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Evaluation of the routine data captured through the Leeds Electronic Palliative Care Co-ordination System (EPaCCS) in 2018

St. Gemma's
ACADEMIC UNIT
OF PALLIATIVE CARE

Leeds Palliative
Care Network

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Executive summary

Analysis of EPaCCS data in Leeds from 2018 – 2019 suggests there have been changes since 2016. More people have an EPaCCS record in place at death and half of all records are being initiated more than 85 days before death.

Key findings

- In Leeds, there has been an increase in the proportion of people with an EPaCCS record in place at death, from 26.9% in 2015 - 2016 to over 50% in 2018-2019
- EPaCCS records are being opened a median of 85 days before death, up from 31 days in 2016.
- There are no clear disparities by age, sex and condition for those who have an EPaCCS record opened 3 or more months before death.
- Ethnicity data is generally well recorded across Leeds (i.e. 93% of all records). For those with ethnicity recorded, there appears to be a slight overrepresentation of patients coded as White when compared to the population demographics for the city. All other ethnicity groupings are underrepresented.
- 82% of people have a preferred place of death recorded at death which is recorded a median of 11 days before death, which has increased from a median of 8 days before death in 2016.
- The health professional group recorded as opening the largest proportion of EPaCCS records is 'Clinical Practitioner Role', accounting for 42% of all records, with nurse and community roles accounting for 33% of all records.

Recommendations

- Items relating to DNACPR status and anticipatory medication should be included in future EPaCCS extracts for analysis. This have been removed since 2016.
- Approaches should be explored to improve the classification of health professional role in EPaCCS data to better understand who is initiating and interacting with EPaCCS records.
- More development of data around condition, particularly cancer, is required to be able to determine which deaths are index cancer deaths (death due to the first primary cancer diagnosed), nonindex cancer deaths (death due to a diagnosed cancer other than the first primary cancer) and noncancer deaths (death attributed to causes other than cancer).
- The inclusion of postcode data or derived deprivation scores would be an important next step in enhancing analysis of EPaCCS.
- The levels of analysis that could be afforded by linked datasets such as the Leeds Data Model should be explored further for analysis of EPaCCS data, including determining differences in those with and without an EPaCCS record at death.

Introduction

This project sought to improve our understanding of who, when and how EPaCCS are being used to support patients with progressive illnesses in Leeds and Bradford. A previous report undertaken in partnership with Leeds clinical commissioning groups determined that around ¼ of all eligible patients are registered on EPaCCS prior to death. Subsequent local initiatives to improve engagement have been undertaken but not formally evaluated. The project was proposed to undertake the following activities to inform a targeted quality improvement process by:

1. Determining current uptake of EPaCCS across Leeds and Bradford through undertaking analysis of routinely collected clinical data.

2. Identifying which health professionals are initiating EPaCCS records in Leeds and Bradford and those updating items on an EPaCCS record (e.g. preferred place of death).

Objective 1 was completed through a secondary analysis of data captured via the EPaCCS template form in Leeds and Bradford, guided by a rigorous evaluation framework developed in partnership with palliative care leads in Leeds during 2015 (e.g. sequential analysis to determine when a record is initiated and items subsequently added prior to death) (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5405823/). Objective 2 was completed through a sub-analysis of the data to determine the job role of those initiating and updating EPaCCS records.

The original proposal included the use of findings to direct a survey to health professionals in Leeds to better understand what currently works or impedes EPaCCS use for patients with progressive illness. However, due to a range of factors, detailed in the report, the survey was not completed.

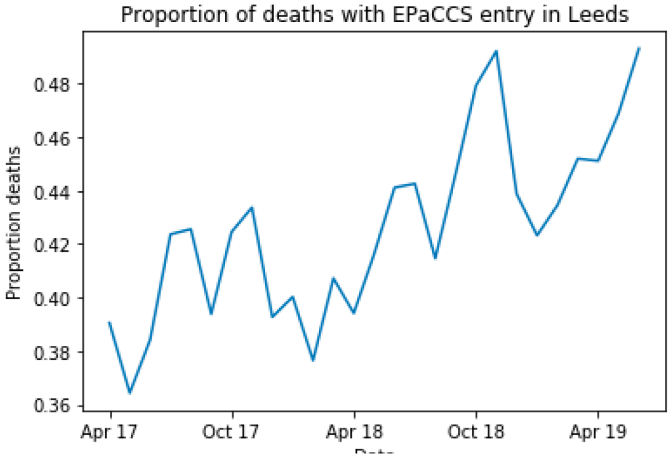
Data presented in this report was acquired through requests to data quality managers in Leeds and Bradford. EPaCCS data were deidentified prior to sharing with the research for analysis. Initially date of death was not available for Leeds EPaCCS data. This hindered the analysis as date of death is a key data point from which interval data is calculated (e.g. number of days between an EPaCCS record being opened and death). Following processing by the Data Services for Commissioners Regional Office in the North East, date of death data was subsequently available. A preliminary report was submitted to the Leeds Palliative Care Network in December 2019 with plans to undertake additional analyses prior to a final report being submitted. The COVID-19 pandemic led to off-campus working by the research team, meaning access to secure folders, only available on campus, was not possible. A workaround solution was implemented in July 2020 enabling the final analyses to be completed and report submitted.

Data presented in the report was drawn from Leeds City Council, combining data from Sue Ryder, St Gemma's Hospice and Leeds Community Healthcare NHS Trust. The data does not include Secondary Uses Service (SUS) data so may not provide a complete picture of EPaCCS use across Leeds.

The report is divided into 13 sections, outlining specific analyses conducted using the EPaCCS data obtained. This includes an overview of current EPaCCS use in Leeds (sections 1 – 10), a comparison of 2015 data in Leeds and recent data from 2018 (section 11), and a comparison between data from Leeds and Bradford (section 12). Recommendations arising from the process of data acquisition and analysis are outlined in the final section of the report.

