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England

**NHS**

*Improving Quality*

# **Electronic Palliative Care Co-ordination Systems (EPaCCS) in England**

Survey of clinical commissioning groups (2013) by the National End of Life  
Care Intelligence Network

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Public Health England  
133-155 Waterloo Road  
Wellington House  
London SE1 8UG  
Tel: 020 7654 8000  
[www.gov.uk/phe](http://www.gov.uk/phe)  
Twitter: @PHE\_uk  
Facebook: [www.facebook.com/PublicHealthEngland](https://www.facebook.com/PublicHealthEngland)

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NHS Improving Quality  
Ground Floor  
No 1 Whitehall Quay  
Leeds LS1 4HR  
Email: [enquiries@nhsiq.nhs.uk](mailto:enquiries@nhsiq.nhs.uk)  
[www.nhsiq.nhs.uk](http://www.nhsiq.nhs.uk)  
Twitter: @NHSIQ

Prepared by: National End of Life Care Intelligence Network (NEoLCIN)  
For queries relating to this document, please contact: [neolcin@phe.gov.uk](mailto:neolcin@phe.gov.uk)

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## Disclaimer

This report has been compiled from survey data submitted by 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 clinical commissioning groups (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 PHE's South West Knowledge and Intelligence Team and Dr Julian Abel, Consultant in Palliative Care, Weston Area Health Trust and Weston Hospicecare.

## Feedback

We welcome feedback from survey respondents and other users of this report. Please send comments to [neolcin@phe.gov.uk](mailto: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 records up-to-date. Please send details to [neolcin@phe.gov.uk](mailto:neolcin@phe.gov.uk). Thank you.

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# Executive summary

## Introduction

*“When the sharing of up-to-date information about a patient and their wishes across agencies works effectively, it is the most fantastic thing and makes a huge difference to the patient, family and those involved in caring for them.”* CCG respondent

Electronic Palliative Care Co-ordination Systems (EPaCCS) enable the recording and sharing of people’s care preferences and key details about their care with those delivering their care. The systems support co-ordination of care and the delivery of the right care, in the right place, by the right person, at the right time.

EPaCCS began with eight locality pilot sites in 2009-2011.<sup>1</sup> Roll-out across England has progressed through the period of NHS re-organisation from 2010 and the creation of clinical commissioning groups (CCGs), which formally came into being on 1 April 2013.

A baseline survey of EPaCCS was carried out in July 2012.<sup>2</sup> This survey was carried out in August 2013. The aim of this survey was to gather information about EPaCCS implementation and their impact, as well as to assess compliance with the national information standard for end of life care co-ordination (ISB 1580).

## Response rates

The survey was sent to the 211 CCGs in England. Responses were received from a variety of organisations, with some submitting on behalf of more than one CCG. In total there were 172 usable responses providing information on 188 (89%) of CCGs. There were 154 unique responding organisations, 127 of which were CCGs (83%). Others were hospital trusts, commissioning support units, hospices or palliative care providers and informatics units.

## Results

### Partnerships

Many CCGs are working in partnership to implement EPaCCS. We identified 33 partnerships involving 139 CCGs (66% of all CCGs). Almost a quarter (49 CCGs) were implementing EPaCCS on their own.

## System status

Sixty-four CCGs (30%) had operational EPaCCS, 111 (53%) had started planning for their implementation and 10 (5%) stated that they had no operational system and that planning had not started. Of those who had started planning, 40 were expecting to have operational systems by January 2014 and an additional 17 by January 2015.

## Hosting

Of the CCGs with operational systems, 33 used NHS trusts as host organisations and seven were hosted by CCGs. Just under half of CCGs in the planning stage (47%) could not report where the system would be hosted. Those who could, reported CCGs, GPs and hospices as the most likely hosts.

## Lead technical systems

Ten different lead technical systems were reported for the 64 CCGs with operational systems and 111 CCGs with systems planned (total 175). The most popular were Aداstra (39 CCGs, 22%), SystemOne (22 CCGs, 13%) and EMIS (14 CCGs, 8%).

However, in almost a third of CCGs with operational systems (20 CCGs, 31%), the lead system used was not reported. In a quarter of CCGs with systems planned (27 CCGs, 24%), it was indicated that multiple systems would be used, and a further 21% (23 CCGs) stated that the lead system had yet to be confirmed.

## Activity on operational EPaCCS

Responses to questions about the patients registered on operational EPaCCS varied. There was information for 49 CCGs on the numbers of patients registered on EPaCCS (over 26,000), number of people dying between June 2012 and May 2013 (just over 6,000) and numbers of people dying of cancer in that same period (over 1,327).

Information provided for CCGs with operational systems who were able to extract the data from their systems (n=11) indicates that fewer people died in hospital and more died at home than the national average (54% in hospital, 20% at home between 2008 and 2010).

## Access to care records

Information on care services with access to EPaCCS and the format of that access was collected for 33 CCGs which had operational systems. Social care services had access

to care co-ordination records in just three cases. The most common form of access was via a shared web interface.

### Contracts compliance

Response rates to questions regarding compliance with the national information standard were low for the 64 CCGs with operational systems and varied across the four questions on this topic.

Fourteen reported that they met the requirement for their system to contain the core content defined in the national information standard; nine that they met the requirement for their system to comply with user interface standards and National Patient Safety Agency guidelines for safe on-screen display of medical information; ten carried out a clinical safety risk assessment prior to implementing their system and had a risk control system in place. Most of the 15 CCGs who responded reported full compliance with all the data items included in the national information standard, with a few exceptions on a small number of individual data items.

### Feedback on guidance

Responses to questions about implementation and record keeping guidance indicated that 80% of respondents found the guidance to be either quite useful, useful or very useful. Responses also suggested that more guidance was required on developing system interoperability between systems and organisations, funding and incentives and provision of national support such as workshops, regular meetings and web based supporting resources.

### General feedback

Forty-six respondents gave feedback on the beneficial impact of EPaCCS implementation and the challenges.

Benefits reported by those with an operational EPaCCS included improved communication and ease of information sharing between professionals involved in a person's care (most frequently mentioned), and supporting carers, clinicians, ambulance and out of hours services to make appropriate decisions about a person's care.

Engaging with clinicians from all areas was seen as key to driving projects forward. For CCGs in the planning stage of implementation, the benefit of EPaCCS in bringing different agencies together and giving participants a better understanding of end of life care needs was highlighted.



Implementing EPaCCS was found to drive training, systems and cultural change in organisations and so forms part of the improvement process for end of life care services.

The challenges that respondents implementing operational systems had to address included interoperability of IT systems (most frequently mentioned), data ownership, consent, engagement of health professionals (particularly GPs) and funding.

## Conclusions

This report is the first to provide a comprehensive overview of EPaCCS in England since the re-organisation of the NHS and the emergence of CCGs. It illustrates that EPaCCS is a complex project that aims to support end of life care co-ordination across a multitude of different agencies. The majority of CCGs are working in partnership with each other and with other agencies to implement EPaCCS.

It is still early days for EPaCCS implementation, with around one third of CCGs with operational systems and only a few of these able to report on data from the systems in this survey. The available data, however, does suggest that the use of EPaCCS helps people to die in their preferred place of death, decreases the percentage of hospital deaths and increases in the percentage of deaths at home and in hospices.

There was much positive feedback in areas where EPaCCS have been implemented. The greatest benefits were identified as improvements in communication and information sharing between healthcare professionals and support for making appropriate decisions about patients' care.

EPaCCS supports patient choice, shared decision making, individual care planning and integration of care across sectors. It is expected to play a significant role in supporting the care integration agenda, including the Integrated Care and Support Pioneers Programme. Over the coming years we expect to see an increase in the number of systems to which social care services have access.

Successful implementation of EPaCCS requires the appropriate configuration of systems, services and infrastructure. For many CCGs this has raised a number of issues, such as system interoperability, stakeholder engagement, data ownership, costs, information support and funding, which need to be resolved to ease implementation.

Although CCGs were able to provide certain information, they often had little access to data and a poor understanding of technical issues for EPaCCS management. We hope to build a better database of EPaCCS leads across the CCGs so that we improve the accuracy and reduce discrepancies in future surveys. Future work needs to determine which stakeholders are best able to provide this kind of information.

## Recommendations and next steps

This report provides an overview of EPaCCS implementation across England. It includes information about systems and approaches being used and shares the learning and experiences of implementers. This will be useful to all those implementing or planning local EPaCCS or other electronic co-ordination systems.

Those planning EPaCCS should be aware of the value and importance of system functionality to report on activity and the impact of implementation, for example on place of death.

The report will also be useful to IT systems suppliers and there are important messages regarding the need for system suppliers to work together to support interoperable systems.

It will inform the national team supporting EPaCCS implementation about the current status of EPaCCS implementation and provides valuable feedback from implementers on the additional support required.

The report also provides information for the Standardisation Committee for Care Information (SCCI) (formerly the Information Standards Board) on the progress of EPaCCS implementation and the impact of the national information standard for end of life care co-ordination.

The report, together with the Electronic Palliative Care Co-ordination Systems mid-2012 survey report, will be used to monitor future progress in EPaCCS implementation.

# 1 Introduction

The End of life Care Strategy (2008)<sup>3</sup> identifies the need to improve the co-ordination of care, recognising that people at the end of life frequently received care from a wide variety of teams and organisations. The development of Locality Registers (now Electronic Palliative Care Co-ordination Systems known as 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 systems support co-ordination of care and the delivery of the right care in the right place, by the right person, at the right time. Eight pilots were established across England in 2009 to test proof of concept and an evaluation carried out by Ipsos MORI reported in June 2011<sup>4</sup>. In March 2012 a national information standard for End of Life Care Co-ordination (ISB 1580)<sup>5</sup> was published with an implementation date of 1 December 2013. This standard identifies and defines the core content to be held in EPaCCS. The standard requires all contracts for EPaCCS to be compliant with its specifications, IT systems suppliers to provide compliant systems and data items included in the systems to be compliant with the specifications of the standard. Responsibility for the national information standard now sits with the Standardisation Committee for Care Information (SCCI) as the Information Standards Board closed on 31 March 2014.

A baseline survey was carried out in July 2012 to determine the roll out of EPaCCS in England and a report, Electronic Palliative Care Coordination Systems (EPaCCS) Mid 2012 Survey Report published in February 2013.<sup>2</sup> Since this survey was conducted in July 2012 the NHS has undergone a major re-organisation. Primary care trusts (PCTs) were abolished and, from 1 April 2013, responsibility for commissioning – including the commissioning of end of life care services – moved to newly established clinical commissioning groups (CCGs).

The survey detailed in this report was completed in August of 2013 and has been carried out to capture progress towards implementing EPaCCS for end of life care across England post re-organisation. CCGs were used as the principal points of contact for questionnaire distribution and in many sections the results are presented by CCG.

## 2 Aim

This survey was designed to gather information about EPaCCS implementation since 2012, the impact and benefit of EPaCCS, and to assess compliance with the national information standard for end of life care co-ordination (ISB 1580).

## 2.1 EPaCCS implementation

The survey aimed to establish the following:

- the status of EPaCCS implementation for each CCG in England (i.e. whether operational, planned or planning not started)
- timescales for planned implementation
- CCG partnership arrangements and identification of the organisation types hosting EPaCCS systems
- technical systems being used by EPaCCS
- an understanding of the scale and system maturity of operational EPaCCS, including details of the types of care provider with access to EPaCCS records and the format used
- to assess the degree of system interoperability in the EPaCCS that are being implemented
- to request feedback on implementation challenges or issues

## 2.2 Information standard

To determine whether the EPaCCS being implemented in England are compliant with the national information standard in respect of:

- the collection of data items specified in the information standard
- compliance with the IT standards specified in the standard
- clinical risk management

The survey also requested feedback on the resources that are available to support implementation of EPaCCS and additional support that could be provided by the national team.

