NHS
National End of Life Care Programme
Improving end of life care




Electronic Palliative Care Coordination Systems (EPaCCS)
Mid 2012 survey report

Contents

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With thanks to the EPaCCS Implementation and dataset management group and all others that contributed to the design and completion of the survey and this report

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Overview

On behalf the National End of Life Care Programme (NEoCLP) and EPaCCS Implementation and Dataset Management Group (I&DMG), a survey was developed that was aimed at gathering PCT-level data on the rollout of EPaCCS. The survey was conducted in July 2012 and will be repeated in December 2012.

Note: An earlier survey was circulated in late 2011/early 2012 to SHA leads to take a snapshot of project implementation status. This report does NOT cover findings from the earlier SHA baseline survey.

Purpose

The survey was required to gather the following data for the EPaCCS implementation support project being led by the I&DMG:

- Completeness of core dataset
- IT Systems being utilised for EPaCCS, where hosted, defined data owner
- Number of people on EPaCCS and eligible population
- Proportion of deaths with EPaCCS recorded within the eligible population
- Number and proportion of people on EPaCCS with preferred place of death (PPD) recorded that died in PPD
- Spread of professional groups with access to EPaCCS:
  - ☐ GP
  - ☐ OOH Services
  - ☐ Ambulance Service
  - ☐ A&E
  - ☐ Community
  - ☐ Social care
  - ☐ Specialist palliative care services

In addition, there was a wider need to measure the spread of EPaCCS, a requirement to measure how consent was managed to both view and upload the record for the Information Standards Board and a desire to support peer-to-peer collaboration between people using specific systems and/or at specific project stages.

Methodology

The original questions were developed in conjunction with the I&DMG and tested with a number of EPaCCS early implementers for comment in advance of circulation in July 2012. Responses were invited from SHA leads (via cascade), EPaCCS roadshow attendees, and known EPaCCS contacts.

Many respondents responded at a PCT or CCG level from across the country. However a regional response was received from the following SHA areas:

- London
- South Central

PCT was used as a basis for responses as this reflected current contact and data organisation, thus enabling easier despatch of the information, and subsequent comparison to other data sources.

About the respondents

The following data indicates where a PCT area could be identified from responses.

SHA region	Responses
East Midlands Strategic Health Authority	3
East of England Strategic Health Authority	12
London Strategic Health Authority	1
North East Strategic Health Authority	6
North West Strategic Health Authority	9
South East Coast Strategic Health Authority	7
South West Strategic Health Authority	12
West Midlands Strategic Health Authority	8
Yorkshire and the Humber Strategic Health Authority	8
#N/A	11
Grand total	**77**

Executive summary

The rollout and impact of EPaCCS is progressing well when compared to the stage the country was at in 2011, when pilot sites reported on progress. Findings support the direction of travel for national EPaCCS support, to mirror local requirements and facilitate the sharing of best practice.

EPaCCS projects are well underway across the country, with 14 sites reporting that they have implemented such systems, and a further 10 partially implemented. This covers much wider than solitary PCT geographical areas; London and the South West are also some way down the track to rolling out EPaCCS. This is an impressive leap from the *2010-11 Locality register pilot sites report*, which featured eight pilot sites.

Adastra is reported as the system most in use, with 10 of the 14 sites who have implemented using the system. Partial implementations use a mixture of Adastra, SystmOne, SCR and other systems. Those who are planning to deploy EPaCCS are looking at the use of the Summary Care Record more than Adastra and SystmOne, perhaps reflecting the more widespread implementation of the record across England.

It would appear that some systems seem to dominate in particular regions, although there are important local variations. In the South West SHA region, for example, Adastra is largely in use (7 respondents). However SCR is also being explored in this area (2 respondents). In the East of England, SystmOne (6) appears popular; but again SCR (1) is being planned. Areas such as London (System C) and North West (Graphnet) are making significant advances. EMIS Web is also being explored in three areas. There is no single solution taking hold across the country. Most (11 of 19) Adastra implementations are hosted by out of hours providers; for SystmOne, various hosts are involved. For SCR, the GP is the host for four from eight projects.

Figures provided show that 29,365 individuals were recorded on EPaCCS. This means around one in seven deaths on average are on EPaCCS in those areas that provided figures. However this masks wide variations; South central reported 5,829 on the EPaCCS; London 1938. Other areas were at too early a stage to provide data. From the data we have, 4363 are reported as having Preferred Place of Death recorded. 1453 are reported as having achieved Preferred Place of Death. Further work on establishing a comparable dataset is underway.

Compliance with the Information Standards Board dataset is healthy; 8 projects were fully compliant, and another 21 had some work to do. Only 3 were non-compliant but were working towards it.. Consent to both upload and view records was used in 17 of the 37 who answered the question.

Access was best for GPs, specialist palliative care and out of hours teams across the board, and using all major systems; social care had little to no access.