1. Proportion of all deaths with an EPaCCS in Leeds

We compared the number of EPaCCS records opened each month against the number of all deaths. An overall month-by-month increase in EPaCCS capture of 0.32% per month was identified, equating to 3.84% each year (between 2017 – 2019).

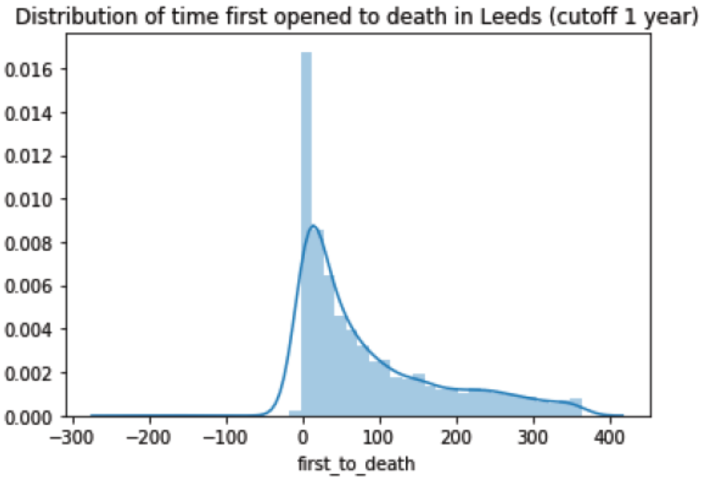


The current denominator being used takes account of all deaths, meaning this includes additional patients that are not eligible for an EPaCCS. The proportion of EPaCCS records for patients eligible for an EPaCCS is likely to be higher than the data presented. This suggests an increase in the number of eligible patients receiving an EPaCCS. Data from 2014 and 2015 analysed by the Academic Unit of Palliative Care identified 26.8% of all deaths had an EPaCCS in place. This has now increased to at least 50% of patients.

2. Time between EPaCCS opening and death

We examined the duration of time between an EPaCCS being opened and death. Of all EPaCCS records, 61.7% were opened within 6 months of death. Around one third were opened within a month before death, and 13.4% in the last week of life.

Median = 85 days before death
In 2016, the median was 31 days



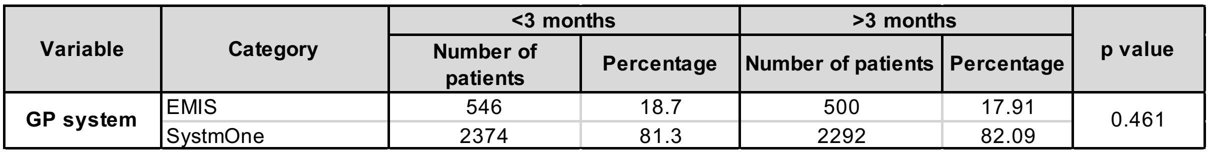
Timing of EPaCCS opening before death	Number of patients	Proportion of patients
After death	7	0.005%
Within one week of death	785	13.4%
Within one month of death	1735	29.6%
Within 6 months of death	3616	61.7%
Within 12 months of death	4426	75.6%

There are 7 patients without a valid EPaCCS opening date in Leeds. These records were opened after death and have most fields missing.

3. Who receives an EPaCCS more than 3 months before death?

		<3 months	>3 months	
Variable	**Category**	**Number of patients**	**Number of patients**	**p value**
All patients		2920 (51.1%)	2792 (48.9%)	
Age		79.66 (SD=13.23)	78.52 (SD=14.19)	0.002
Sex	Female	1583 (54.2%)	1557 (55.8%)	0.249
	Male	1337 (45.8%)	1235 (44.2%)	

We sought to determine whether there are differences in patients who receive an EPaCCS record more or fewer than 3 months prior to death. Those receiving an EPaCCS record fewer than 3 months before death accounted for 51.1% of patients with an EPaCCS, with the remainder (i.e. 48.9%) receiving an EPaCCS record more than 3 months before death. We conducted statistical analyses to determine whether there were any systematic differences between the two groups. t-tests were used for age, with Chi-squared used for sex and condition. Differences in percentages across the two groups is small and significant differences are likely due to the large population sizes in the groups, which suggests there are no concerning or clear differences between these two groups.



Variable	Category	<3 months		>3 months		p value
		Number of patients	Percentage	Number of patients	Percentage	
GP system	EMIS	546	18.7	500	17.91	0.461
	SystmOne	2374	81.3	2292	82.09	

We explored whether the system people were using influenced timing of EPaCCS initiation. We identified the number of EPaCCS records that exist across SystmOne and EMIS practices to determine the spread. In total, 88.6% of records are being recorded in SystmOne and 11.4% in EMIS. We examined whether the differences between the operating systems in use in Leeds and differences in initiation of an EPaCCS record before death. Similar to the wider split between those receiving an EPaCCS before or within 3 months, there are no significant differences, suggesting the operating systems are not influencing the timing of an EPaCCS record being opened.

Variable	Category	<3 months		>3 months		p value
		Number of patients	Percentage	Number of patients	Percentage	
Cancer	Yes	1737	59.49	1740	62.32	0.03
	No	1183	40.51	1052	37.68	
Dementia	Yes	652	22.33	717	25.68	0.003
	No	2268	77.67	2075	74.32	
Parksinsons	yes	79	2.71	79	2.83	0.838
	no	2841	97.29	2713	97.17	
LTC	AF	217	7.43	174	6.23	0.005
	Asthma	63	2.16	80	2.87	
	CHD	158	5.41	160	5.73	
	CKD	213	7.29	190	6.81	
	COPD	248	8.49	308	11.03	
	Diabetes	222	7.6	225	8.06	
	Heart Failure	243	8.32	207	7.41	
	Hypertension	382	13.08	382	13.68	
	Missing	694	23.77	678	24.28	
	Other	281	9.62	217	7.77	
	Stroke	199	6.82	171	6.12	
LTC count	0	586	20.07	567	20.31	0
	1	2261	77.43	2098	75.14	
	2	73	2.5	125	4.48	
	3	0	0	2	0.07	

We sought to determine differences in those receiving an EPaCCS before or within 3 months of death by variables relating to a patient's condition. There are statistically significant differences but percentages across the different conditions are similar so it doesn't appear there is any bias towards particular groups in the timing of initiation of an EPaCCS record. Around a quarter of all patients with an EPaCCS had a dementia diagnosis, with three quarters having a least one long-term condition. However, the data on long-term conditions was not straightforward to assess in the raw data. The number of long-term conditions recorded alongside a patient's EPaCCS was limited to one column and the number of different conditions mentioned tallied for each patient. This is unlikely to provide a comprehensive summary of long-term conditions that may have been recorded for patients with an EPaCCS.

