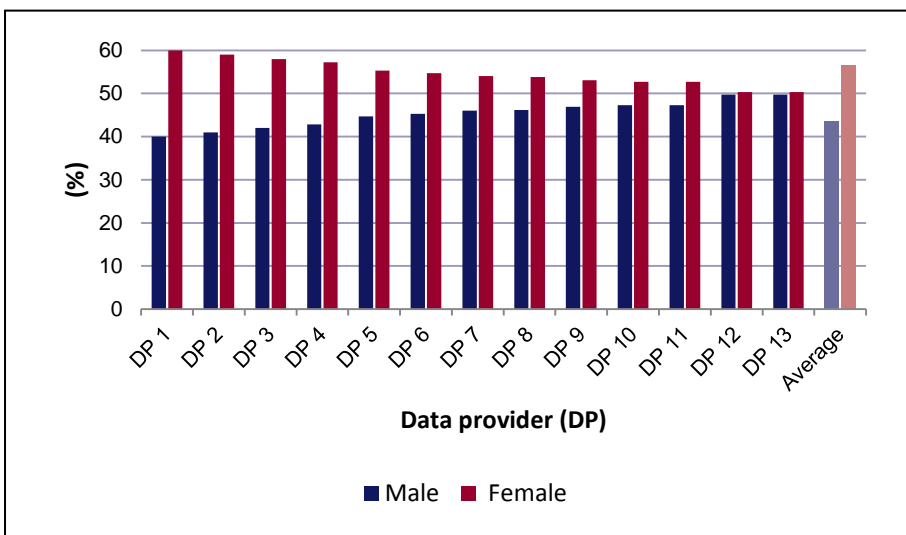
Figure 1: Proportion of deaths for persons on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015, dying during the 12 months from 1 April 2014.



Gender

Gender was recorded for 36,486 people of which 15,875 were male (43.5%) and 20,611 were female (56.5%) (data reported by 13 data providers representing a 91% level of data completeness). Gender ratios within each data provider ranged from 60% female and 40% male to 50.3% female and 49.7% male (Figure 2).

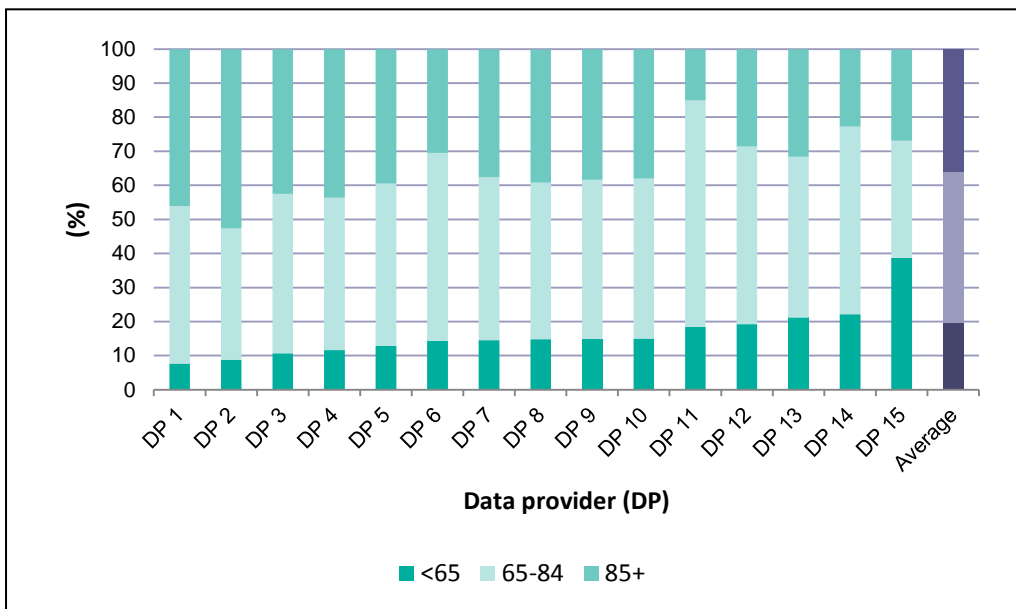
Figure 2: Proportion of males and females on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Age

Data providers were asked to submit the age of the patient at the system record creation date. Patient age was recorded for 37,830 persons (data reported for 15 data providers representing a 94.7% level of data completeness). 19.6% of the cohort were aged under 65 years (7,426 people), 44.3% were aged 65 to 84 (16,759 people) and 36.1% (13,645 people) were aged 85 or over. The proportion in each age group varies by data provider (Figure 3). The proportion of patients aged under 65 years ranged from 7.7% to 38.7%. The proportion aged 65 to 84 ranged from 34.4% to 66.4%. The proportion ranged 85+ ranged from 15.1% to 52.8%.