Most respondents were willing to share contact details (56 of 77) and information about their projects (49); and most predicted they would be able to respond to the survey in six months' time (63).

Lessons learned

Although data gathering is at an early stage, EPaCCS implementations show that they are having a positive effect on quality and productivity.

PCT contacts are disappearing due to system reconfiguration changes; it is therefore important to maintain contact with survey respondents over the coming weeks and months.

The survey questions need further definition, especially around performance data.

Recommendations

- **Revise data requested – potentially through national reporting framework**
- **Encourage co-working between users of similar systems**
- **Provide guidance on use of SCR as EPaCCS**
- **Identify and share good practice in providing access for social care**

Project status

SHA region	Responses
EPaCCS has been implemented throughout the area	14
EPaCCS is partially implemented throughout the area	10
EPaCCS planning has not started	7
EPaCCS planning started but not yet implemented	17
(blank)	29
Grand total	**77**

Project spread

The following graphic indicates the spread of EPaCCS from the 2010-11 Locality register pilot sites, to the reported activity from the survey. The background layer represents CCG (Clinical Commissioning Group) boundaries.

Locality register pilots (2010-11)

Projects being planned/partially implemented

Mid 2012 status update

Projects being planned
Partial implementation
Full implementation

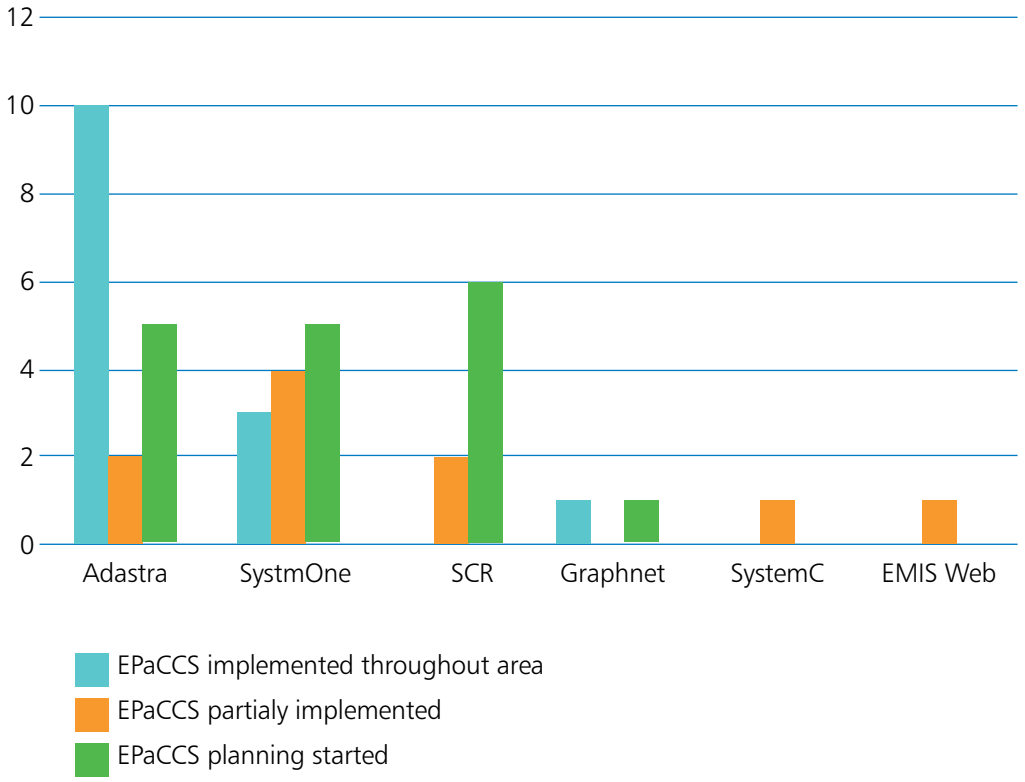
Map data © 2012 Basarsoft, GIS Innovatsia, GeoBasis-DE-BKG (©2009), Google, Tele-Atlas 2011 Google CCG geographical data sourced from NHS Commissioning Board, June 2012

Total systems in use/planned

This includes free text fields, and so will be greater than the total numbers of systems by status number.

System	Number
Adastra	19
SystmOne	13
SCR	8
EMIS Web	3
Graphnet	2
SystemC	1
GP systems EMIS, Vision	1
IPM, Emis, Lorenzo, Crosscare	1
iSOFT EPR	1
Web based in house system	1

EPaCCS systems by project status



System by SHA

This information is worked out from the PCT covered by the respondent.