4. Recoding preferred place of death (PPD)

82.1% of patients had a PPD recorded

Median = 11 days before death
In 2016, the median was 8 days

Time point updated before death	PPD first recorded in EPaCCS record (% of EPaCCS records)	Last record made in EPaCCS (% of EPaCCS records)
After death	0.6%	0.1%
Week of death	30.3%	17.6%
Last month prior death	47.3%	36.9%
within 6 months prior to death	63.8%	67.9%
Within 12 months	68.0%	79.3%

When examining the timing of PPD being recorded before death, we examined both the first and last PPD record. Around two thirds of all records had a PPD recorded within 6 months of death. Moving closer to the point of death there is less updating of PPD, with the last record being reported within a month of death for 36.9% of people, and for 17.6% in the last week of life.

5. Recording of actual place of death

85.6% of patients had an APD recorded

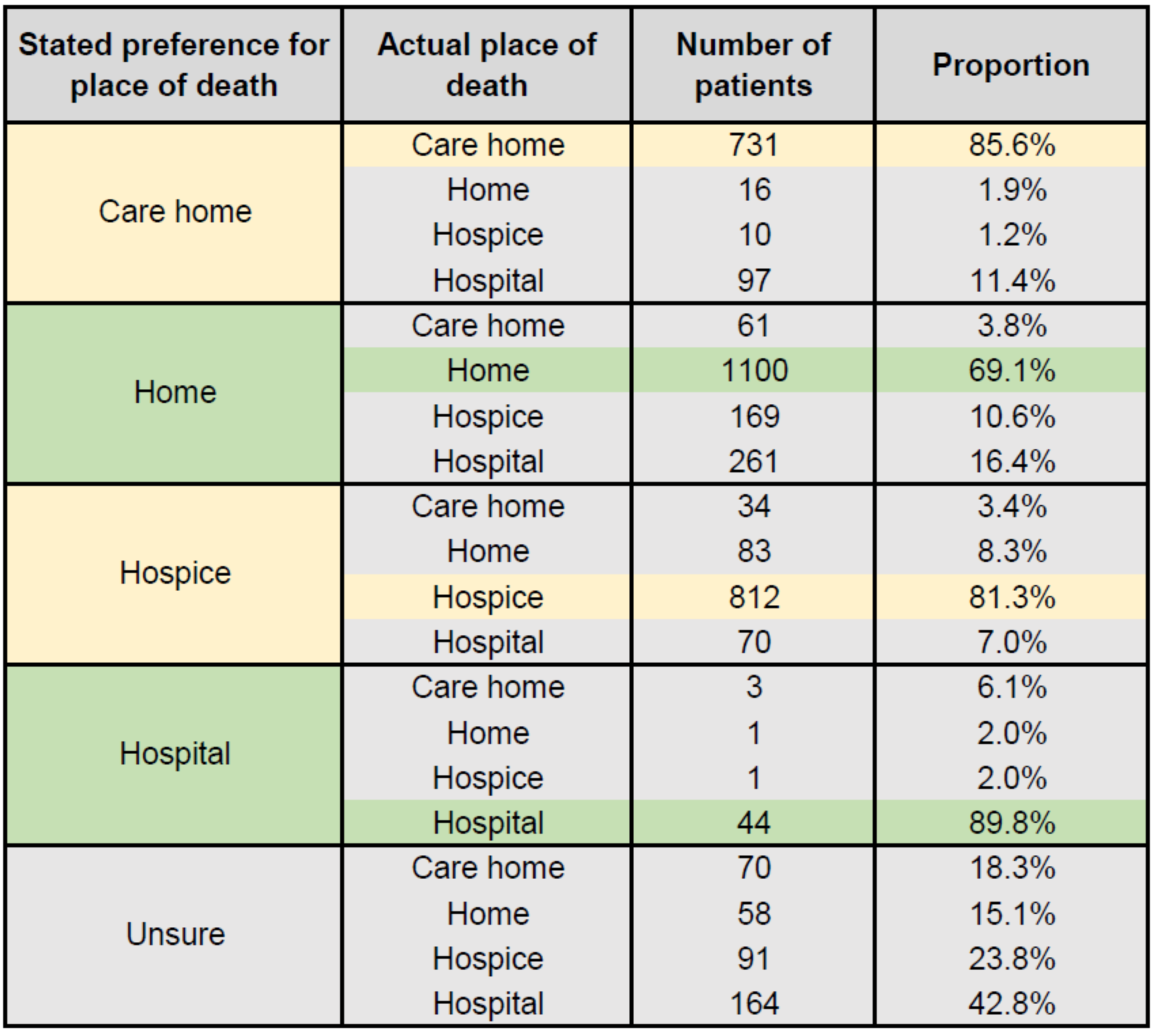
Time point updated after death	APD recorded (% of EPaCCS records)
Before death	0.3%
Week of death	68.4%
Within one month after death	77.4%
Within 6 months after death	80.0%
Within 12 months after death	80.0%

Recording of actual place of death occurred for over two thirds of patients with an EPaCCS within a week of death.

Of those with both a PPD and APD recorded, 69.3% of patients achieved death in their preferred place.

6. Who achieves their PPD?

Of the 69.3% who achieved their stated preferred place of death, there was variation across stated preferences for place of death. Those wishing to have a home death had the lowest level of achieving this preference (69.1%) when compared to those achieving their preferred place of death for hospice (81.3%), care homes (85.6%) and hospital (89.8%).