Figure 3: Proportion of persons by age group on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Diagnosis

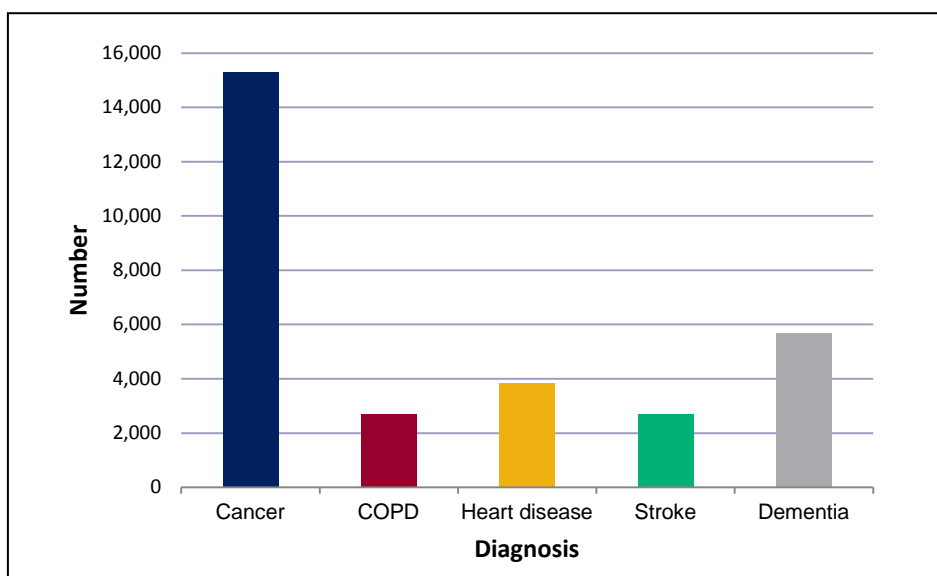
Data providers were asked to provide the primary patient diagnosis, if recorded, for cancer, chronic obstructive pulmonary disease (COPD), heart disease, stroke and dementia.

A single primary diagnosis was unobtainable for many providers due to the way in which data systems are organised. Some providers were only able to submit information for multiple diagnoses for any given patient. In some cases multiple diagnoses were given if patients had more than one long term condition.

Other respondents reported that they were unable to obtain a primary diagnosis through the GP systems as they didn't record diagnosis in that way; unlike secondary care organisations.

30,229 records of diagnosis were submitted (data reported for 11 data providers). The highest number of diagnoses was associated with cancer (15,308). The number for COPD, heart disease, stroke and dementia were 2,715, 3,840, 2,692 and 5,674 respectively (Figure 4).

Figure 4: Number of diagnoses for persons on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Average length of EPaCCS record

Four data providers provided information on the average length of an EPaCCS record. Values ranged from 46 days to 334 days. Many data providers were unable to extract this information from their respective systems.

Prognosis

Data providers were asked to provide a count of the number of EPaCCS patients with a prognosis of days, a prognosis of weeks and a prognosis of months. 875 people were reported as having a prognosis of days (data reported by 10 data providers), 2487 people were reported as having a prognosis of weeks (data reported by five data providers) and 4,921 people were reported as having a prognosis of months (data reported by six data providers).

Main carer/care worker

Data providers were asked to provide a count of the number of EPaCCS patients with a main carer, a care worker and both a main care and care worker. 7,882 people were recorded as having a main carer (data reported by 14 data providers), 10,037 people were recorded as having a care worker (data reported by 10 data providers) and 2,848