# 3 Methodology

A link to the online survey (see Appendix 1) was sent to every CCG in England (211 in total). CCGs were contacted prior to the circulation of the survey to identify end of life care leads and address any issues regarding changed geographies and staff changes as of 1 April 2013.

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 PHE's South West Knowledge and Intelligence Team. The survey was delivered via the online SurveyMonkey tool.

The survey ran from 5 August to 6 September 2013. There was a two-week follow up period during which non-responders were contacted.

This report is compiled using the survey information submitted. It should be noted that we are aware that the information received did not always match what we might have expected. An example is that we are aware of the London-wide EPaCCS being implemented called Coordinate My Care. At the time of the survey the IT system used for Coordinate My Care was System C. However, three CCGs in London reported their lead system as Health Analytics.

## 4 Results: EPaCCS implementation

### 4.1 Response rates

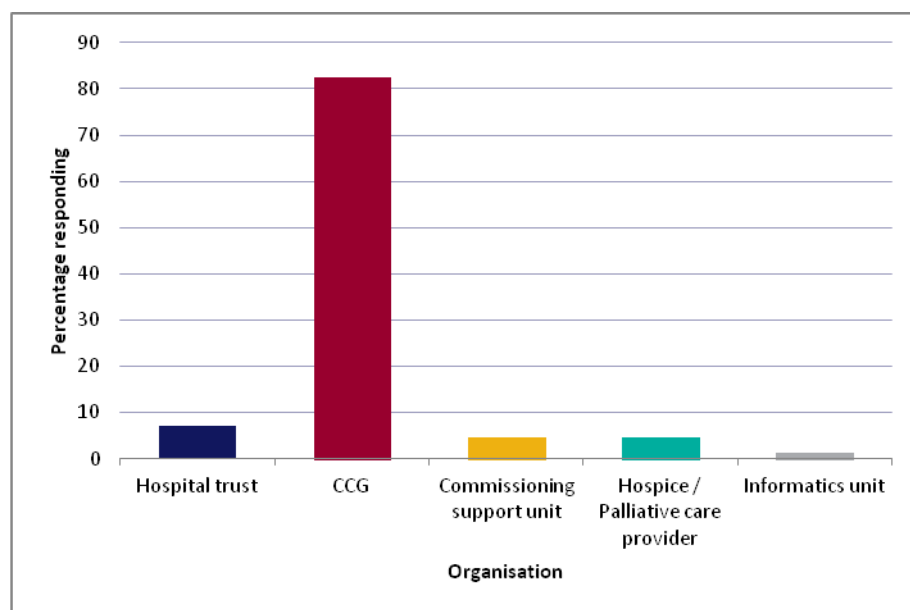
#### 4.1.1 Response rates (organisations)

There were 215 responses from a variety of organisations (not just CCGs), with some submitting on behalf of more than one CCG. Of these, 172 were usable and provided information on 188 CCGs (89% coverage). Eighteen of these responded more than once (for more than one CCG). There were, therefore, 154 unique responding organisations, 127 of which were CCGs (83%).

The response rates by organisation are summarised in Table 1 and Figure 1.

**Table 1: Number and percentage of unique responding organisations grouped by type**

Organisation	Total	Per cent
Hospital trust	11	7.1
CCG	127	82.5
Commissioning support unit	7	4.5
Hospice/palliative care provider	7	4.5
Informatics unit	2	1.3
Total	154	100

**Figure 1: Percentage of unique organisations responding grouped by type**

#### 4.1.2 Response rates (respondents)

Of the 172 usable responses, 171 individual respondents were identified and categorised into one of eight different role groups depending on their job title. Multiple responses from organisations are included in this section where the respondents were different individuals.

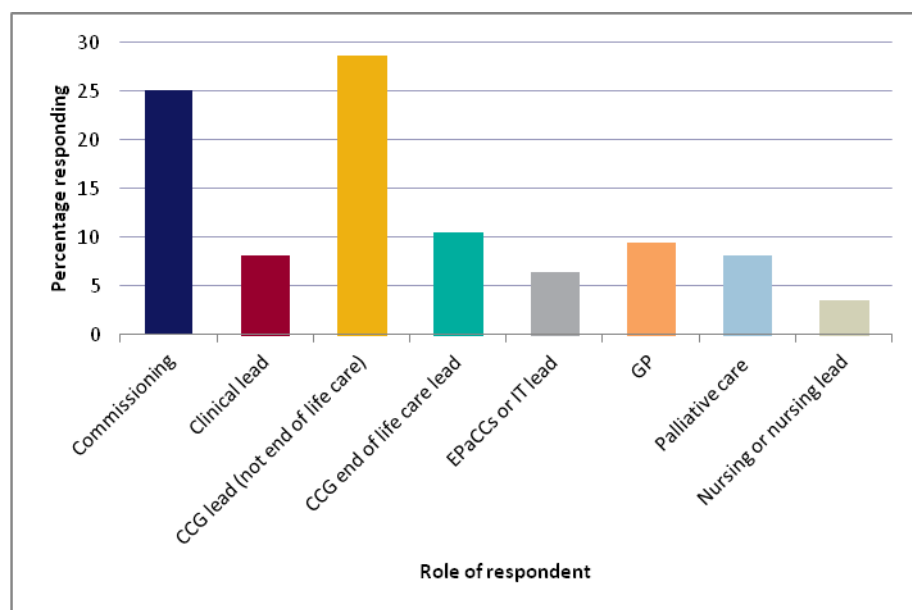
A breakdown of the roles of respondents is shown in Table 2 and Figure 2. Over half of respondents worked either in commissioning or as CCG leads (not specified as end of life care leads) and around 20% of respondents were GPs or end of life care leads.

73% of respondents (125 in total) were happy to share their contact details.

**Table 2: Individual respondents put into role groups based on their job title**

Role of respondent	Number	Per cent
Commissioning	43	25.1
Clinical lead	14	8.2
CCG lead (not end of life care)	49	28.7
CCG end of life care lead	18	10.5
EPaCCs or IT lead	11	6.4
GP	16	9.4
Palliative care	14	8.2
Nursing or nursing lead	6	3.5
Total	171	100

**Figure 2: Individual respondents put into role groups based on their job title (percentage of respondents)**



## 4.2 EPaCCS in CCGs

The information presented in this section relates to CCG respondents rather than any other type of responding organisation. Multiple responses from CCGs were used when they enhanced the information received.

### 4.2.1 Partnership working

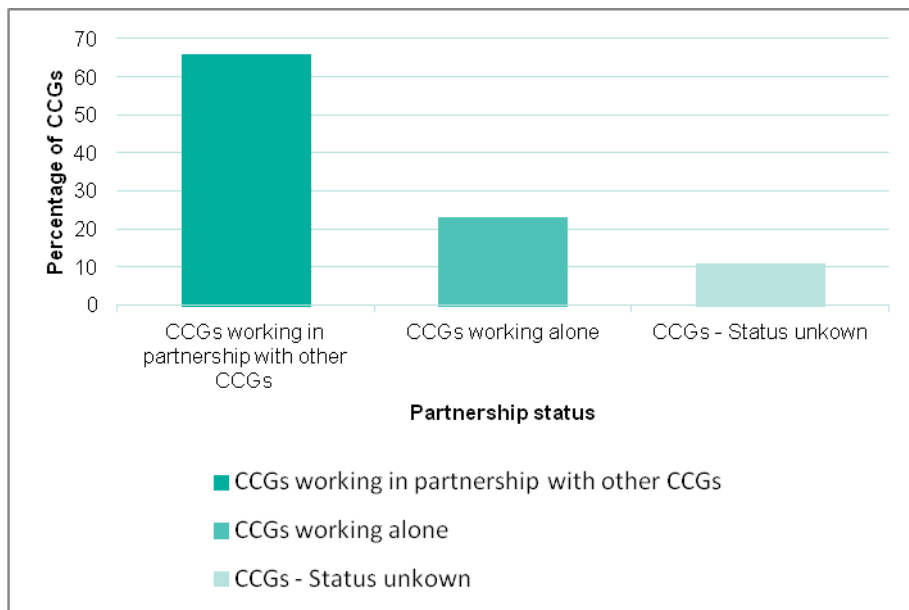
Many CCGs are working in partnership to implement EPaCCS. We identified 33 partnerships involving 139 CCGs (66% of all CCGs). Almost a quarter (49 CCGs) were working on their own.

The working arrangements of CCGs are summarised in Table 3 and Figure 3. Partnerships between CCGs are shown in Map 1. The London partnership, Coordinate my care, was the largest with 29 CCGs involved.

**Table 3: Working arrangements of CCGs**

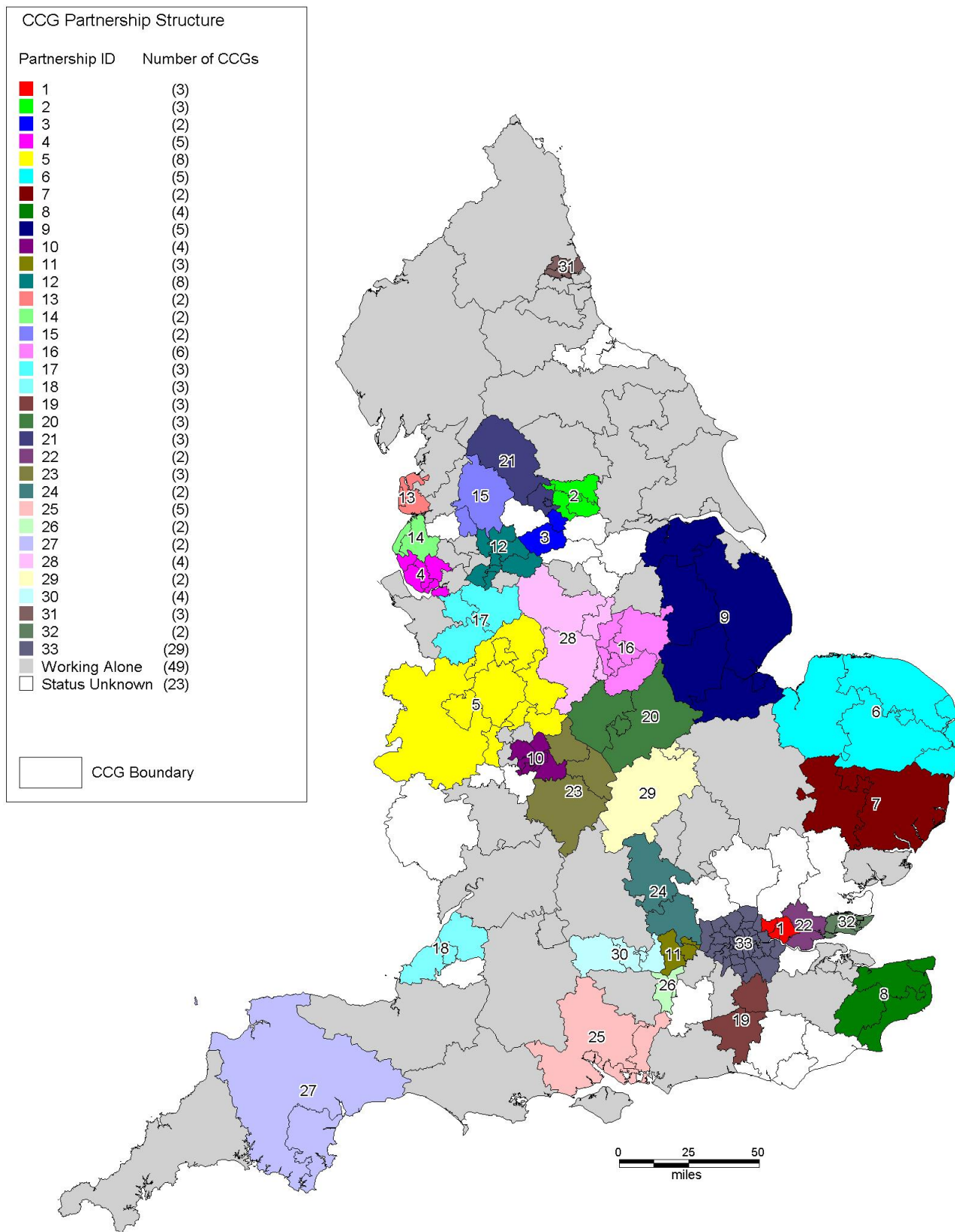
	Number of CCGs	Per cent
CCGs working in partnership with other CCGs	139	65.9
CCGs working on their own	49	23.2
CCGs - status unknown	23	10.9
Total	211	100

**Figure 3: Working arrangements of CCGs**





**Map 1: CCG partnership arrangements for EPaCCS implementation**



Note: Despite many London CCGs not responding, they have been included in the figures for a London partnership. However, Havering, Barking and Dagenham and Redbridge CCGs (partnership 1) were not included in the London partnership because their response indicated that they were working as a self-contained group.