Stated preference for place of death	Actual place of death	Number of patients	Proportion
Care home	Care home	731	85.6%
	Home	16	1.9%
	Hospice	10	1.2%
	Hospital	97	11.4%
Home	Care home	61	3.8%
	Home	1100	69.1%
	Hospice	169	10.6%
	Hospital	261	16.4%
Hospice	Care home	34	3.4%
	Home	83	8.3%
	Hospice	812	81.3%
	Hospital	70	7.0%
Hospital	Care home	3	6.1%
	Home	1	2.0%
	Hospice	1	2.0%
	Hospital	44	89.8%
Unsure	Care home	70	18.3%
	Home	58	15.1%
	Hospice	91	23.8%
	Hospital	164	42.8%

7. Ethnicity

Ethnicity	Number of patients	Proportion of EPaCCS records	2011 census proportion
White	5131	87.55%	85.0%
Mixed/Multiple ethnic groups	15	0.25%	2.7%
Asian/Asian British	131	2.23%	7.7%
Black/African/Caribbean/Black British	70	1.20%	3.5%
Other ethnic group/not defined	255	4.34%	1.1%
Missing data	259	4.42%	-

Compared with Leeds ethnicity demographic data, a slight overrepresentation of patients coded as White was found for people with an EPaCCS record in place. All other groups are underrepresented against the city demographic data. However, 4.42% of data is missing, which may have affected the distribution of ethnicity codes further if they were available.

8. Who is interacting with EPaCCS records?

Part of the analysis is seeking to determine which health professionals are interacting with EPaCCS records, both to initiate records and update preferred place of death information. This information was initially sought to inform how best to target any training initiatives. There is a spread across multiple staff roles, but 85.2% of records were opened by three groups:

Role	Number of patients	Proportion of all EPaCCS records
Clinical Practitioner Access Role	1524	41.7%
General Medical Practitioner	381	10.4%
Nurse Access Role	1208	33.1%

The ‘Clinical Practitioner Access Role’ causes issues in terms of determining who initiates an EPaCCS record as it may comprise general practitioners, hospice doctors, consultants, and specialist nurses alongside a number of Leeds Community Healthcare Trust senior clinicians, such as community matrons and any non-medical prescribers. This may suggest there is crossover in those in the Clinical Practice Access Role and senior staff in nursing and community roles.

We requested details of the site to which health professional is assigned to infer their role (e.g. for example, Clinical Practitioner Access Role at a hospice is likely to be a hospice doctor compared to a GP if assigned to a practice) but this information was not available.

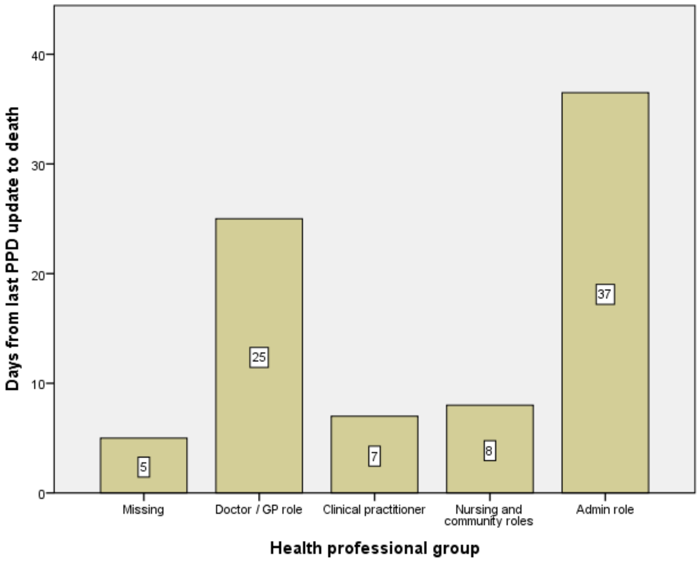
We further explored differences in the median time between an EPaCCS record being opened and death across the health professional groups. As shown below, admin roles were included in this as they accounted for 11.3% of all records being initiated. The admin group also accounted for the longest median time, with nursing and community teams accounting for the shortest (i.e. a median of 58 days).

Health professional group	EPaCCS initiation	Percentage of EPaCCS records opened	Timing of EPaCCS to death (days)
Missing	335	5.6	75
Doctor / GP	1030	17.1	82
Clinical practitioner	2336	38.8	77
Nursing and community	1639	27.2	58
Admin	681	11.3	229
Total	**6021**		

In terms of those interacting with EPaCCS records, we identified which health professional provided the last preferred place of death entry on a patients EPaCCS before death. When identifying who is updating information on a patient’s preferred place of death (table below), entry by nurses increases to 35% and the involvement of the General Medical Practitioners role reduces slightly to 8.9%.

Role	Number of patients	Proportion of all EPaCCS records
Clinical Practitioner Access Role	1711	41.7%
General Medical Practitioner	363	8.9%
Nurse Access Role	1456	35.5%

We explored variation in the numbers of days prior to death that the last preferred place of death was recorded across the health professional groups. The closest to death were entered by clinical practitioner roles (a median of 7 days before death) with the last entry for admin roles occurring the longest time before death (a median of 37 days).



Below is a list of the health professional labels as they were categorised under the four health professional groups, alongside the number of times the role was recorded against the initiation of an EPaCCS record.