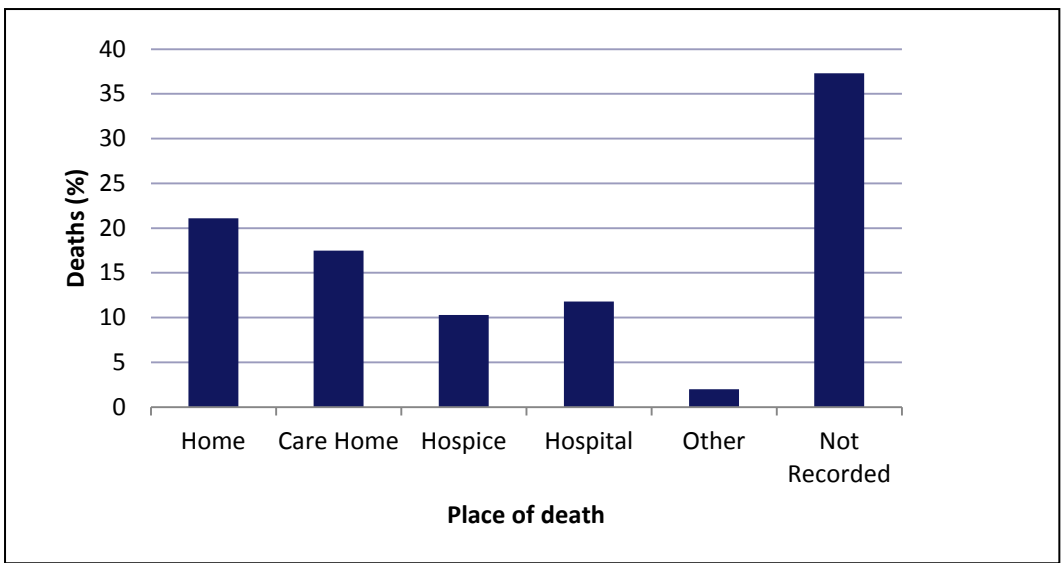
people were recorded as having both a main carer and a care worker (data reported from eight data providers).

Place of death

Data providers were asked to provide a count of place of death for the following categories, home, care home, hospice, hospital, other and not recorded. 15 data providers provided information, however it was reported that users tend not to get round to entering after death information leading to gaps in the data and place of death could be entered more than once on a system.

A place of death was recorded 22,420 times with 8,361 counts (37.3%) where place of death was classified as 'not recorded' (Figure 5).

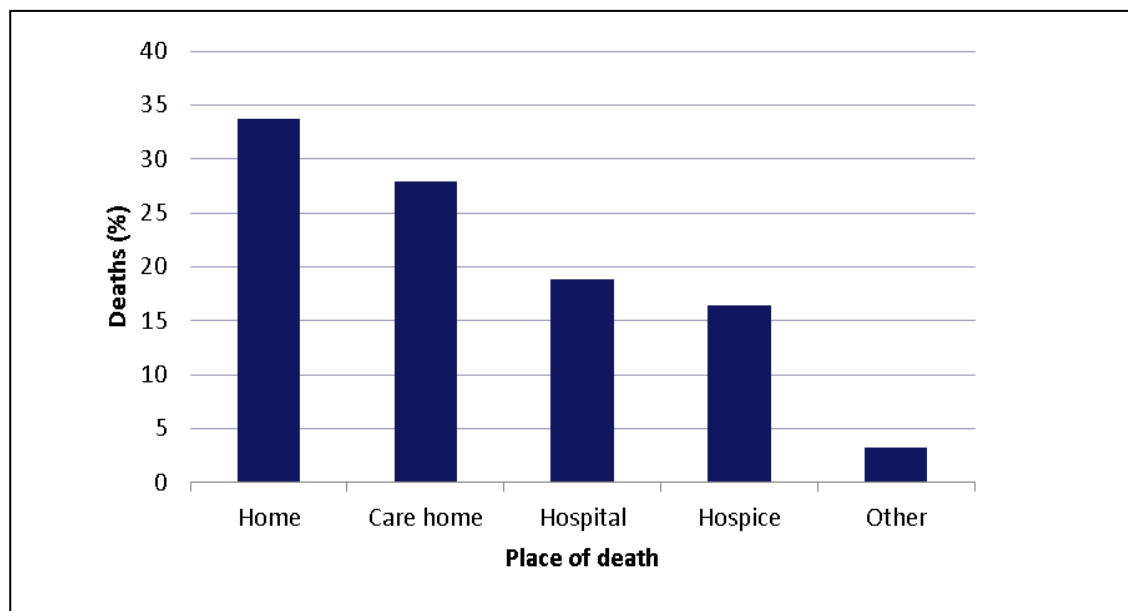
Figure 5: Place of death for persons dying whilst on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Home deaths accounted for 21.1% of records, care homes 17.5%, hospital 11.8%, and hospices 10.3%.