Partnerships between CCGs also involved many different agencies working together (for example ambulance trusts, hospices and providers, out of hours services) to create an integrated record of care.

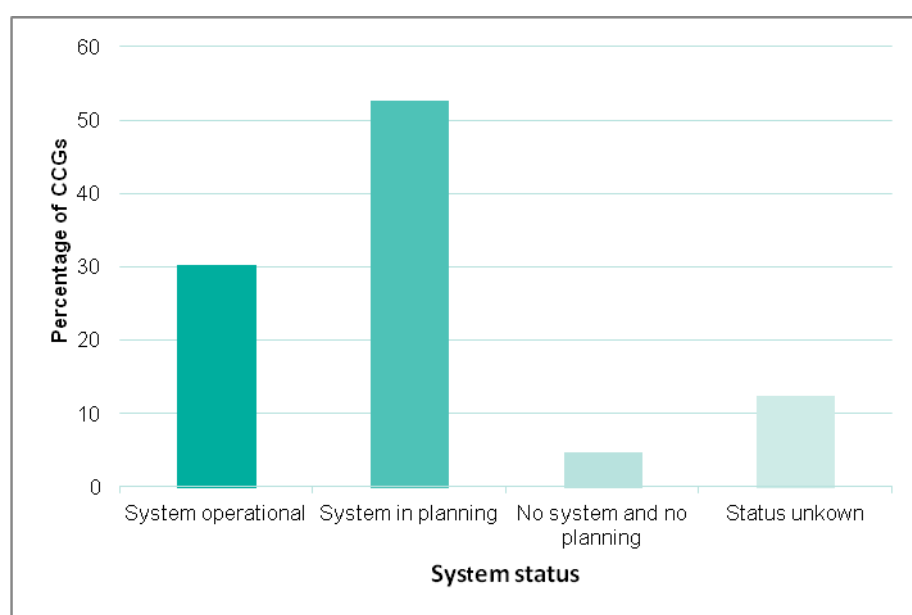
#### 4.2.2 System status

Sixty-four out of a possible 211 CCGs in England (30.3%) were identified as having operational EPaCCS (defined as a functioning electronic system(s) or process(es) linking care providers across a locality), 111 (53%) stated that planning had started and 10 CCGs (5%) stated that they had no operational system and that planning had not started (Table 4, Figure 4 and Map 2). Operational status could not be determined from the responses of three CCGs and no information was obtainable for 23 CCGs.

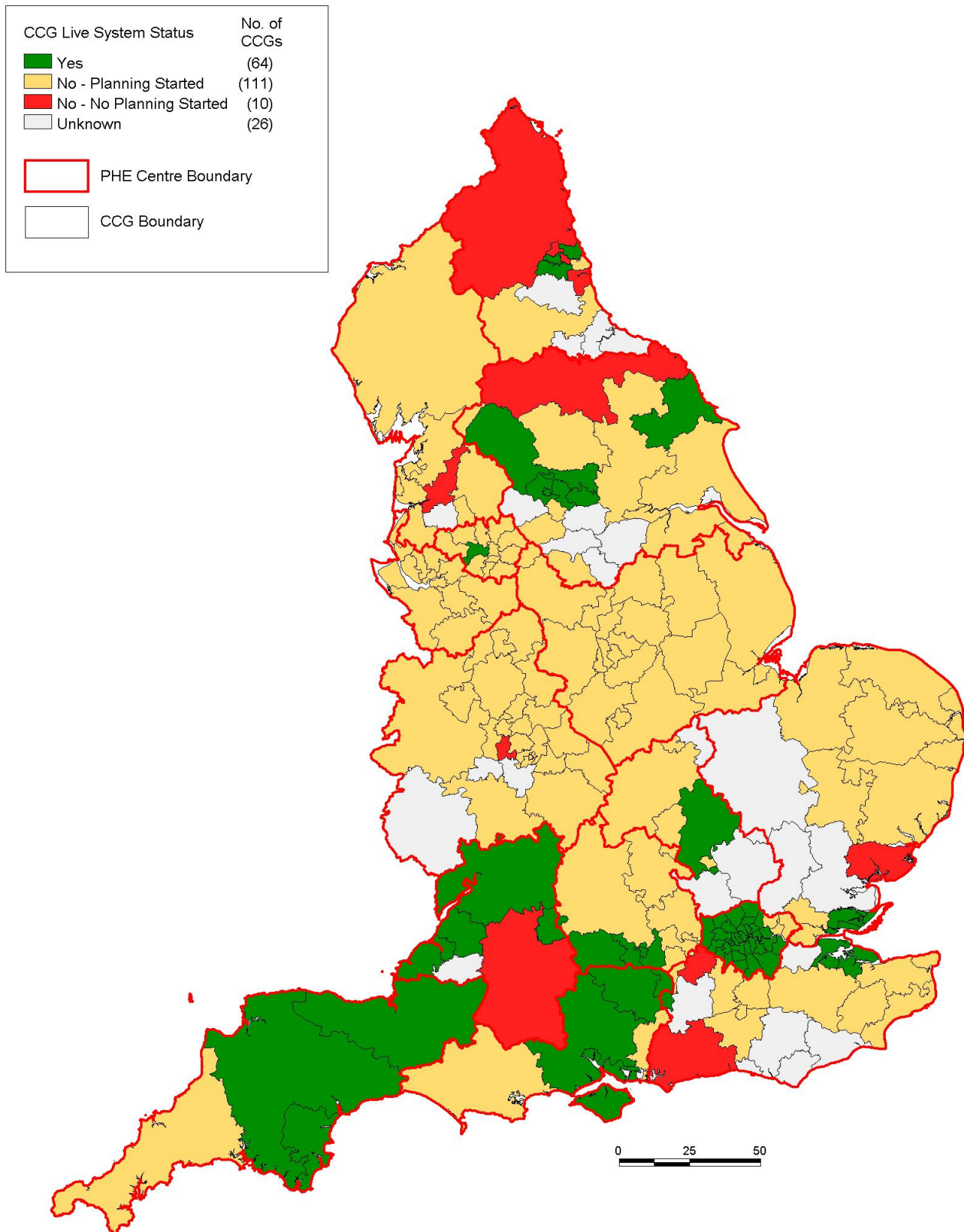
**Table 4: System status for CCGs responding to the survey**

System status	Number of CCGs	Per cent
System operational	64	30.3
System in planning	111	52.7
No system and no planning	10	4.7
Status unknown	26	12.3
Total	211	100

**Figure 4: System status for CCGs responding to the survey (percentage of all CCGs)**



**Map 2: Operational status of EPaCCS in CCGs**



Of the 49 CCGs working on their own (not in a partnership, Table 3), 11 stated that they had operational systems, 26 stated that planning had started, and nine stated that planning had not started. The operational status of a further three was unknown.

Seven partnerships had operational systems, three had semi-operational systems (not all members of a partnership had an operational system) and 23 had planning underway.

#### 4.2.3 Start dates for systems in planning phase

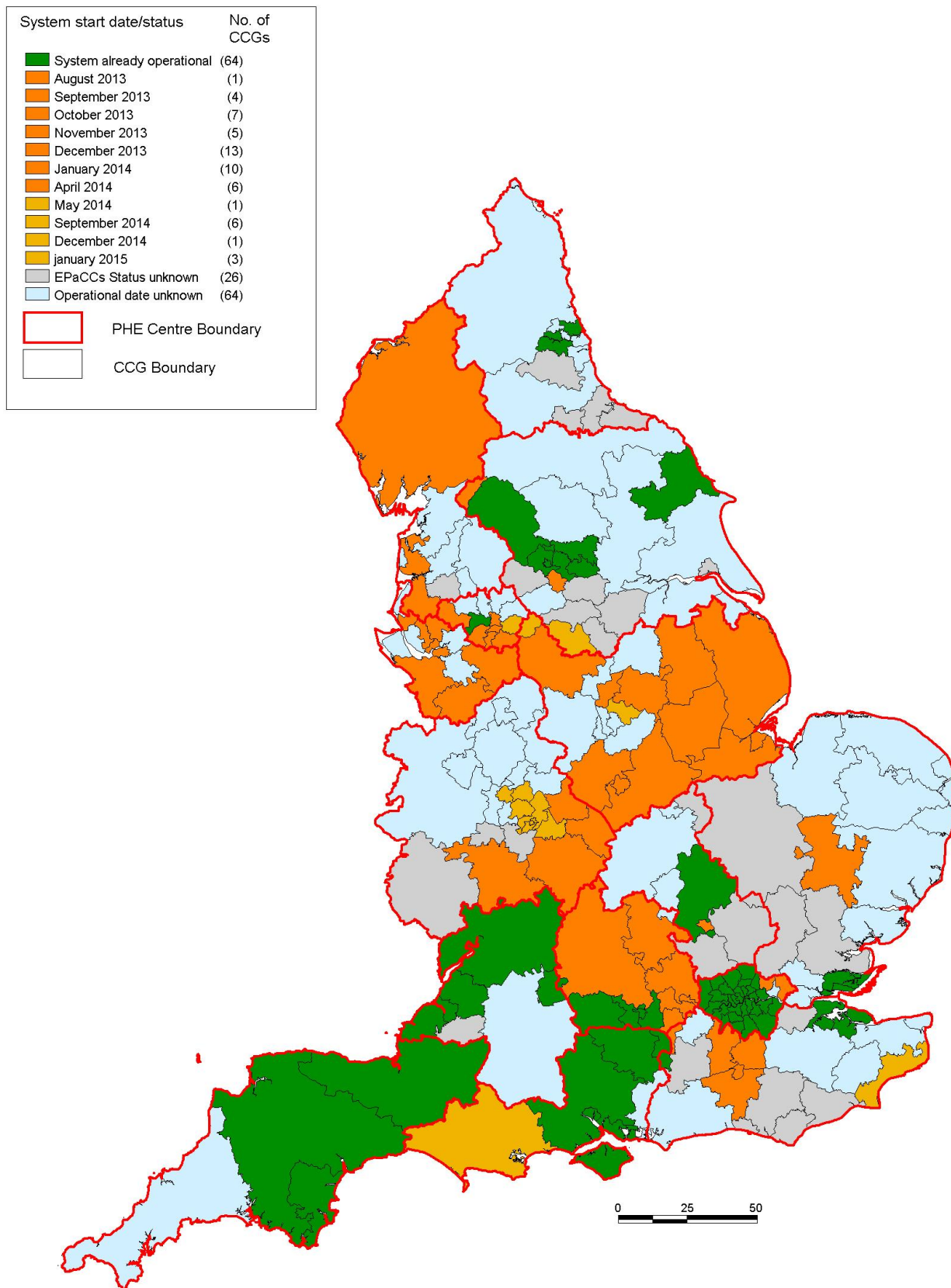
Of the 111 CCGs planning EPaCCS implementation, information about start dates was provided for 107 (Table 5). Forty (36%) expected to have an operational system in place by January 2014 and an additional 17 (15%) by January 2015. Fifty (47%) did not have a designated start date.