	Frequency	Percentage of all patients	Total
Clinical Practitioner Access Role			
Clinical Practitioner Access Role	2336	38.8	**2336**
Doctor / GP			
General Medical Practitioner	816	13.6	**1030**
Health Professional Access Role	60	1	
Salaried General Practitioner	45	0.7	
GP Registrar	29	0.5	
Doctor	24	0.4	
GP Surgery	26	0.4	
Consultant	16	0.3	
Sessional GP	9	0.1	
Locum GP	2	0	
Trust Grade Doctor - Career Grade level	2	0	
GP Partner	1	0	
Nursing and community			
Nurse Access Role	1174	19.5	**1639**
Health Care Support Worker	73	1.2	
Manager	67	1.1	
Community Practitioner	64	1.1	
Macmillan Palliative Care Specialist Nurse	54	0.9	
Nurse Manager	50	0.8	
Specialist Nurse Practitioner	39	0.6	
Community Nurse	37	0.6	
Modern Matron	28	0.5	
Community Team Manager	16	0.3	
Enrolled Nurse	15	0.2	
Staff Nurse	6	0.1	
Nurse Practitioner	4	0.1	
'Other' Community Health Service	3	0	
Macmillan Nurse	3	0	
CMO/School nurse	1	0	
Healthcare Assistant	1	0	
Nurse Manager Access Role	1	0	
Pharmacist	1	0	
Senior Manager	1	0	
Trainee Practitioner	1	0	
Admin			
Admin/Clinical Support Access Role	333	5.5	**681**
Clerical Access Role	252	4.2	
Clerical Worker	52	0.9	
Receptionist	23	0.4	
Receptionist Access Role	5	0.1	
Clinical Coder	3	0	
Desktop Support Administrator	3	0	
Senior Administrator	3	0	
SystmOne Administrator	2	0	
Information Officer Access Role	1	0	
Medical Secretary Access Role	1	0	
Network Administrator	1	0	
Secretary	1	0	
System Administrator	1	0	
Missing			
Missing	335	5.6	**335**
Total	**6021**	**100**	

9. A&E utilisation data

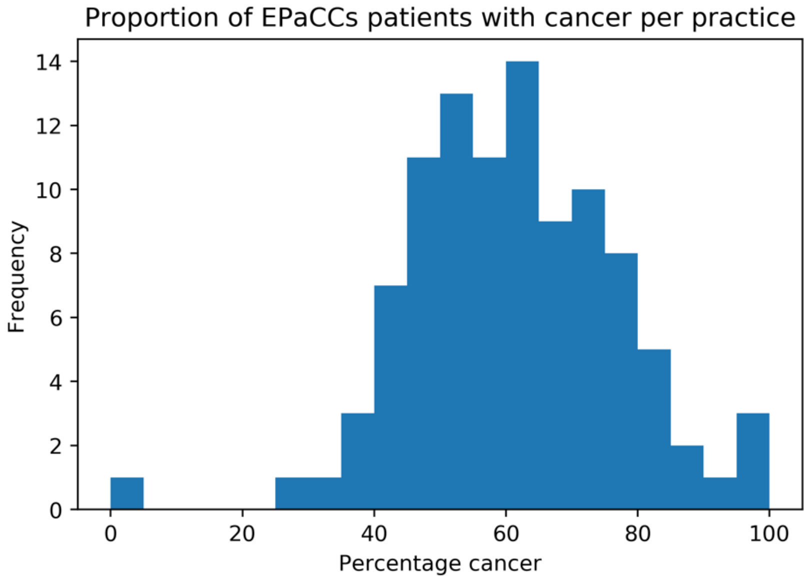
	Number of patients	**Proportion**	**Median (days)**
All deaths	4245	65.79%	174
Within 3 months of death	1706	40.19%	24
3 months or more before death	2539	59.81%	618

A&E code	**Number of patients**	**Proportion**	**Median (days)**
Referral to A&E	34	1.99%	23.5
Seen by A&E	1339	78.49%	24
Seen by eye accident A&E	5	0.29%	38
Seen in hospital casuality	185	10.84%	26
Self-referral to A&E	143	8.38%	28
Total	**1706**		

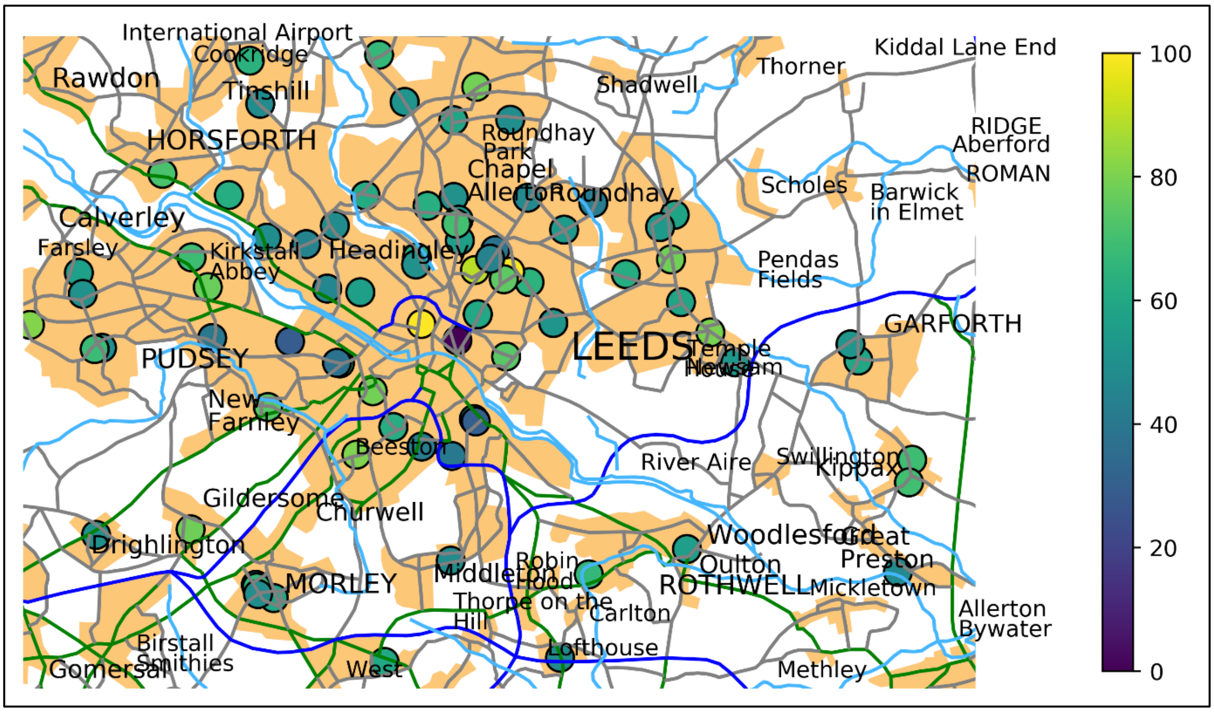
We explored the A&E data contained in EPaCCS data extracts but have doubts about the accuracy or completeness of the data. This includes A&E data drawn only from primary care records. From data available, 65.8% of all patients with an EPaCCS had an A&E code. A third of all patients (n=1,706, ≈30%) with an EPaCCS record had their first A&E record within 3 months of death. A range of codes were recorded, but the most common was ‘Seen by A&E’ which occurred a median of 24 days before death and accounted for 78.5% of patients in this group.