A place of death (home, care home, hospice, hospital or other) was recorded 14,059 times. Where recorded, the most common places of death were home (33.7%) and care home (27.9%), followed by hospital (18.8%) and hospice (16.4%), together accounting for about a third (Figure 6).

Figure 6: Place of death (home, care home, hospice, hospital or other) for persons dying whilst on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Preferred place of death

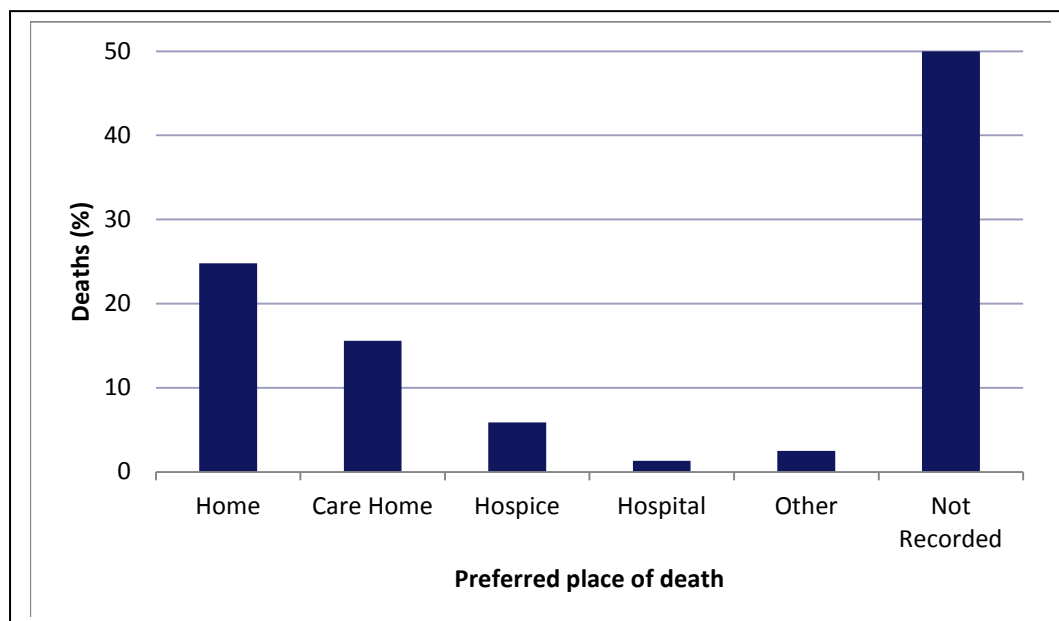
Data providers were asked to provide a count of preferred place of death for the following categories: home, care home, hospice, hospital, other and not recorded. 15 data providers provided information.

A preferred place of death was recorded for 39,693 records of which 50% (19,833) were classified as not recorded (Figure 7). Some data providers reported that if a patient does not express a particular preferred place of death, e.g. the patient is undecided or unable to express a preferred place of death, then this is classified as 'not recorded'.

Other data providers stated that the proportion of patients who die in their preferred place of death was monitored on the basis of all patients who die at home (without a preferred place of death recorded) as having died in their preferred place of death.