CCG start dates are also shown in Map 3.

**Table 5: Start dates for CCGs planning implementation of EPaCCS**

Date	Number of systems becoming operational	Per cent
August 2013	1	1.0
September 2013	4	3.7
October 2013	7	6.5
November 2013	5	4.7
December 2013	13	12.1
January 2014	10	9.3
April 2014	6	5.6
May 2014	1	0.9
September 2014	6	5.6
December 2014	1	1.0
January 2015	3	2.8
Not known	50	46.7
Total	107	100

**Map 3: Start dates for systems in planning**



#### 4.2.4 Host organisations

This section is based on information from CCGs with operational systems (64 CCGs) or who have started planning (111 CCGs). The top three hosting organisations for CCGs with operational systems were: NHS trusts (33 CCGs, 52%), out of hours services (11 CCGs, 17%) and CCGs themselves (7 CCGs, 11%).

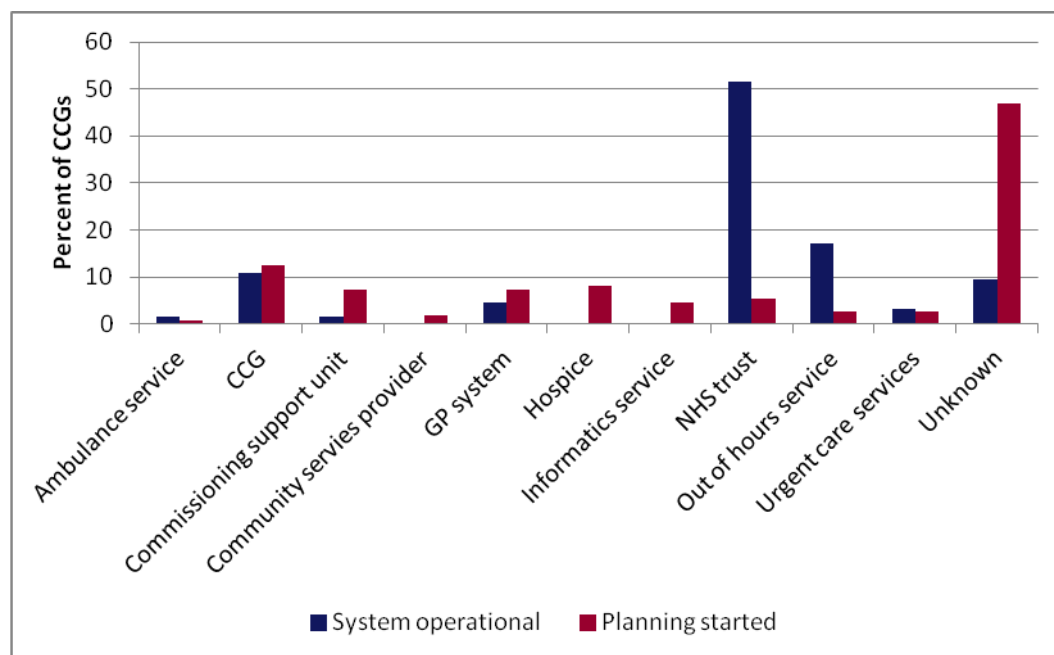
The majority of CCGs in the planning stage (47%) could not report where the system would be hosted. Of the respondents who could give a host organisation, CCGs, GPs and hospices were the most likely (Table 6 and Figure 5).

**Table 6: Host organisations for CCGs with operational or planned EPaCCS systems**

Host organisation	Number of CCGs			Per cent		
	System operational	Planning started	Total	System operational	Planning started	Total
Ambulance service	1	1	2	1.6	0.9	1.1
CCG	7	14	21	10.9	12.6	12
Commissioning support unit (CSU)	1	8	9	1.6	7.2	5.1
GP	3	8	11	4.7	7.2	6.3
Community services provider		2	2		1.8	
Hospice		9	9		8.1	5.1
Informatics service		5	5		4.6	2.9
NHS trust	33	6	39	51.6	5.4	22.3
Out of hours service	11	3	14	17.2	2.7	8
Urgent care services	2	3	5	3.1	2.7	2.9
Unknown	6	52	58	9.4	46.8	33.1
<b>Total</b>	<b>64</b>	<b>111</b>	<b>175</b>	<b>100</b>	<b>100</b>	<b>100</b>



**Figure 5: Host organisations for CCGs with operational or planned EPaCCS systems**



#### 4.2.5 Lead technical systems

Ten different lead technical systems were reported for the 64 CCGs with operational systems and 111 CCGs with systems planned (total 175). The most popular were Aداstra (39 CCGs, 22%), SystemOne (22 CCGs, 13%) and EMIS (14 CCGs, 8%).

Aداstra was the most popular for CCGs with operational systems, accounting for 36% of those in use (Table 7).

However, in almost a third of CCGs with operational systems (20 CCGs, 31%), the lead system used was not known. In a quarter of CCGs with systems planned (27 CCGs, 24%), it was indicated that multiple systems would be used, and a further 21% (23 CCGs) stated that the lead system had yet to be confirmed.

**Table 7: Lead systems in CCGs with operational systems or who are implementing EPaCCS**

System	Lead system		Per cent	
	CCGs with operational systems	CCGs planning EPaCCS implementation	CCGs with operational systems	CCGs planning EPaCCS implementation
Adastra	23	16	35.9	14.4
SystemOne	7	15	10.9	13.5
EMIS	2	12	3.1	10.8
SystemC	5	1	7.8	0.9
Coordinate my care	1		1.6	0
SCR		2	0	1.8
Graphnet		11	0	9.9
MIG		1	0	0.9
Health Analytics Cleo		3	0	2.7
	1		1.6	0
Multiple systems	5	27	7.8	24.3
To be confirmed		23	0	20.7
Unknown	20	1	31.3	0.9
Total	64	111	100	100

Although many operational EPaCCS are in their infancy, some CCGs reported that they were able to share information through EPaCCS with clinical systems.

#### 4.2.6 Activity on operational EPaCCS

Where EPaCCS were operational, respondents were asked to provide details of the numbers of people added since inception, the numbers added between 1 June 2012 and 31 May 2013, and the number of people with an EPaCCS record who had cancer as the main cause of death. Responses were supplied either directly by CCGs or by partnerships. In total, there were 18 responses for 49 CCGs (77% of CCGs with operational systems). Table 8 summarises the results.



**Table 8: Numbers of people registered on operational EPaCCS, numbers who died between 1 June 2012 and 31 May 2013, and the number of people with cancer as the main cause of death**

Organisation	Number of people added to the EPaCCS register since inception	Number of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013	Number of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 and had cancer as the main cause of death
Bradford District Care Trust and Marie Curie. Working on behalf of Bradford City, Bradford District and Airedale/Wharfedale/Craven CCGs	3,000	1,403	365
Leeds South & East, Leeds North and West Leeds CCGs	1,105	309	
West Leeds CCG	285	77	74
Salford CCG	2,046		
Sheffield CCG	1,713		
Central Eastern CSU working on behalf of Southend, Castle Point and Rayleigh CCGs	3,010	1,009	
Bedfordshire CCG	1,051	620	564
London - Coordinate my Care covering 31 CCGs	8,570	1,302	
Merton CCG	974		
Hammersmith and Fulham CCG*	216	38	
West London CCG*	102	19	
Central London CCG*	119	23	
Wandsworth CCG	250		
Medway CCG and Medway Council	928	190	
West Hampshire CCG	60		
Somerset CCG**	2,718	1,013	324
Southampton City CCG	22		
Portsmouth, South East Hants and Fareham & Gosport CCGs	80		
Total	26,249	6,003	1,327

Notes: \* Figures are from January 2013; \*\*Figures are from September 2012 to 31 May 2013

CCGs with operational systems were also asked about place of death for the number of people who died between June 2012 and May 2013, whether their preferred place of death had been recorded on EPaCCS, and the number who actually died in their preferred place of death during the same period.

There were seven responses for 11 CCGs (17% of CCGs with operational systems). The results are shown in Tables 9 and 10.

For the CCGs that did respond the percentage of people dying in their preferred place of death ranged from 61.5% to 81.5%.

The percentage of hospital deaths ranges from between 4% and 40% and the percentage of home deaths between 35% and 54%. Between 2008 and 2010 in England, hospital was the place of death for 54% of those dying and home the place of death for 20%.<sup>6</sup>

**Table 9: Place of death and preferred place of death of people with an EPaCCS record**

Organisation	Number of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 and who had their preferred place of death recorded	Number of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 and who died in their preferred place of death	Number of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 in the following places:				
			Hospital	Care home	Home	Hospice	Other
Central Eastern CSU working on behalf of Southend, Castle Point and Rayleigh CCGs	807	658	82	349	405	163	10
West Leeds CCG	39	24	31	5	33	4	4
Leeds South & East, Leeds North and West Leeds CCGs	145	95					
Medway CCG and Medway Council	131	105	8	8	103	56	15
Bedfordshire CCG	620		68	211	217	118	6
Bradford District Care Trust and Marie Curie. Working on behalf of Bradford City, Bradford District and Airedale/Wharfedale/ Craven CCGs	589	659 <sup>†</sup>	196	337	491	379	
Somerset CCG	726 <sup>**</sup>	852 <sup>†</sup>			515		
<b>Total</b>	<b>3,057</b>	<b>2,393</b>	<b>385</b>	<b>910</b>	<b>1,764</b>	<b>720</b>	<b>35</b>

Notes: <sup>\*\*</sup>Figures are from September 2012 to 31 May 2013 <sup>†</sup>Please note that, the number of people reported as dying in their preferred place of death is higher than the number of people reported to have had their place of death recorded

**Table 10: Place of death and preferred place of death of people with an EPaCCS record (percentage)**

Organisation	Percentage of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 and had their preferred place of death recorded <sup>^^</sup>	Percentage of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 in their preferred place of death	Percentage of people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 in the following places:				
			Hospital	Care home	Home	Hospice	Other
Central Eastern CSU (working on behalf of Southend, Castle Point and Rayleigh CCGs)	80.0	81.5	8.0	34.6	40.1	16.2	1.0
West Leeds CCG	51.0	61.5	40.3	6.5	42.8	5.2	5.2
Leeds South & East, Leeds North and West Leeds CCGs	46.9	65.5					
Medway CCG and Medway Council	68.9	80.2	4.2	4.2	54.2	29.5	7.9
Bedfordshire CCG	100		11.0	34.0	35.0	19.0	1.0
Bradford District Care Trust and Marie Curie. Working on behalf of Bradford City, Bradford District and Airedale/Wharfedale/Craven CCGs	42.0	†	14.0	24.0	35.0	27.0	
Somerset CCG**	72.0**	†			51.0		

Note: \*\*Figures are from September 2012 to May 2013 † Percentages not calculated as the number of people reported as dying in their preferred place of death is higher than the number of people reported to have had their place of death recorded.

<sup>^^</sup>The denominator for Column 1 is Column 2, Table 8; the numerator is Column 1 in Table 9.