10. Practice-level variation

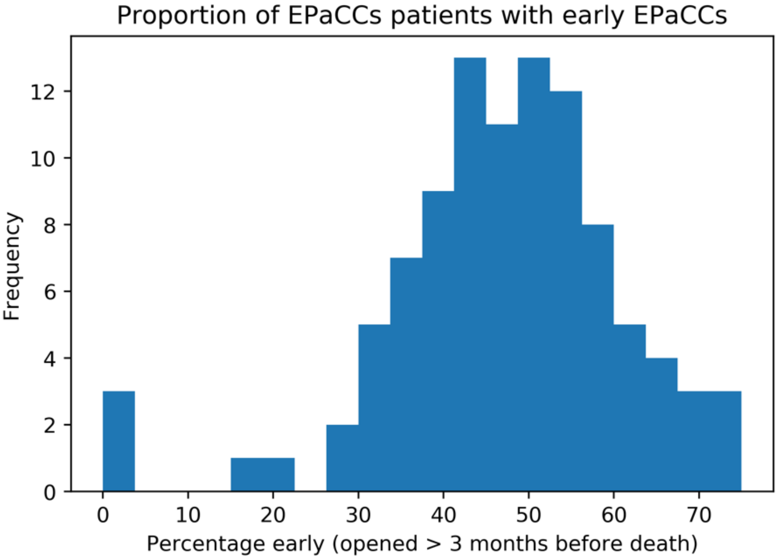
We sought to explore practice-level variation for patients with an EPaCCS. We looked at the proportion of patients with an EPaCCS record who had a cancer diagnosis recorded (although this may not have been the cause of death). As shown in the graph below, there was widespread variation, with one practice having no patients with a cancer recorded in the medical record. Two practices also had around 25 – 40% of patients with an EPaCCS record with a cancer diagnosis. Most practices had around 40 – 70% of patients with an EPaCCS record and cancer diagnosis.



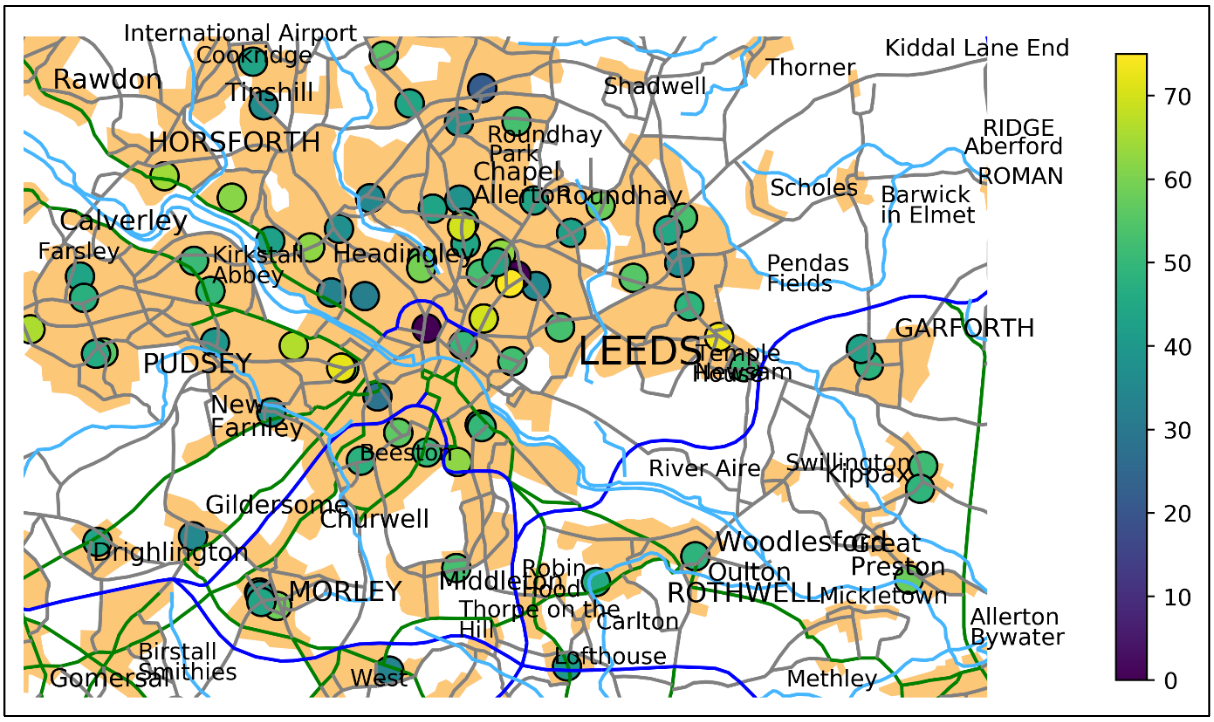
We also explored geographical plotting of data by practice, looking at the proportion of patients with an EPaCCS record and a cancer across practices. Close to the centre of Leeds is where the extremes are present, with one practice with no patients with an EPaCCS record and a cancer diagnosis, alongside 2 – 3 practices where over 80% of patients with an EPaCCS record have a cancer diagnosis recorded. Broadly there are many practices with a likely disproportionate number of patients with a cancer diagnosis on EPaCCS. Across Leeds, patients on EPaCCS are made up of 40% or more of patients, whilst only 27.4% of all deaths in Leeds are attributable to cancer (Public Health England Palliative and End of Life Care Profiles, 2019). However, it is not clear whether cancer was the underlying cause of death, or whether a comorbidity for patients with an EPaCCS record.