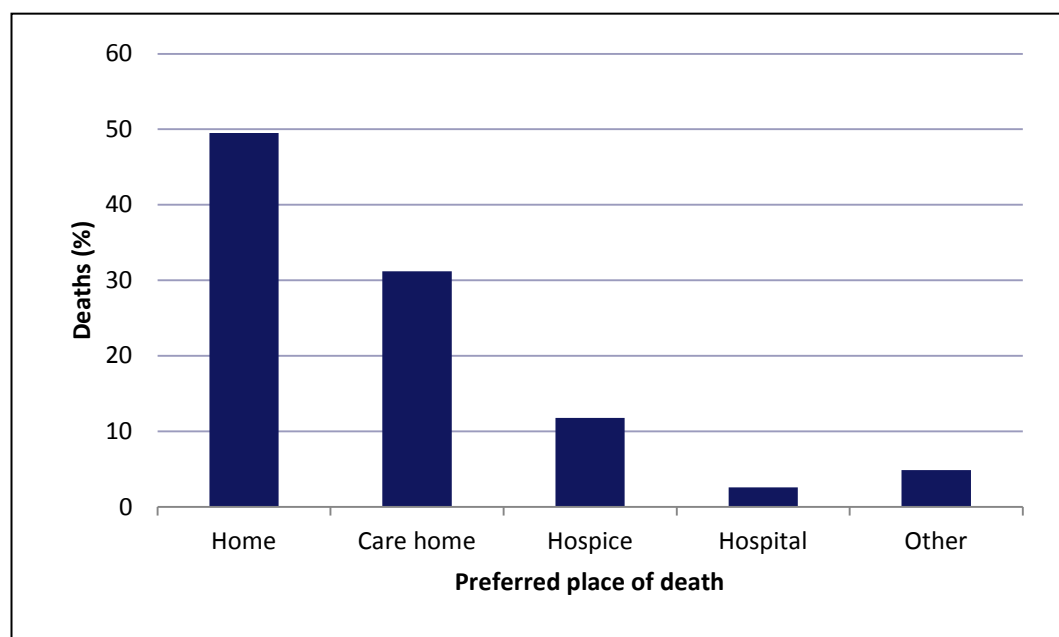
Other providers reported that there are relatively few records where both actual place of death and preferred place of death are both recorded.

Figure 7: Preferred place of death for persons dying whilst on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Where recorded, the most common preferred places of death were home (49.5%), care home (31.2%) and hospice (11.8%). 2.6% of those expressing a preference that was recorded wanted to die in hospital (Figure 8).

Figure 8: Preferred place of death (home, care home, hospice, hospital or other) for persons dying whilst on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.

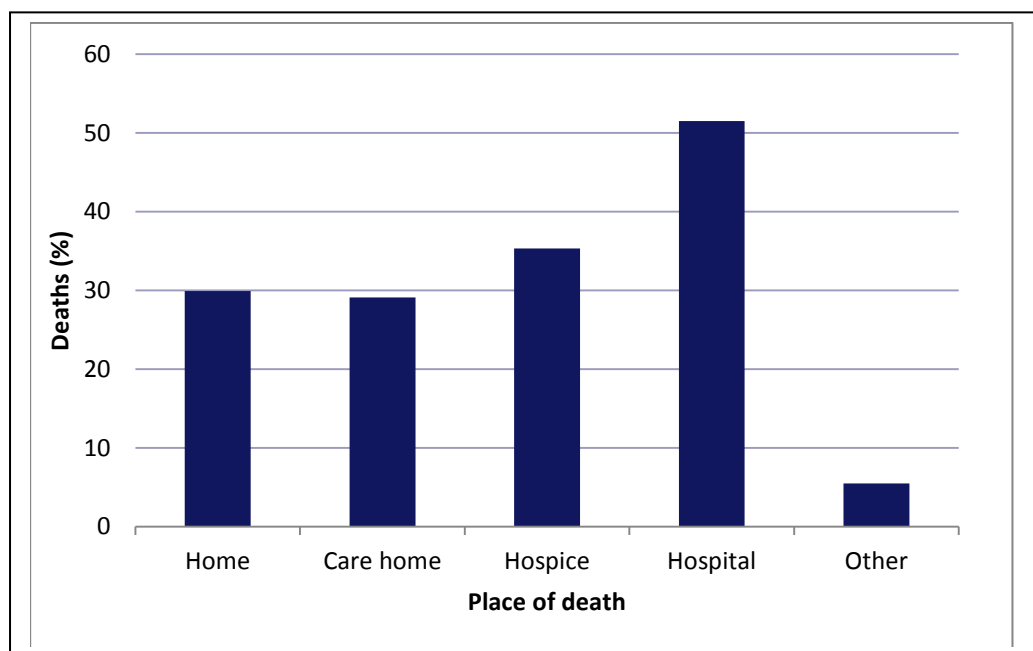


Dying in the preferred place of death

Data providers were asked to provide a count of persons who died in their preferred place of death. A preferred place of death was recorded for 11,620 records (data was reported by 15 data providers). 5,889 records (50.6%) related to persons where the preferred place of death was not recorded and the place of death was not recorded.

Where recorded, 29.9% of people who expressed a wish to die at home died at home, 29.1% of people who expressed a wish to die at a care home died at a care home, 35.3% of people who expressed a wish to die at a hospice died at a hospice, 51.5% of people who expressed a wish to die at a hospital died at a hospital, 5.5% of people who expressed a wish to die in another place died in another place (Figure 9).