Finally, respondents were asked whether any information on EPaCCS had been incorporated into and/or synchronised with clinical systems. There were nine responses for 11 CCGs (Table 11).

**Table 11: Information on EPaCCS incorporated into and/or synchronised with clinical systems**

CCG	Clinical system	Responses
North East Leicester CCG	via SystmOne	1
Hammersmith and Fulham, West London and Central London, Wandsworth, Leeds South and East and Somerset CCGs	111 GP Out of Hours	6
Central Eastern CSU working on behalf of Southend, Castle Point and Rayleigh CCGs	Ambulance CAD	1
Salford CCG	Care First (social care)	1
Salford CCG	Emis / Vision (GP systems)	1
Salford CCG	Allscripts (Acute trust EPR)	1
Ashford CCG	Share My Care (Emis/Vision)	1
Somerset CCG	SWAST Adastra system	1

#### 4.2.7 Access to care records and format

The survey included questions about the scope of access to EPaCCS for service providers within the CCG localities and the format of systems being used to transfer information between professionals. Information was provided for 33 CCGs with operational EPaCCS. Results are shown in Table 12.

Social care had the least access to systems – out of the just 15 who responded about social care access, 12 said that there was none.

The most used data formats for access to the EPaCCS record were via shared web interface/viewer and direct electronic system to system transfer. These formats were especially used by hospital departments and community health providers, GPs and ambulance services. Information was shared with out of hours services by automated email, batch systems and overnight electronic transfer.

**Table 12: Care setting access and format as reported by 33 CCGs with an operational system**

Care setting	Access format (responses)							Total
	No access	Direct electronic system to system transfer	Batch/overnight electronic transfer	Access via shared web interface/viewer	Access via co-ordination centre	Information shared by automated email	Sent by letter or FAX	
GP	0	8	2	11	5	2	4	32
Out of hours	1	9	0	9	4	1	0	24
Ambulance	2	4	0	5	4	4	5	24
Hospital A&E	5	5	0	3	5	0	0	18
Hospital other than A&E	5	4	0	7	2	0	0	18
Community health providers	2	7	0	10	4	0	0	23
Social care	12	1	0	0	2	0	0	15
Specialist Palliative Care	1	9	0	9	4	0	0	23

## 5 Results: compliance with the national information standard

National guidance was produced to support organisations implementing EPaCCS (implementation guidance) and for professionals using EPaCCS (record keeping guidance). The national information standard ISB 1580 defines the core content to be held in EPaCCS or other end of life care co-ordination systems and specifies the requirements for implementation. The implementation date for the standard was 1 December 2013.

### 5.1 Contracts compliance

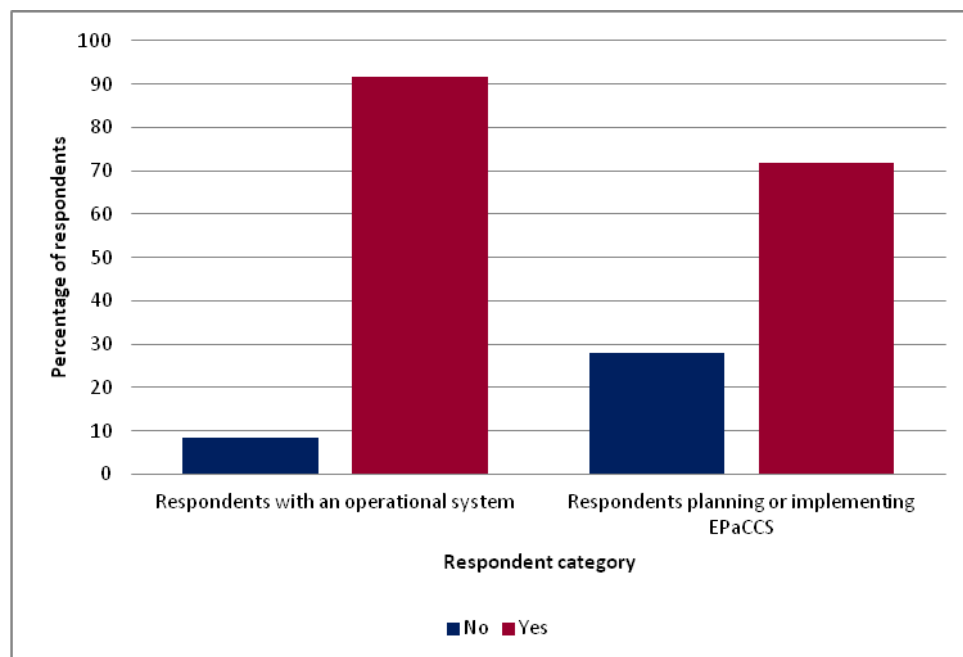
Respondents were asked whether all contracts for electronic palliative care co-ordination systems issued after March 2012, included the requirement for the system to contain the core content defined in the national information standard.

Out of the 64 CCGs with operational systems, 15 responded to this question. Of these, 14 met the requirement. Of the 111 CCGs in the planning stage, 32 responded of which 23 (72%) complied with the requirement (Table 13 and Figure 6).

**Table 13: CCGs with EPaCCS contracts issued after March 2012 specifying the requirement for the system to comply with the national information standard**

Response	Respondents with an operational system		Respondents planning or implementing EPaCCS	
	Total	Per cent	Total	Per cent
No	1	6.7	9	28.1
Yes	14	93.3	23	71.9
Total	15	100	32	100

**Figure 6: CCGs with EPaCCS contracts issued after March 2012 specifying the requirement for the system to comply with the a national information standard**



## 5.2 Compliance with user interface standards and National Patient Safety Agency (NPSA) guidelines

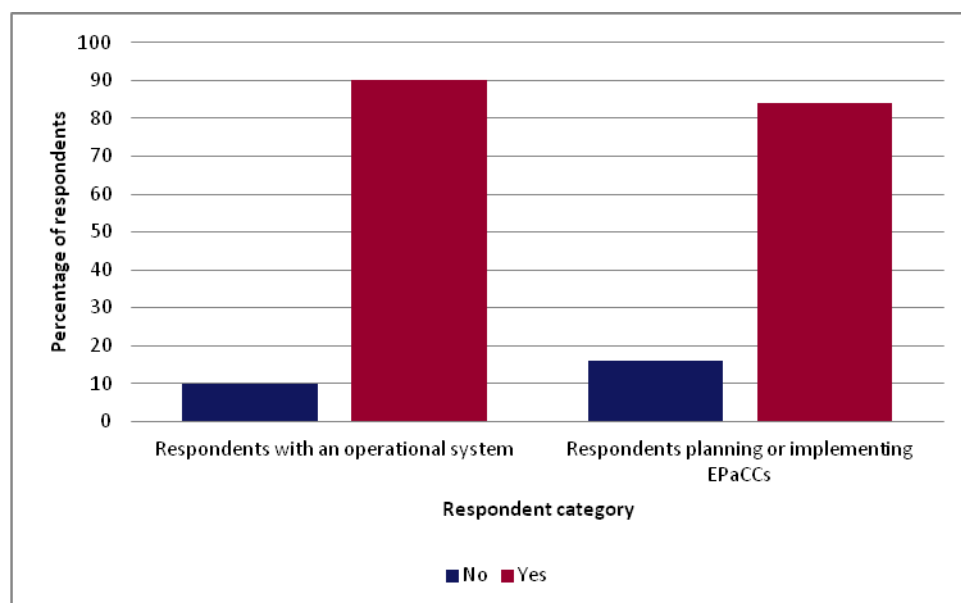
Respondents were asked whether their EPaCCS or other IT end of life care co-ordination system complied with user interface standards and NPSA guidelines for safe on-screen display of medical information.

Of the 64 CCGs with an operational system, ten responded to this question and nine met the requirement. Of those with a system planned or being implemented, 21 out of the 25 responding CCGs (84%) met the requirement (Table 14 and Figure 7).

**Table 14: Respondent status for the requirement for a palliative care system to comply with interface standards and to NPSA guidelines for safe on-screen display of medical information**

Response	Respondents with an operational system		Respondents planning or implementing EPaCCS	
	Total	Per cent	Total	Per cent
No	1	10.0	4	16.0
Yes	9	90.0	21	84.0
Grand total	10	100	25	100

**Figure 7: Respondent status for the requirement for a palliative care system to comply with interface standards and to NPSA guidelines for safe on-screen display of medical information**



### 5.3 Clinical safety and risk management

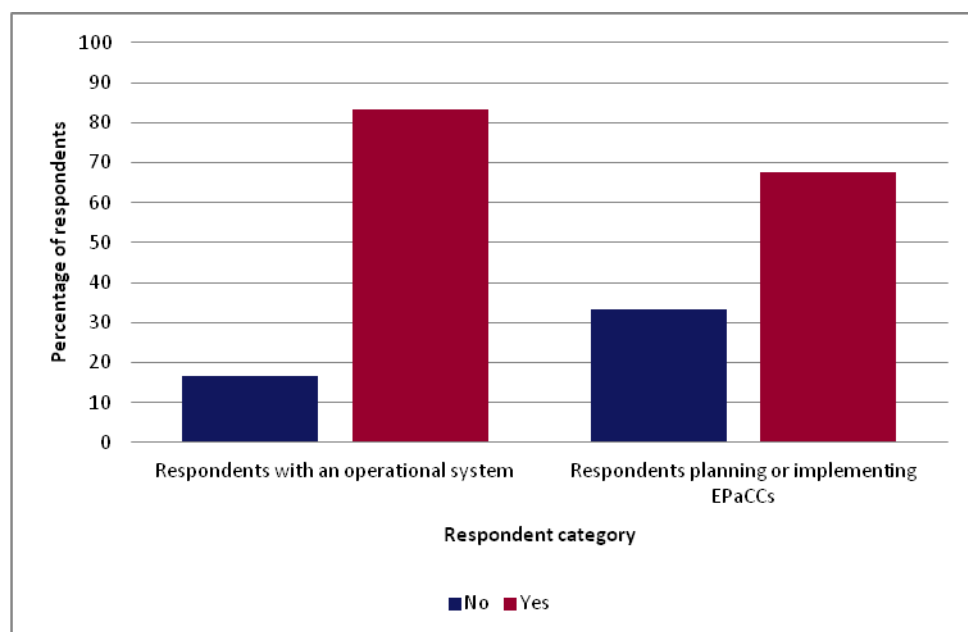
Respondents were asked whether a clinical safety risk assessment was carried out prior to implementing EPaCCS or other IT end of life care co-ordination system and a risk control system put in place.

The response rate for this question was 12 out of a possible 64 CCGs with operational systems with ten meeting the requirement. For those in the planning stage, 21 out of 109 CCGs responded of which 14 (66.6%) complied with the standard (Table 15 and Figure 8).

**Table 15: Respondent status for clinical safety risk assessments carried out prior to implementing EPaCCS or other IT co-ordination system and a risk control system put in place**

Response	Respondents with an operational system		Respondents planning or implementing EPaCCS	
	Total	Per cent	Total	Per cent
No	2	16.7	7	33.3
Yes	10	83.3	14	66.6
Grand total	12	100	21	100

**Figure 8: Respondent status for clinical safety risk assessments carried out prior to implementing EPaCCS or other IT co-ordination system and a risk control system put in place**



#### 5.4 Compliance of data items

Respondents were asked whether IT systems that hold any of the data items included in the national information standard (ISB 1580) complied with the standard?

The response rate for all parts of this question was 15 out of 64 CCGs with operational systems. Almost all respondents operating EPaCCS systems were fully compliant with ISB standards in respect of the data items. The only areas where respondents were not fully compliant were planned review date, name and contact details of Lasting Power of Attorney and names and contact details of others to be involved in decisions about care (Table 16).