SHA region	Adastra	SystmOne	SCR	Graphnet	SystemC	Other
East Midlands Strategic Health Authority	1	1				1
East of England Strategic Health Authority		6	1			1
London Strategic Health Authority	1				1	1
North East Strategic Health Authority	2		2			
North West Strategic Health Authority	1			2		6
South Central Strategic Health Authority	1					
South East Coast Strategic Health Authority	3		2			2
South West Strategic Health Authority	7		2			
West Midlands Strategic Health Authority	3	2				4
Yorkshire and the Humber Strategic Health Authority		4	1			2

System host

Host	Number
Out of hours	12
Other	10
GP	6
Hospice	6
Hospital	2
Community nursing	1

The Other responses covered various hosts, including a cross-PCT hub, NHS Shared Services, a community provider, a Foundation Trust, and a CCG.

Host organisation by system

Host	Adastra	SystmOne	SCR	Graphnet	SystemC	EMIS Web
Community nursing		1				
GP			4	1		1
Hospice	3	1				
Hospital	1				1	
Other	3	6	2			1
Out of hours	11	3				1
(blank)	1	2	2	1		

PCTs and CCGs covered

Five respondents were based in the same PCT. Six respondents answered for more than one PCT, mostly around systems that cover more than one PCT. The EPaCCS implementations in London cover 4 PCTs; in South Central, 2. This means that responses covering 61 PCTs were gathered through the survey.

PCTs covered	Responses
Bath and North East Somerset	1
Bedfordshire	1
Berkshire East	1
Bolton	1
Bournemouth and Poole Teaching	2
Bradford and Airedale Teaching	1
Cambridgeshire	1
Central and Eastern Cheshire	1
Derbyshire County	1
East Sussex Downs and Weald AND Hastings and Rother	1
Eastern and Coastal Kent	1
Gloucestershire	1
Halton and St Helens	1
Kirklees	1
Leeds	2
Lewisham	1
Medway	2
Norfolk	1
North Somerset	2
North Staffordshire	1
North Tyneside	1
North Yorkshire and York	1
Nottingham City	1

PCTs and CCGs covered (continued)

PCTs covered	Responses
Nottinghamshire County Teaching	1
Peterborough	1
Salford	1
Sefton	1
Sheffield	1
Shropshire County	1
Somerset	1
South East Essex	1
South Gloucestershire	1
Stockton-on-Tees Teaching	1
Stoke on Trent	1
Suffolk	1
Sunderland Teaching	2
Swindon	1
Trafford	1
Warwickshire	1
West Kent	1
Wiltshire	1
Wolverhampton City	1
Worcestershire	1
(blank)	29
Grand Total	**77**

When prompted, 13 respondents indicated they were answering on behalf of a Clinical Commissioning group (CCG).

PCTs covered	Responses
NHS Bedfordshire CCG	1
NHS Dorset CCG	2
NHS Gloucestershire CCG	1
NHS Medway CCG	1
NHS North Derbyshire CCG	1
NHS North Somerset CCG	1
NHS North Staffordshire CCG	1
NHS North Tyneside CCG	1
NHS South Worcestershire CCG	1
NHS Southend CCG	1
NHS Stoke on Trent CCG	1
NHS Wolverhampton CCG	1
Grand Total	**13**

Performance data

Not all respondents indicated eligible population. Of those that did, a population of 17,968,616 is covered.

Around 1% of the population dies each year. As such, around 180,000 deaths would be estimated for the eligible population.

Figures provided show that 25,177 were on EPaCCS. This means around one in seven deaths on average are on EPaCCS in those areas that provided figures.

However this masks wide variations; South central reported 5,829 on the EPaCCS; London 1938. Other areas were at too early a stage to provide data.

- 3,950 are reported as having Preferred Place of Death recorded.
- 1,502 (38%) are reported as having achieved Preferred Place of Death.

However the provision of accurate data was seen as problematic due to project lifecycle, multiple systems, data 'hugging', and no standard reports in place. Comments included:

- Because we are using GP systems (we have 4 different systems in the CCG) we have not got central reporting routes set up yet.
- Data being held elsewhere, ie in hospice and non-EPaCCS systems.
- The PCT is not being helpful with sharing data
- PCT has previously recorded place of death rather than preferred.
- The implementation of this project has been difficult, [system] reporting is not good and has significantly impacted the progress we have been able to make
- One project reported that they have not been able to separate data for living and deceased patients.

However audits are under development and Somerset has a reporting template in use across many areas of the South West. The data supplied, and feedback on the questions from survey respondents, will inform future question sets (see ***Lessons learned*** below).

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As the data is still in development, the figures below are indicative only. The eligible population given is less than the one indicated above as the table below includes only those respondents that included numbers on EPaCCS.