Figure 9: Proportion of people dying in their preferred place of death for persons dying whilst on EPaCCS systems prior to 1 April 2014 or added between 1 April 2014 and 31 March 2015.



Data providers were asked to provide a count of persons who died in hospital when their preferred place of death was either home, care home, hospice or other. 975 records were submitted by 15 data providers. Two thirds of counts (66.7%) related to persons who had expressed home as the preferred place of death but who died in hospital. 12.7% related to persons who preferred to die in a care home, 17.8% for persons who preferred to die in a hospice.

Do not attempt cardiopulmonary resuscitation (DNACPR) decision

Data providers were asked to provide a count of persons for who there was a DNACPR decision. 14 data providers were able to provide data for 20,948 records (52.4% of records) with levels of completeness ranging from 12% to 82%.

Lasting power of attorney (LPA) appointed

Data providers were asked to provide a count of persons for who an LPA had been appointed. 13 data providers were able to provide data for 622 records (1.6% of records) with levels of completeness ranging from 0.3% to 7.7%.

Advance decision to refused treatment (ADRT) recorded

Data providers were asked to provide a count of persons for who an ADRT had been recorded. 13 data providers were able to provide data for 155 records (0.4% of the total) with levels of completeness ranging from 0.1% to 1.9%.

Advance statements

Data providers were asked to provide a count of persons who an advance statement about preferences, wishes, beliefs and values regarding their future care had been recorded. 13 data providers were able to provide data for 3,859 records (9.7% of the total) with levels of completeness ranging from 0.1% to 51%.

Anticipatory medicines/medications

Data providers were asked to provide a count of persons who there was a record for anticipatory medicines. 14 data providers were able to provide data for 5,952 records (14.9% of the total) with levels of completeness ranging from 7.7% to 33.8%.

Discussion

This study has shown that information from EPaCCS systems can be collated to an aggregated level, although few organisations are in a position to submit a comprehensive and complete set of data.

Collating data from different providers sets challenges for both data providers and data collators. Feedback from providers indicates that there is wide variation in the way in which data is stored, recorded and accessed. Issues around data confidentiality and ownership, variation in the interpretation of data items, data coding, data formatting issues and resourcing prevented respondents from either submitting data or restricted them to submitting partially completed submissions. Some data providers are forced to extract information from two or more systems that run concurrently; each of which producing different sets of figures.

Few data providers were able to provide all the information asked for in the data audit template. Where information was supplied, data completeness for any given item of information varied from over 90% for variables such as patient age group and patient gender (94% and 91% respectively) to under 1% for patients with an advance decision to refuse treatment.

Place of death was not recorded for 37.3% of deaths reflecting the fact that systems are not always updated once a patient has died. Recording information about place and cause of death on EPaCCS becomes a retrospective process and not a priority when the emphasis for using EPaCCS is as a tool for care co-ordination and the documentation of information relating to patient preferences. Cause and place of death is recorded on to other systems (eg Office for National Statistics (ONS) mortality file) which could be linked to EPaCCS if required at an aggregated level.

Cause and place of death can provide information about the care pathway at the end of life especially when used in conjunction with information about patient preferences. Where a preferred place of death was recorded 29.7% of patients died in the preferred place of death

Where place of death is recorded, one third of patients died at home with 18.8% dying in hospital. This compares to an England average of 23% dying at home and 47% dying in hospital during 2014.⁴

In terms of preferences of care and advance care planning levels of data completeness vary considerably. A preferred place of death was recorded for 99% of records, although 50% of these were classified as 'not recorded', something which might reflect

coding practices when patients are not able or do not have a preference for considerations like place of death.

Data items associated with advance care planning (for example the numbers of patients with anticipatory medicines, advance statements, those with a lasting power of attorney and those with an advance decision to refuse treatment) were less well coded, suggesting that, in many cases, patient's wishes and preferences were not always recorded.

Past studies have documented that there are considerable benefits to sharing data.⁵ Collation to an aggregated level can provide an epidemiological insight into the cohort of patients included on EPaCCS. This study has shown that the cohort on EPaCCS systems varies by locality. The aggregated perspective shows that just over half of people (56.5%) on EPaCCS are female, the percentage of females ranging between 50% and 60% locally.