**Table 16: Level of compliance of IT systems that hold any of the data items included in ISB1580 (CCGs with operational EPaCCS)**

Data item	Responses				Percent		
	Fully compliant	Not fully compliant	Not collected	Total	Fully compliant	Not fully compliant	Not collected
Record creation date and record amendment date	15			15	100		
Planned review date	11	1		12	91.7	8.3	
Person's details	15			15	100		
Main informal carer	15			15	100		
GP details	15			15	100		
Key worker	14			14	100		
Formal carers	14			14	100		
Medical details	14			14	100		
Just in case box/anticipatory medicines	14			14	100		
End of life tools in place	14			14	100		
Advance statement	14			14	100		
Preferred place of death	15			15	100		
Do not attempt cardio-pulmonary resuscitation	15			15	100		
Person has made an advance decision to refuse treatment (ADRT)	15			15	100		
Name and contact details of Lasting Power of Attorney	14	1		15	93.3	6.7	
Other relevant issues or preferences around provision of care	13			13	100		
Names and contact details of others that the person wants to be involved in decisions about their care	14	1		15	93.3	6.7	

## 6 Respondent feedback

### 6.1 Information standard resources

National guidance was produced to support organisations implementing EPaCCS (End of Life Care Co-ordination: Implementation Guidance) and for professionals using EPaCCS (End of Life Care Co-ordination: Record Keeping Guidance).

### 6.1.1 Implementation guidance

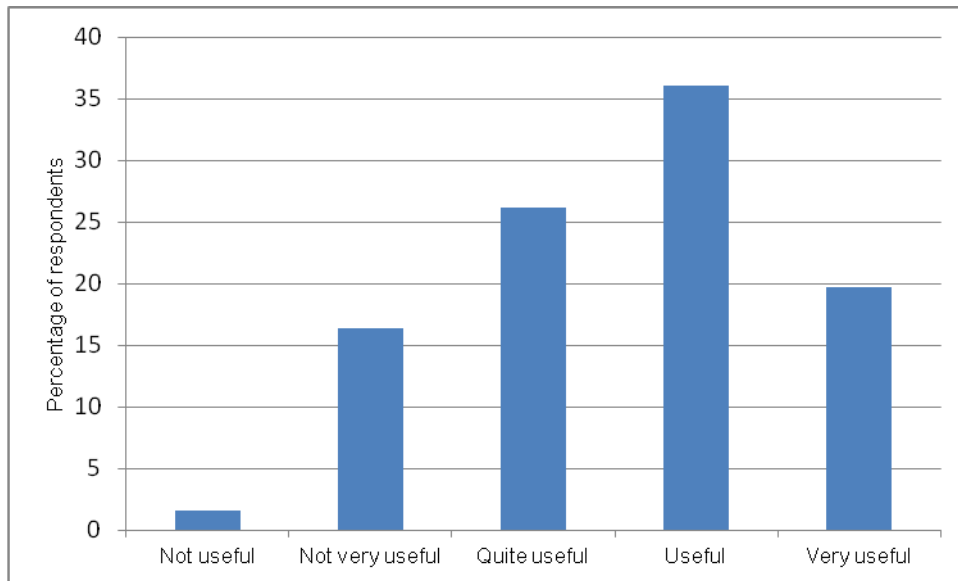
Respondents were asked how useful the implementation guidance has been in helping them or their system suppliers to implement the national information standard.

There were 61 responses and over 60% found the implementation guidance to be either ‘quite useful’ or ‘useful’. A further 20% found the guidance to be ‘very useful’ (Table 17 and Figure 9).

**Table 17: The usefulness of implementation guidance for respondents planning, implementing or operating EPaCCS**

Response	Responses	Per cent
Not useful	1	1.6
Not very useful	10	16.4
Quite useful	16	26.2
Useful	22	36.1
Very useful	12	19.7
Total	61	100

**Figure 9: The usefulness of implementation guidance for respondents planning, implementing or operating EPaCCS**



### 6.1.2 Record keeping guidance

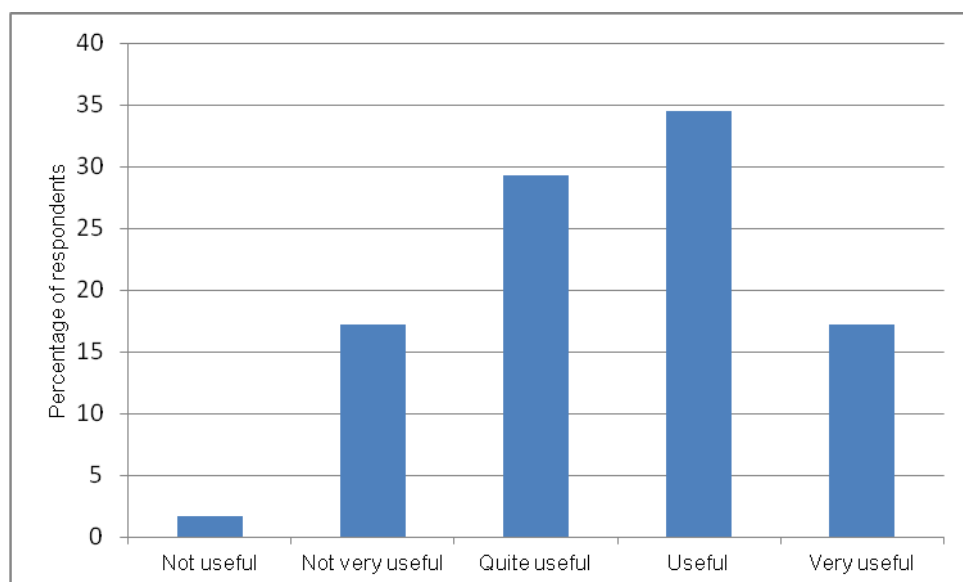
Respondents were asked how useful the record keeping guidance has been in helping them or staff who deliver end of life care to implement the national information standard (ISB 1580).

There were 58 responses and over 60% of respondents found the record keeping guidance to be either ‘quite useful’ or ‘useful’. A further 17% found the guidance to be ‘very useful’ (Table 18 and Figure 10).

**Table 18: The usefulness of record keeping guidance for respondents planning, implementing or operating EPaCCS**

Response	Responses	Per cent
Not useful	1	1.7
Not very useful	10	17.2
Quite useful	17	29.3
Useful	20	34.5
Very useful	10	17.2
Grand Total	58	100

**Figure 10: The usefulness of record keeping guidance for respondents planning, implementing or operating EPaCCS**



## 6.2 Requests for additional support

Respondents were asked if there was anything else they would like produced to assist other CCGs with implementation of the national information standard.

The most cited areas of feedback regarding ISB implementation included guidance and technical support around system interoperability, leadership around implementation of targets and milestones, national resources and information about funding and costs.

### 6.2.1 Guidance around system interoperability:

Feedback included requests for:

- access to technical advice and support
- guidance on system interfacing

- clearer guidance to clinical system suppliers around the interoperability requirements
- information about access options for GPs, hospices, 111 and out of hours
- clarity on the use of codes in GP practice systems

Respondents highlighted the importance of scoping IT systems in use across their locality when planning their EPaCCS solution.

### 6.2.2 Resources

Feedback around resources included:

- the value of regular meetings and workshops
- using workshops to develop guidelines around consent, information governance, clinical governance, public relations, and reporting requirements
- sharing experiences and information including a summary of the lessons learned
- guidance on developing information governance arrangements across multi-agency users/stakeholders
- provision of national guidance on sharing documents between disparate IT systems
- named person in national team to contact for support
- national guidance on engaging GPs, community services and acute hospitals
- linking guidance on advance care planning with implementation of EPaCCS
- easy access to all resources on an appropriate website

### 6.2.3 Information about national policies

Respondents asked for:

- clear and achievable milestones to be set out
- national data sharing protocols and policies
- more clarity about requirements and deadlines

### 6.2.4 Costs, funding, capacity and stakeholder issues

Respondents identified a need for:

- greater understanding of costs associated with all aspects of implementation in addition to the IT system solution, for example training, project management, maintenance and development costs
- greater appreciation that there are competing priorities and capacity issues that affect implementation
- provision of funding to support development

They also suggested that a publicity campaign to explain the advantages of EPaCCS to the public and professionals and guidance on getting clinical engagement would be useful.

## 7 General feedback

Respondents were asked to give examples of things that have gone well, impact for staff, for people and their families and examples of any difficulties encountered in the implementation of EPaCCS.

This section contains selected items of feedback to illustrate the main points made. A full list can be found in Appendix 2 (46 responses).

### 7.1 Benefits

Benefits reported by those with an operational EPaCCS included improved communication and ease of information sharing between professionals involved in a person's care (most frequently mentioned), and supporting carers, clinicians, ambulance and out of hours services to make appropriate decisions about a person's care.

Engaging with clinicians from all areas was seen as key to driving projects forward.

“Clinical engagement and leadership at all stages within the process has been key, as has engagement with other key providers of care e.g. community services, ambulance services.

“EPaCCS has made a great difference: OOH doctors and ambulance staff report that it is invaluable - if correctly updated. Our data shows that it makes a huge difference to where people die: All [local area] patients including those on EPaCCS: Home 20.6%, Acute Hospital 37.8%. [Local area] patients on EPaCCS: Home 47%, Acute Hospital 6%. We now have about a fifth of all deaths in [local area] on EPaCCS - the next challenge will be to increase this.”

For CCGs in the planning stage of implementation, the benefit of EPaCCS in bringing different agencies together and giving participants a better understanding of end of life care needs was highlighted.

“So far, during the planning phase, multi-stakeholder engagement and interest has been excellent. Planning meetings that started back in March 2012 have been well attended and a productive ten months of meetings have been held (prior to proof of concept and business case submission).”

“We have engagement and commitment from all key stakeholders. We have recently commissioned a new 24 hour palliative care service with a co-ordination hub and expect that the EPaCCS we develop will inform this work.”

Implementing EPaCCS was found to drive training, systems and cultural change in organisations and so forms part of the improvement process for end of life care services.

“Commissioning of a system with a provider that can also manage the training and implementation was considered vital to ensure that there are resources to dedicate to the implementation and the relevant skills to provide the training required.”

“There has been a clear improvement in communication among different parties looking after terminal patients in the community (GP practices, district nurses, hospices, matrons...). More non cancer patients have been added to End of Life register, although not showing yet on the sample. There has been no practice that once engaged has decided to drop out, perhaps the more clear indication it is a helpful tool.”

## 7.2 Challenges

For those respondents with an operational EPaCCS, the main challenges were reported as system interoperability, data ownership and consent, the engagement of GPs, clinicians and nurses, and the cost and funding of EPaCCS.

System interoperability was the most frequently mentioned challenge. Where providers within a partnership were using different lead systems that did not interface there were instances where data had to be entered manually or twice. The need for software suppliers to collaborate to resolve interoperability problems was highlighted and it was felt that NHS organisations had little influence in this area.

“One of the biggest local challenges is the different IT systems across the health community, which do not currently communicate with each other.”

“Main difficulty remains the IT interoperability with Ambulance, 111 and OOH [out of hours] and the fact GPs have to enter information twice as unable to 'cut and paste' from their existing IT software. [...] is exploring an IT solution and electronic system to capture and share patient information wider than EOL and whilst this is a positive step has resulted in conflicting priorities.”

Data ownership and consent was something also raised as an issue by a number of CCGs.

“There are big concerns from GP colleagues about the impact on confidentiality and getting consent from patients for sharing information. This will be our biggest hurdle to overcome in implementing EPaCCS.”