We also explored practice variation with regards to the proportion of patients with an EPaCCS record initiated more than three months before death. The graph below indicates that three practices did not open an EPaCCS record for any patients prior to three months before death. Most practices had around 35 – 60% of patients with an EPaCCS opened more than 3 months before death.



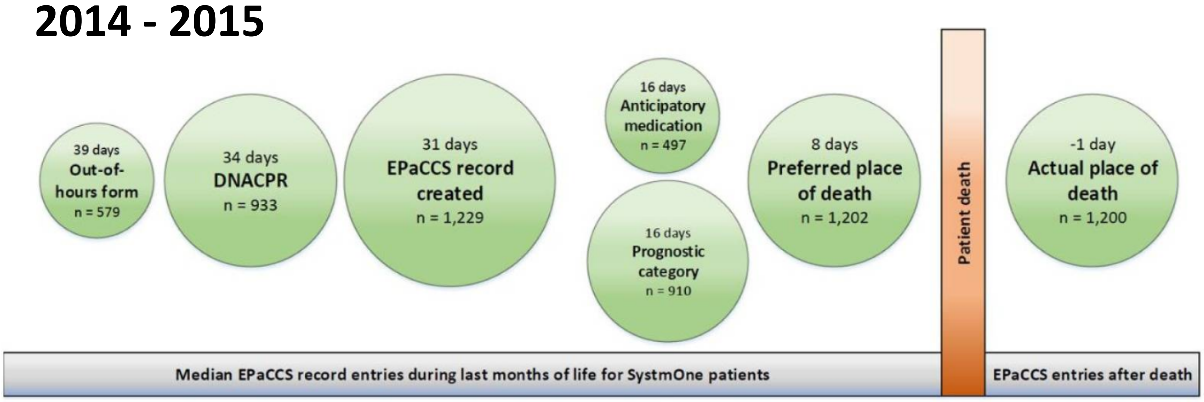
Through geographical mapping of variation, as outlined in the figure below, there is citywide variation in when practices are initiated EPaCCS prior to death. Although the around 50% of EPaCCS records are opened more than three months before death, this is not uniformly applied across all practices. Future further analyses of EPaCCS data may stratify practices as high and low performers in terms of the timing of initiating an EPaCCS record. Such an approach may be a useful metric for evaluating practice-level initiation of EPaCCS records.



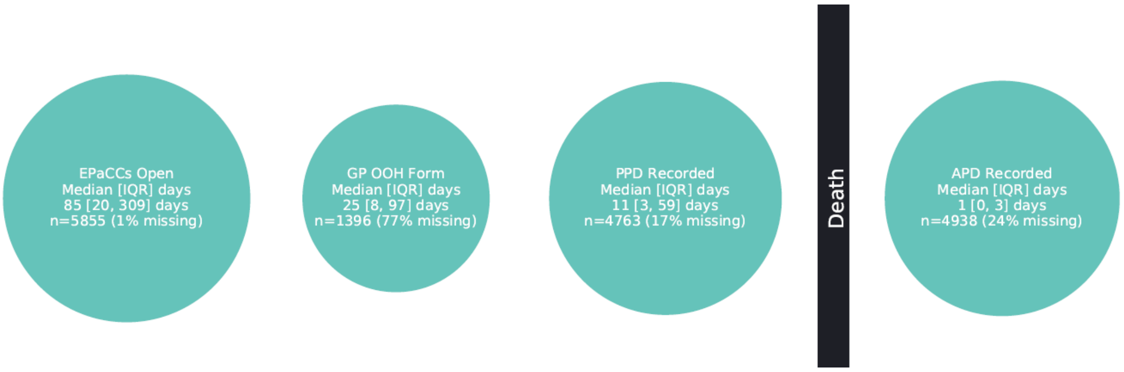
11. Comparative analysis: Leeds

We compared data from 2014 – 2015 with more recent data from 2017 – 2019. Data on when an EPaCCS is opened, when out-of-hours forms are completed, preferred place of death recording and actual place of death recording were available across both datasets.

2014 - 2015



2017 - 2019



The most recent data from 2017 – 2019 suggests that:

- EPaCCS records are being initiated much earlier for patients (from 31 days to 85 days before death) and records are being created for more people (from 26.8% of all deaths in 2015 to at least 50% of deaths in 2020)
- That out-of-hours forms are being completed closer to death (from 39 days to 25 days). However, the use of out-of-hours forms in Leeds has been discontinued and this information is no longer included on EPaCCS records.
- That the last preferred place of death is being recorded further away from death, increasing from 8 days to 11 days
- Actual place of death remains the same, with this occurring a median of one day after death

12. Comparative analysis: Leeds and Bradford regions

Comparative data covering Bradford has been provided through the Data Quality Manager at Bradford District and Craven CCG. We received data on 5,854 unique patients covering those who died with an EPaCCS between April 2017 and April 2019.

Over the 2-year reporting period, there were an estimated 11,794 deaths, suggesting around 49.64% of people have an EPaCCS record at death in Bradford. The average age of people who died with an EPaCCS was 80.05 (SD=12.78).

The table below outlines the key characteristics of those with an EPaCCS record at death.