More than one third of people on EPaCCS are aged 85 and over with a further 44% aged 65 to 74 years and cancer is the most common diagnosis with patients on EPaCCS often associated with multiple diagnoses.

Data collation can also help facilitate the development of consistent and comparable data provide information on how the use of EPaCCS can support the co-ordination and quality of care at the end of life, provide a framework of support for those collecting data or looking to begin the task of creating EPaCCS. Support might include common ground for best practice, improving data quality and data reporting, support service development, support the provision of information on patient outcomes and how EPaCCS cohorts vary across England.

As well as obtaining information about the composition of the EPaCCS cohort, the aggregation of data has provided an insight into EPaCCS as a tool for achieving people's preferences for care, advance care planning and the co-ordination of care..

Conclusions

This report highlights that despite benefits there are many significant challenges to aggregating data from EPaCCS systems.

The aggregation of data has provided a wider perspective about the cohort of people on EPaCCS, the impacts of EPaCCS, the way information is managed and the relationship between patient preferences and pathways of care towards the end of life. The data suggests that there are differing levels of data completeness but, whilst it may not matter that the place of patient death (for example) is not always completed, gaps in the data items associated with advance care planning may suggest that systems are not being used to their full potential.

References

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2. NHS England. **Five Year Forward View.** October 2014
3. NHS National Information Board. **Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens. A Framework for Action.** November 2014
4. Public Health England. **End of Life Care Profiles.** August 2016
5. National End of Life Care Intelligence Network. **Electronic Palliative Care Co-ordination Systems in England. Survey of clinical commissioning groups.** April 2014

Appendix A: EPaCCS data items

Palliative Care Co-ordination: core content (SCCI1580)

Data Items

1. Consent status
2. Record creation date
3. Planned review date
4. Date and time of last amendment
5. Person family name
6. Person forename
7. Person preferred name
8. Person birth date
9. NHS number
10. NHS number status indicator code
11. Person gender
12. Person address
13. Person telephone numbers
14. Need for an Interpreter
15. Preferred spoken language
16. Main carer name
17. Main carer telephone numbers
18. Is main carer aware of person's prognosis?
19. Usual GP name
20. Practice details including phone and fax numbers
21. Key worker name if not usual GP
22. Key worker telephone number
23. Care workers involved in care: name
24. Care workers involved in care: professional group
25. Telephone numbers for care workers involved in care
26. Primary end of life care diagnosis
27. Other relevant end of life care diagnoses and clinical issues
28. Disability
29. Functional status
30. Allergies/adverse drug reactions
31. Anticipatory medicines/just in case box issued
32. Location of anticipatory medicines/just in case box
33. EoLC tool in use? (eg GSF, PPC, other)
34. Likely prognosis
35. Advance statement requests and preferences
36. Preferred place of death 1st choice

37. Preferred place of death organisation name (1st choice)
38. Preferred place of death address (1st choice)
39. Preferred place of death (1st choice) is usual place of residence
40. Preferred place of death 2nd choice
41. Preferred place of death organisation name (2nd choice)
42. Preferred place of death address (2nd choice)
43. Preferred place of death (2nd choice) is usual place of residence
44. Cardiopulmonary resuscitation decision
45. Date of cardiopulmonary resuscitation decision
46. Date for review of cardiopulmonary resuscitation decision
47. Location of cardiopulmonary resuscitation documentation
48. Awareness of cardiopulmonary resuscitation decision
49. Person has made an advance decision to refuse treatment
50. Location of advance decision to refuse treatment documentation
51. Name of Lasting Power of Attorney for personal welfare
52. Authority of LPA
53. Telephone number(s) concerning Lasting Power of Attorney
54. Name of additional person to be involved in decisions (1)
55. Telephone number of person (1) to be involved in decisions
56. Name of additional person to be involved in decisions (2)
57. Telephone number of person (2) to be involved in decisions
58. Other relevant issues or preferences about provision of care
59. Date of death
60. Actual place of death