Engaging with general practice and other clinical services was challenging when systems did not meet expectation, or when staff did not integrate EPaCCS into existing clinical systems.

“Major difficulty we have is getting the GPs to use the register. Biggest win we could have is the software to pre-population register from GP clinical system.”

Funding was also a consideration for some, including in one area identifying the need to “secure funding for the long term provision of excellent palliative care support.”

## 8 Conclusions

This report is the first to provide a comprehensive overview of EPaCCS in England since the re-organisation of the NHS and the emergence of CCGs. It illustrates that EPaCCS is a complex project that aims to support end of life care co-ordination across a multitude of different agencies. The majority of CCGs are working in partnership with each other and with other agencies to implement systems.

It is still early days for EPaCCS implementation, with around one third of CCGs with operational systems and only a few of these able to report on data from the systems in this survey. The available data, however, does suggest that the use of EPaCCS helps people to die in their preferred place of death, decreases the percentage of hospital deaths and increases in the percentage of deaths at home and in hospices.

There was much positive feedback in areas where EPaCCS have been implemented. The greatest benefits were identified as improvements in communication and information sharing between healthcare professionals and support for making appropriate decisions about patients' care.

EPaCCS supports patient choice, shared decision making, individual care planning and integration of care across sectors. It is expected to play a significant role in supporting the care integration agenda, including the Integrated Care and Support Pioneers Programme. Over the coming years we expect to see an increase in the number of systems to which social care services have access.

Successful implementation of EPaCCS requires the appropriate configuration of systems, services and infrastructure. For many CCGs this has raised a number of issues, such as system interoperability, stakeholder engagement, data ownership, costs, information support and funding, which need to be resolved to ease implementation.

Although CCGs were able to provide certain information, they often had little access to data and a poor understanding of technical issues for EPaCCS management. We hope to build a better database of EPaCCS leads across the CCGs so that we improve the

accuracy and reduce discrepancies in future surveys. Future work needs to determine which stakeholders are best able to provide this kind of information.

## 9 Recommendations and next steps

This report provides an overview of EPaCCS implementation across England. It includes information about systems and approaches being used and shares the learning and experiences of implementers. This will be useful to all those implementing or planning local EPaCCS or other electronic co-ordination systems.

Those planning EPaCCS should be aware of the value and importance of system functionality to report on activity and the impact of implementation, for example on place of death.

The report will also be useful to IT systems suppliers and there are important messages regarding the need for system suppliers to work together to support interoperable systems.

It will inform the national team supporting EPaCCS implementation about the current status of EPaCCS implementation and provides valuable feedback from implementers on the additional support required.

The report also provides information for the Standardisation Committee for Care Information (SCCI) (formerly the Information Standards Board) on the progress of EPaCCS implementation and the impact of the national information standard for end of life care co-ordination.

The report, together with the Electronic Palliative Care Coordination Systems mid-2012 survey report, will be used to monitor future progress in EPaCCS implementation.



## References

1. NHS Improving Quality. **Economic evaluation of Electronic Palliative Care Co-ordination Systems (EPaCCS) early implementer sites**. February 2013.
2. National End of Life Care Programme. **Electronic Palliative Care Coordination Systems (EPaCCS) Mid 2012 Survey**. Report October 2013.
3. Department of Health. **End of Life Care Strategy: promoting high quality care for adults at the end of their life**. July 2008.
4. Ipsos Mori. **End of Life Locality Registers Evaluation**. Final report June 2011.
5. **ISB 1580 End of Life Care Co-ordination: Core Content**
6. Public Health England. **What we know now. New information collated by the National End of Life Care Intelligence Network**. November 2013.

# Appendix 1: Survey questionnaire

## EPaCCS: 2013 Survey

This survey aims to capture progress towards implementing EPaCCS (Electronic Palliative Care Co-ordination Systems) for end of life care across England. Your response will help to inform the national team how local implementation can be best supported. It is hoped that this survey will also contribute towards the case for change, building end of life intelligence and supporting people to experience a better death.

It is suggested that the survey is completed by CCG end of life care leads or their nominated representative.

Please contact Robert Mulliss at [robert.mulliss@swpho.nhs.uk](mailto:robert.mulliss@swpho.nhs.uk) if you have any questions.

### Section 1. Respondent Details

1. Respondent name

*Freetext*

2. Respondent job title

*Freetext*

3. Your organisation (CCG)

*Freetext*

4. Telephone contact number

*Freetext*

5. Email address

*Freetext*

6. Are you happy for us to share your contact details with others interested in EPaCCS?

*Yes / No*

### Section 2. EPaCCS in your CCG

7. Is EPaCCS operational in your CCG?

Note: EPaCCS (to co-ordinate end of life care) is defined as operational when there is a functioning electronic system(s) or process(es) linking care providers across a locality.

*Yes / No*

8. If EPaCCS is not operational has planning started?

*Yes / No*

9. If planned or operational, is EPaCCS limited to your own CCG geography?

*Yes / No*

*If no, please list the other CCG's covered*

*Freetext*

10. Which organisation hosts (or will host) the EPaCCS system being used in your CCG?

Free text

11. Please tell us the date that EPaCCS went live or if in planning stage what is the anticipated start date?

Free text

12. Which lead technical system is being used or planned to be used if the project is in the planning phase?

- Adastra
- SystemOne
- Vision
- SCR
- Graphnet
- Other (please specify)
- SystemC
- EMIS

### Section 3. Live EPaCCS Systems in your CCG

13. How many people have been added to the EPaCCS register since inception?

14. How many people with an EPaCCS record died between 1 June 2012 and 31 May 2013?

15. How many people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 had their preferred place of death recorded?

16. How many people with an EPaCCS record who died between 1 June 2012 and 31 May 2013 died in their preferred place of death?

17. Of those with an EPaCCS record, dying between 1 June 2012 and 31 May 2013, how many died at:

Hospital	
Care Home	
Hospice	
Home	
Other	

18. What percentage of people with an EPaCCS record that died between 1 June 2012 and 31 May 2013 had cancer as the main cause of death?

 %

19. Please indicate in the table below which care settings have access to the information in the EoLC co-ordination record and in which formats.

	No access	Sent via letter or fax	Access via co-ordination centre	Access via shared web interface/viewer	Information shared via automated email	Direct electronic system to system transfer	Batch/overnight electronic transfer
GP							
Out of hours							
Ambulance							
Hospital A&E							
Hospital other than A&E							
Community health providers							
Social care							
Specialist palliative care							

Other:

*Freetext*

20. Is any information shared through EPaCCS incorporated into and / or synchronised with other clinical systems

Yes / No

21. Please specify the CCGs that the information provided for in this section (Section 3) represents

*Freetext*

#### **Section 4. EPaCCS and the National Information Standard**

This section is to be completed by CCGs where an EPaCCS or other end of life care co-ordination system is in operation or where implementation has started. The national information standard ISB1580 defines the core content to be held in EPaCCS or other EoLC co-ordination systems and specifies the requirements for implementation. Guidance has been produced to support the implementation of the national information standard (ISB1580)

- Implementation guidance
- Record Keeping Guidance

22. How useful has the implementation guidance been in helping you, or your system suppliers to implement ISB1580?

*Very useful*

*Useful*

*Quite useful*

*Not very useful*

*Not useful*

23. How useful has the record keeping guidance been in helping you or your professional staff that deliver EoLC to implement ISB1580?

- Very useful*
- Useful*
- Quite useful*
- Not very useful*
- Not useful*

24. Is there anything else you would like produced to assist other CCGs with implementation?

*Free text*

25. Do all contracts for electronic palliative care co-ordination systems issued after March 2012, include the requirement for the system to contain the core content defined in the national information standard for end of life care co-ordination?

*Yes / No*

26. Do IT systems that hold any of the data items included in ISB1580 comply with the standard?

Category	Fully compliant	Not fully compliant	Not collected
Record creation date AND record amendment dates			
Planned review date			
Person's details			
Main informal carer			
GP details			
Key worker			
Formal carers			
Medical details			
Just in case box/anticipatory medicines			
End of life care tools in place			
Advance statement			
Preferred place of death			
Do not attempt cardio-pulmonary resuscitation			
Person has made an advance decision to refuse treatment (ADRT)			
Name and contact details of Lasting Power of Attorney			
Other relevant issues or preferences around provision of care			
Names and contact details of others that the person wants to be involved in decisions about their care			

Comments

*Freetext*

27. Does the EPaCCS or other IT co-ordination system comply with user interface standards and to NPSA guidelines for safe on-screen display of medical information? For further information please see guideline for safe on-screen display of medical information and the website of the Health and Social Care Information Centre.

*Yes / No*

28. Was clinical safety risk assessment carried out prior to implementing EPaCCS or other IT co-ordination system and a risk control system put in place? For further information please refer to the Information Standards Board for Health and Social Care ISB 0129 and ISB 0160.

*Yes / No*

29. Please inform us if any high risk/ unacceptable clinical risks were identified?

*Freetext*

### **Section 5. Feedback**

Your feedback is important and we invite you to give any comments you may have about the implementation of EPaCCS; examples of things that have been gone well, impact for staff, for people and their families and examples of any difficulties encountered.

*Free text*

Thank you for completing this survey

## Appendix 2: Full list of feedback

“As this has been a project led locally by The Hospice in our area - we have had some teething problems with the integration of IT systems and are now planning to implement it using [system] and will have more information to share in future months.”

“Three month trial currently under way in a large practice [...] - information to be available to inform full roll out in the autumn/early winter.”

“EPaCCS is only at the discussion stage in [...] - meetings are talking place and it remains on the agenda for the future but it will be some time before any definite progress is made with regard to implementation.”

“Frustratingly slow for staff in hospitals to have been given access to the [system] viewer. Still no progress on integration with hospital IT systems. No integration with [system] (used by 111 provider) or [system]. The lack of integration with other computer systems is a disgrace. Sadly, no one seems to be capable of forcing software companies to cooperate over this.”

“GPs maintain that functionality of the [...] EPaCCS system is poor. All demographic data has to input manually and cannot be populated from GPs systems currently. This results in a lack of willingness to use the system. We are working with service users to improve data entry onto the system. In [...] the platform was moved from the [...] Hub to a Hub provided by [...] (as the new provider) in March 2013. The CSU or CCG does not hold the license for [system] which has resulted in difficulties in accessing expertise to extract the data required for this return. [...] are currently working with [system] on this. All [...] CCGs are working to resolve this issue. The [system] platform transferred from the [...] Hub to [...] (the new host provider) in March 2013. This caused additional problems for users and data retrieval which compounded the issues articulated above.”

“The EPaCCS will be a component of our [...] Integrated Care Records system and cannot be seen as a separate entity. This is clearly a large piece of work but it is our intention that End of Life Care information provision should be one of the first deliverables and that any functionality should be compliant with the requirement.”

“We use a single electronic patient record across all NHS palliative care settings. The only exception is the in-patient facility at the local hospice who are planning to move to [system] but funding now the PCT's have gone needs to be established. All information regarding this patient groups is recorded once and once only into each services clinical record. There is no requirement to keep a register updated. There is no duplication of record keeping. When palliative information is recorded for the first time in any clinical setting the system prompts the clinician to record a [note] on the record. That note acts

as a flag which is immediately visible to the NHS111 call handlers who use the same system, the caller is then transferred to a clinical member of staff who can with patient consent open and review the very latest clinical information.”