Variable		Number of patients (%)
Total number of patients		5,854 (100)
Gender	Female	2,616 (44.7)
	Male	3,238 (55.3)
Cancer	Yes	3,171 (54.2)
	No	2,683 (45.8)
EPaCCS opened <90 days before death	Yes (<90 days)	4,475 (76.4)
	No (>90 days)	1,058 (18.1)
	Missing data	321 (5.5)
Most commonly recorded health professional groups opening an EPaCCS record	Clerical access role	320 (5.5)
	Clinical Practitioner Access Role	2,434 (41.6)
	General medical practitioner	351 (6.0)
	Health professional access role	321 (5.5)
	Nurse access role	1,076 (18.4)
	Specialist nurse practitioner	209 (3.6)
	SystmOne Administrator	243 (4.1)

The number of people who receive an EPaCCS before death in Bradford (49.6%) is marginally lower than those in Leeds (~50%). In Bradford, there is a predominance of males with an EPaCCS record before death, rather than females as reported in Leeds. Figures for a cancer diagnosis recorded on a medical record is similar across Leeds (60.9%) and Bradford (54.2%).

There are differences in the proportion of people having an EPaCCS opened within 90 days of death. For Leeds, this occurs for 48.9% of people, and for 18% with an EPaCCS in Bradford.

As is the case in Leeds, the most commonly recorded health professional group to open an EPaCCS record in Bradford is ‘Clinical Practitioner Access Role’ (41.6%), similar to the proportion reported in Leeds (38.8%). Similar to Leeds, nursing roles are the second most common health professional group reported to open EPaCCS records in Bradford. The proportion of 'General Medical Practitioners' opening EPaCCS records (6.0%) is lower than Leeds (10.4%). However, as with the Leeds data, general practitioners may be captured under the 'Clinical Practitioner Access Role', leading to difficulties in reliably interpreting these data.

Median time variable	Bradford data	Leeds data
Median time from EPaCCS opening to death	11 days	85 days
Median time between PPD first recorded and death (data for n = 3,588;61.29%)	16 days	11 days
Median time between APD recorded and death (data for n=3,684;62.93%)	-1 day	-1 day

There is variation in the timing of initiation of an EPaCCS record before death when comparing across Leeds and Bradford. An EPaCCS record is initiated a median of 85 days before death in Leeds when compared to 11 days in Bradford.

For the data where PPD was recorded in Bradford (61.3% of EPaCCS records) this was recorded a median of 16 days before death, when compared to 11 days (as recorded for 82.1% of EPaCCS records) in Leeds.

There was no difference in the median number of days between death and recording actual place of death on an EPaCCS record, with a median of -1 day in both Leeds and Bradford.

While we present data for Bradford, it must be noted that the completeness of the data cannot be guaranteed. The data were drawn from SystmOne records and may only contain primary care data rather than the network of hospices and wider services that also access and edit EPaCCS records.

13. Health professional survey

The initial plan for the EPaCCS project was to determine when and by whom EPaCCS is used, to inform the conduct of a survey of health professionals to determine facilitators to EPaCCS use in Leeds and Bradford.

Multiple factors have led to the survey not being completed:

- Delays in data being obtained and analysed following the need for linkage of data through the Data Services for Commissioners Regional Office in the North East to access date of death data
- Limitation in the information stored on health professional role alongside EPaCCS data, in particular the need to better define the ‘Clinical Practitioner Access’ role. This is necessary to ensure clarity of which health professionals are initiating and interacting with EPaCCS records
- Following success in obtaining National Institute for Health Research funding, there are plans to undertake an extensive online survey and follow-up interviews on EPaCCS use by health professionals in West Yorkshire and London. Findings from the survey, including those relating specifically to Leeds, can be shared with the Leeds Palliative Care Network by the research team.

Recommendations

During delivery of the project, observations were made on the process of acquiring and content of EPaCCS data. The following are highlighted as areas that may be considered to improve subsequent audit or evaluation of EPaCCS in Leeds:

- A number of EPaCCS items are no longer included in the data reporting that had been available previously. These include DNACPR status and anticipatory medication. The DNACPR data would be useful to include the next revision of data sharing agreements with practices.
- To determine the role of health professionals in the use of EPaCCS across Leeds, development of the staff role included alongside EPaCCS data will need to be refined. This may be partly resolved through including details of the site to which a health professional is assigned in the data (e.g. hospice, general practice). Without further development there will remain uncertainty around the health professional role of a large proportion of those entering and interacting with EPaCCS records.
- The current way in which cancer conditions are captured as part of an EPaCCS record makes it difficult to determine whether this was also the cause of death. More development of data around condition, particularly cancer, is required to be able to determine which deaths are index cancer deaths (death due to the first primary cancer diagnosed), nonindex cancer deaths (death due to a diagnosed cancer other than the first primary cancer) and noncancer death (death attributed to causes other than cancer).
- The inclusion of postcode data or derived deprivation scores would be an important next step in enhancing analysis of EPaCCS. The importance of better understanding the impact of deprivation on access to palliative care in increasing, and understanding how this may influence initiation of an EPaCCS would be useful to determine.
- The levels of analysis that could be afforded by the Leeds Data Model should be explored further for analysis of EPaCCS data. We acknowledge that the data presented in the report was drawn from Leeds City Council, combining data from Sue Ryder, St Gemma's Hospice and Leeds Community Healthcare NHS Trust. The data does not include Secondary Uses Service (SUS) data so may not provide a complete picture of EPaCCS use across Leeds. Despite this, analysis of the dataset provides an insigh into current interaction and utilisation of EPaCCS in Leeds. A crucial next step will be to utilise a linked dataset, such as the Leeds Data Model, to determine differences to those with and without an EPaCCS record. The Academic Unit would be keen to lead and undertake such an analysis with support from the Leeds Palliative Care Network.
- The project has fed into local discussions about access to palliative and end of life care data in Leeds. Access to and inclusion and date of death data in the EPaCCS dataset is crucial for the types of analysis undertaken and should remain a key data item in future EPaCCS datasets.
- This project has provided an important springboard for further funding at the Academic Unit to explore the status of implementation of EPaCCS nationally. This continues to support Leeds as a recognised lead in the development of EPaCCS in England. Through working with Public Health England and NHS England on the new EPaCCS project, this will further strengthen links between Leeds and national end of life care teams.