Appendix B: EPaCCS audit template

Data period 1 April 2014 to 31 March 2015

| Item | Data Required |
|------|---|
| 1 | Total number of EPaCCS patients as at: 31/03/2014 |
| 2 | Number of EPaCCS patients ADDED during the year: 01/04/2014 -31/03/2015 |
| 3 | Number of male EPaCCS patients on system during the year: 01/04/2014 - 31/03/2015 |
| 4 | Number of female EPaCCS patients on system during the year: 01/04/2014 - 31/03/2015 |
| 5 | Number of EPaCCS patients aged <65 on system during the year: 01/04/2014 - 31/03/2015 |
| 6 | Number of EPaCCS patients aged 65-84 on system during the year: 01/04/2014 - 31/03/2015 |
| 7 | Number of EPaCCS patients aged 85 and over on system during the year: 01/04/2014 -31/03/2015 |
| 8 | Number of cancer patients with EPaCCS file during the year: 01/04/2014 - 31/03/2015 |
| 9 | Number of COPD patients with EPaCCS file during the year: 01/04/2014 - 31/03/2015 |
| 10 | Number of heart disease patients with EPaCCS file during the year: 01/04/2014 - 31/03/2015 |
| 11 | Number of stroke patients with EPaCCS file during the year: 01/04/2014 - 31/03/2015 |
| 12 | Number of dementia or Alzheimer's patients with EPaCCS file during the year: 01/04/2014 -31/03/2015 |
| | EPaCCS records and completion of records |
| 13 | Number of deaths for EPaCCS patients during the year: 01/04/2014 -31/03/2015 |
| 14 | The average length of time that patients have an EPaCCS record |
| 15 | Number of EPaCCS patients with prognosis completed in days |
| 16 | Number of EPaCCS patients with prognosis completed in weeks |
| 17 | Number of EPaCCS patients with prognosis completed in months |
| 18 | Do you differentiate between different consent status for EPaCCS patients? (answer Yes or No) |
| 19 | Number of EPaCCS patients with 'main carer' recorded as 'has a carer' |
| 20 | Number of EPaCCS patients with 'care worker involved in care' |

| Item | Data Required |
|-------------|---|
| 21 | Number of EPaCCS patients with 'main carer', who also have a 'care worker' |
| | Place of death (PoD) |
| 22 | Number of EPaCCS patients that record PoD as HOME |
| 23 | Number of EPaCCS patients that record PoD as CARE HOME |
| 24 | Number of EPaCCS patients that record PoD as HOSPICE |
| 25 | Number of EPaCCS patients that record PoD as HOSPITAL |
| 26 | Number of EPaCCS patients that record PoD as OTHER |
| 27 | Number of EPaCCS patients that record PoD as NOT RECORDED |
| | Preferred place of death (PPD) |
| 28 | Number of EPaCCS patients that specify PPD as HOME |
| 29 | Number of EPaCCS patients that specify PPD as CARE HOME |
| 30 | Number of EPaCCS patients that specify PPD as HOSPICE |
| 31 | Number of EPaCCS patients that specify PPD as HOSPITAL |
| 32 | Number of EPaCCS patients that specify PPD as OTHER |
| 33 | Number of EPaCCS patients that specify PPD as NOT RECORDED |
| | Achieving preferred place of death (PPD) |
| 34 | Number of EPaCCS patients that specify PPD as HOME who died at HOME |
| 35 | Number of EPaCCS patients that specify PPD as CARE HOME who died at CARE HOME |
| 36 | Number of EPaCCS patients that specify PPD as HOSPICE who died at HOSPICE |
| 37 | Number of EPaCCS patients that specify PPD as HOSPITAL who died at HOSPITAL |
| 38 | Number of EPaCCS patients that specify PPD as OTHER who died at OTHER |
| 39 | Number of EPaCCS patients that specify a PPD who died with PoD NOT RECORDED |
| | Place of death (PoD) - Hospital |
| 40 | Number of EPaCCS patients that specify PPD as HOME who died at HOSPITAL |
| 41 | Number of EPaCCS patients that specify PPD as CARE HOME who died at HOSPITAL |

| Item | Data Required |
|-------------|---|
| 42 | Number of EPaCCS patients that specify PPD as HOSPICE who died at HOSPITAL |
| 43 | Number of EPaCCS patients that specify PPD as OTHER who died at HOSPITAL |
| | Cardiopulmonary resuscitation |
| 44 | Number of EPaCCS patients that include DNACPR decision as 'not for attempted cardiopulmonary resuscitation' |
| | Advance care planning |
| 45 | Number of EPaCCS patients that record LPA appointed |
| 46 | Number of EPaCCS patients that record ADRT (advance decision to refuse treatment) |
| 47 | Number of EPaCCS patients that record advance statements |
| 48 | Number of EPaCCS patients that record anticipatory medications |