“Staff, are always presented with the latest information in all care settings. They are able to always build upon the assessments of colleagues in other services rather than start from scratch. They are able to communicate directly through the system to all other providers of care. They are able to see exactly what other services are involved and refer electronically to services not yet involved. Patients who present in both planned and unplanned care settings are met by staff who have direct access (with their consent) to the full care record creating a seamless provision of service across multi-agencies. The introduction of the new data sharing model with [system] has caused issues in the short term with some practices being unwilling to share their records as they are not confident with the new process. However this is being overcome by the obvious clinical need of this patient group to provide integrated care. All information is recorded contemporaneously during the consultation and when appropriate, this is done on mobile devices from within the patient’s home. We are fortunate to have one system for 95% of our GP’s, all of community services, including District and MacMillan Nursing, 111 & OOH, in-patient secondary care, A&E, day care and hospice at home services. The only palliative care service currently outside of this is the in-patient hospice facility who are planning to move to the same system in early 2014.”

The EPaCCS model chosen for [...] is at implementation stage. We were keen from the start to design a register which would be adopted and updated by GPs, and easily accessible to, in particular, the [...] Ambulance Services Trust for facilitating urgent and out of ours care. We chose [system] as the strategic option, and given the high achievement of generating [system] records in [...] most compliant systems have now been turned on and tested for electronic messaging. Where a record as been enriched the feedback has been positive from the Urgent Care Services who have many examples of the electronic record avoiding admission. Roll out is at an early stage with challenges around the GP ownership of the enrichment of records and the slow move to other professionals having data entry rights.”

“The [...] CCG has been working with colleagues from a range of agencies to consider the approach to be taken to develop the EPaCCS, this has included the neighbouring CCG ([...]), the [...] NHS Trust, the [...] NHS Foundation Trust, the [...] City Council, the [...] Council, and local hospices, particularly the [...] Hospice and Marie Curie. The recommendations from the group undertaking this work was that [system] should be the system of choice in this area. The [...] CCG held a workshop for the Governing Body to consider how the EPaCCS should be implemented locally and it is hoped that a decision will be made in October.”



“So far, during the planning phase, multi-stakeholder engagement and interest has been excellent. Planning meetings that started back in March 2012 have been well attended and a productive 10 months of meetings have been held (prior to proof of concept and business case submission).”

“We have half of our practices using [system] and half on [system]. We don't really feel that we have EPaCCS as, although [system] links with community nursing and our acute trust there is no linkage with LA.”

“The questions in Section 4 of this survey cannot be answered accurately as it assumes that the respondent is knowledgeable about the technical aspect of the [...] system and the [system] data ware house reporting facility which can only be directly accessed by [system] and not the respondent. Some of the issues we have had with [system] are: interoperability issues between GP systems and Connectivity issues in Nursing homes unable to access [system] as a result. Some of the positive examples include the ease of information sharing between health care professionals involved in patients care. 111 Provider from [...] noted that the records are useful in helping their clinical advisors to further probe the patient to understand their symptoms and recommend the most appropriate care setting that aligns with their care plan.”

“The National Evaluation of EPaCCS was incredibly helpful as it enabled the clinical group to understand the issues experienced by other areas during the pilot. Personal contact with pilot site representatives was illuminating in terms of challenges and continuing practical issues. Implications of implementing in line with guidance now fully understood. Local learning has been the importance of 'end to end' sign up across the health community, especially at primary care level before EPaCCS can deliver. The Economic Impact of EPaCCS document was also very useful in understanding the modelling required to understand the entire cost of implementation and for commissioners to understand the likely potential gains achieved through the investment. Where areas are already performing above national averages (like [...]), the investment required is unlikely to yield a correlated improved performance. Therefore, clinicians are now considering next steps.”

“We have engagement and commitment from all key stakeholders. We have recently commissioned a new 24 hour palliative care service with a co-ordination hub and expect that the EPaCCS we develop will inform their work.”

“Good points: Promoted record sharing, more co-ordinated meetings, information easier to find in patients records leading to better co-ordinated care, supports identification of palliative care patients. Problems: Difficulty in recording requested information due to codes not being in existence, lack of interoperability between clinical systems, initial engagement & sustainability with General Practice Services across a large city using different clinical systems.”

“Major difficulty we have is getting the GPs to use the register. Biggest win we could have is the software to pre-populate the register from GP clinical system.”

“The EoL Board has discussed this and agreed to take it forward. The CCGs are tendering for a Principal Provider/ Managing Agent role for this area of work and the electronic register will be something we expect them to implement.”

“Project has brought providers and commissioners closer together and improved their working relationship. The acute hospital has been unrealistic in their expectations. They wanted a system that interfaced automatically with their IT system so that EoL details would be apparent to any clinician accessing the hospital's electronic records. Unfortunately, their own system is not yet complete, so this expectation was impossible to fulfil! They have finally agreed a compromise and should be able to access all information as required.”

“We are looking at solution currently as we have 2 key systems that currently do not connect therefore it is difficult to answer the attached questions.”

“One of the biggest local challenges is the different IT systems across the health community, which do not currently communicate with each other.”

“We would need to consider further the benefits or otherwise of EPaCCs. At this stage we have not considered this any further. Thank you.”

“Although we are not currently progressing this workstream in our EOLC programme we have considered the benefits and are not currently swayed enough of this but would be keen to hear how others are doing on this and will keep this ‘on hold’ as a project until we have more information. We do believe that we want to create the ‘behaviours’ that would be required if we did have a system where care plans could be shared i.e. identification of people who may be at the end of life, personalised care planning/advance care planning, integrated care across all providers. We also feel GP education and training (as well as other health and allied professionals) in having difficult conversations etc will be key and we want to take these aspects forward first. We are developing a local model of care and are focusing as a priority on ensuring that patients receive high quality end of life care at all stages.”

“Loads of enthusiasm to overcome IT difficulties. Communicating between several different IT systems has been problematical but we believe that all appropriate clinical personnel will now have access to EOLC special notes by the end of September.”

“During the end of 2012, [system] training was delivered to clinicians within the [...] health economy as a part of the 111 rollout. Unfortunately this training programme did not result in a successful go-live of [system]. The following items were identified as

requiring resolution prior to any further [system] training delivery in the [...] health economy: - The lack of Integration between IT systems thus causing duplication - A clear system process of how [system] works between various providers - The future costs of [system] and CCG approval - A clear transition/cut over plan for moving to [system] from special patient notes - Clear decision around who owns the record and who is responsible for ensuring consent - No funding available to support any [...] arrangements for GPs to raise records on [system] - A clear workaround process for Nursing homes and Hospices that is agreed and sustainable until Non N3 access is working - The role of [...] in the rollout and transition to [system] from special patient notes as the Out of Hours provider - A local policy on e-mail alerts - The impact of the lack of no “real time” updating of [system] on clinical risk from District/Community Nurses.”

“We have completed the survey as far as possible. However, please note that we do not have a fully implemented EPaCCS system. A number of MDTs and specialist palliative care services identify patients who are in their last year of life and record information regarding diagnosis, patients’ understanding of their diagnosis, prognosis and aims of treatment, key workers and contact details, foci of care and management plan recommendations for consideration by GPs. This information is then emailed or faxed in letter format to the relevant GP so they can consider adding the patient to their own practice EOLC register and implementing the management plan recommendations.[...]”

“We are actually in a pre-implementation stage - a bid for funds has been made to the DH but the outcome is not yet known. We have had a couple of false starts where funding has not been forthcoming for other ideas. These answers would also hold true for [...] CCG.”

“EPaCCS has made a great difference: Out of hours Drs and ambulance staff report that it is invaluable - if correctly updated. Our data shows that it makes a huge difference to where people die: All [local area]patients including those on EPaCCS: Home 20.6%, Acute Hospital 37.8%. [Local area] patients on EPaCCS: Home 47%, Acute Hospital 6%. We now have about a fifth of all deaths in [local area] on EPaCCS - the next challenge will be to increase this.”

“Main difficulty remains the IT interoperability with Ambulance, 111 and out of hours and the fact GPs have to enter information twice as unable to 'cut and paste' from their existing IT software. [...] is exploring an IT solution and electronic system to capture and share patient information wider than end of life and whilst this is a positive step has resulted in conflicting priorities.”

“We are in very early stages we have produced an Initial Proposal which we are discussing at a [local area] wide group on 9th September then will go to the Governing Bodies.”

“We have not implemented EPaCCS yet and so we have no local learning to share - other than to say that we are procuring our EPaCCS to work with the operational system locally for our end of life patients and not change anything just to suit a software system.”

“It has been difficult to get GPs to fully embrace it and integrate it into their clinical systems. We plan to have another stab at it before the end of the year to look into what things have hampered practices.”

“Although not yet in place, we can see the benefit of having instant access to records which can be updated at that time, and then accessible to anyone who requires them.”

“We carried out an electronic consultation prior to clinical workshops to keep the clinical time required down to a minimum. This worked really well. We are about to go into Development of the Product.”

“Commissioning the system whilst managing the NHS transition has been challenging and this has delayed the implementation within the CCG. To ensure success the CCG has made end of life care and the implementation of an EPaCCS system a priority within the organisation and linking the use of the system across the health economy through CQUINS, QOF/QP. Clinical engagement and leadership at all stages within the process has been key as has engagement with other key providers of care e.g. Community services, Ambulance services. Commissioning of a system with a provider that can also manage the training and implementation was considered vital to ensure that there is the resources to dedicate to the implementation and the relevant skills to provide the training required.”

“The whole EOLC system in [...] recognises the value of the [system] EPaCCS. However, the current version is "clunky" and not user friendly which puts users off! Systems need to be slick, intuitive and integrated with other systems eg [system] to be fully effective and utilised to their full capacity. We are hoping [system] will be vastly improved with the re-procurement process that is currently underway. When the sharing of up-to-date information about a patient and their wishes across agencies works effectively, it is the most brilliant thing and makes a huge difference to the patient, family and those involved with the patient. We all need to hold on to that thought when working through the implementation difficulties!.”

“There are big concerns from GP colleagues about the impact on confidentiality and getting consent from patients for sharing information. This will be our biggest hurdle to overcome in implementing EPaCCS.”

“Its early days for use in [...] CCG and records have been uploaded slowly/reports and analysis not yet in a position to be conducted due to go live in June 2013. We will start analysing some initial results around Christmas time.”

“There has been a clear improvement in communication among different parties looking after terminal patients in the community (GP practices, district nurses, hospices, matrons...) More non cancer patients have been added to End of Life register, although not showing yet on the sample. There has been no practice that once engaged has decided to drop out, perhaps the more clear indication it is a helpful tool.”

“Very useful to work on joint approach in [...] and [...] palliative care academy.”

“Project leads are now re-connected but the landscape and architecture is still developing!”

“It is difficult to provide answers to Q10, Q11 and Q12 as a decision hasn't been made by the CCG as to who the preferred host organisation will be. An options paper to understand the benefits and risks of the systems available will be prepared and considered by the various CCG approval bodies. EPaCCS will form part of the Integrated Care programme that is currently being developed across [...] providers which is being led by the Community Trust. The CCG is currently experiencing delays in receiving technical support from the local IT service.”

“We have requested many times over the years to be connected in any way to the NHS system to ensure effective coordination of care.”

“Project leads are now re-connected but the landscape and architecture is still developing!”

“It's very early in the planning here – PID not done yet.”

“Implementing an EPaCCS is so much more than the setup of an IT system; it represents a culture change and requires a change management approach for the clinicians and patients involved. The commissioning requirements for an EPaCCS includes an electronic solution, as well as the provision of clinical knowledge, training, education, governance infrastructure, reporting facility and project management capacity to effectively implement this system in Primary, Community Care and other providers. Having provided initial training for professionals in EoLC it will be important for this to be consolidated with extended professional development in palliative care. [...] has plans to offer advanced training as part of its service and training delivery. In addition, [...] will be developed to offer personalised care plans for patients with long term conditions, dementia and extended to additional groups.”