What is the eligible (total adult) population covered by the system?	How many people are on the EPACCS system? Please enter for calendar year if possible.	What % age of all deaths in your district were on register? Please enter for calendar year	Please enter the timeframe for the data you have provided	How many people have Preferred Place of Death (PPD) recorded?	Proportion with PPD recorded (overall)	What number of people achieved PPD?	Of those who died in last 12 months and on register, what %tage achieved PPD?	Place of death: Hospital	Place of death: Care home	Place of death: Hospice	Place of death: Home	Place of death: Other
409,200	1,421	10.60%	Jan 2011-Dec 2011	957		474						
335,000	1,371		not possible									
196,000	175	11%	April 2011 - March 2012	63		23	64%	11.0%	37.0%	19.0%	27.0%	5.0%
7,000	90	100%	02.04.12 to date	90		51	100%	1.0%	0.0%	1.0%	98.0%	0.0%
400,000	653	49%	December 2012 to July 2012	135		85		12.0%	3.0%	22.0%	62.0%	1.0%
800,000	115		Nov 2011 - July 2012	153								
280,000	200	12%	quarter 1 2012/13	71			70%					
555,500	624		1/11/11 to 30/6/12									
178,000	200						60%					
179,700	695			193		12						
360,000	1,053	33%	April 2011- April 2012	524		420	70%	18.3%	21.5%	9.2%	45.6%	4.0%
550,000	10,000	20%	11/12/2012	200				21.0%	3.0%	11.0%	31.0%	4.0%
610,000	39											
200,000	1,000		04/11/2012									
878,100	5,829		as of April 2012									
500,000	1,591		Jan-Dec 2011	643		295	46%	18.0%	22.0%	27.0%	33.0%	0.0%
600,000	17		Financial year Apr 2011 to Mar 2012									
292,400	989		12/01/2011	989				56.5%	16.0%	0.0%	25.4%	2.0%
256,700	500		Go live was July 2011.									
770,000	1,938		07/01/2012					25.0%	18.0%	13.0%	31.0%	13.0%
190,316	865		Apr 2011 – March 2012	345		93	42%	4.0%	35.0%	3.0%	14.0%	44.0%
8,547,916	**29365**	**33.66%**		**4363**	**15%**	**1453**	**59%**	**18.5%**	**17.3%**	**11.7%**	**40.8%**	**8.1%**
n=21	n=21			n=12	n=12	n=8	n=7	n=9	n=9	n=9	n=9	n=9

ISB dataset compliance

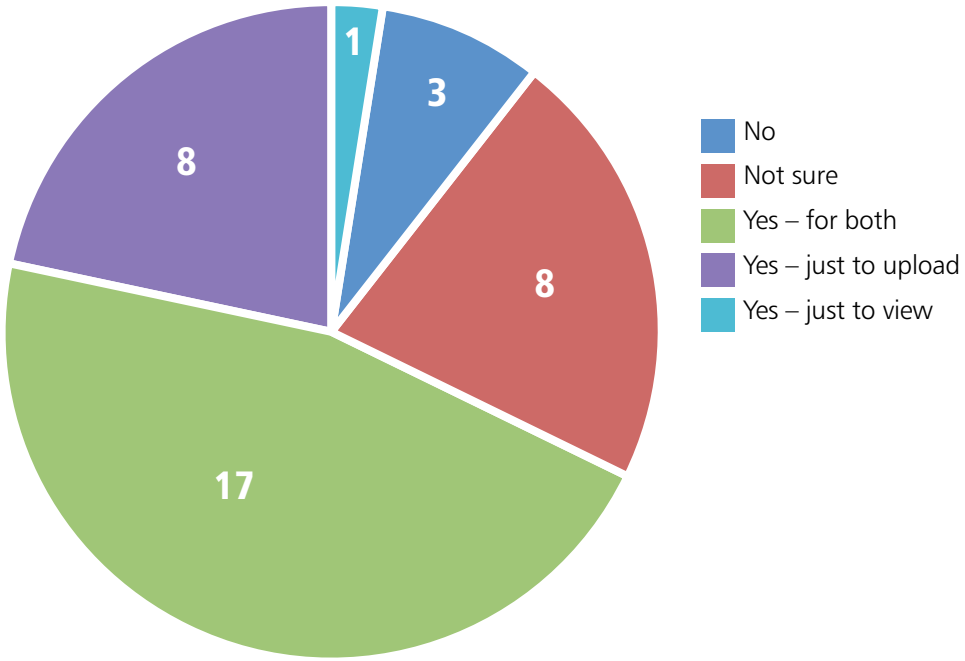
Compliance with ISB dataset	Number
Full	8
Non-compliant	3
Other	5
Partial - significant work required	3
Partial - some work required	18
(blank)	40

Those that reported Other indicated that this was because they were at an early stage of the project.

One respondent who said significant work was required noted: "At the moment we use our own out of hours and ambulance communication form. We are looking to fully adopt the ISB data set and roll out full EPaCCS to all providers within the next 18 months." No negative issues around the ISB dataset were reported.

Consent to view and upload

When asked if consent was required to view and to upload, the following responses were given.

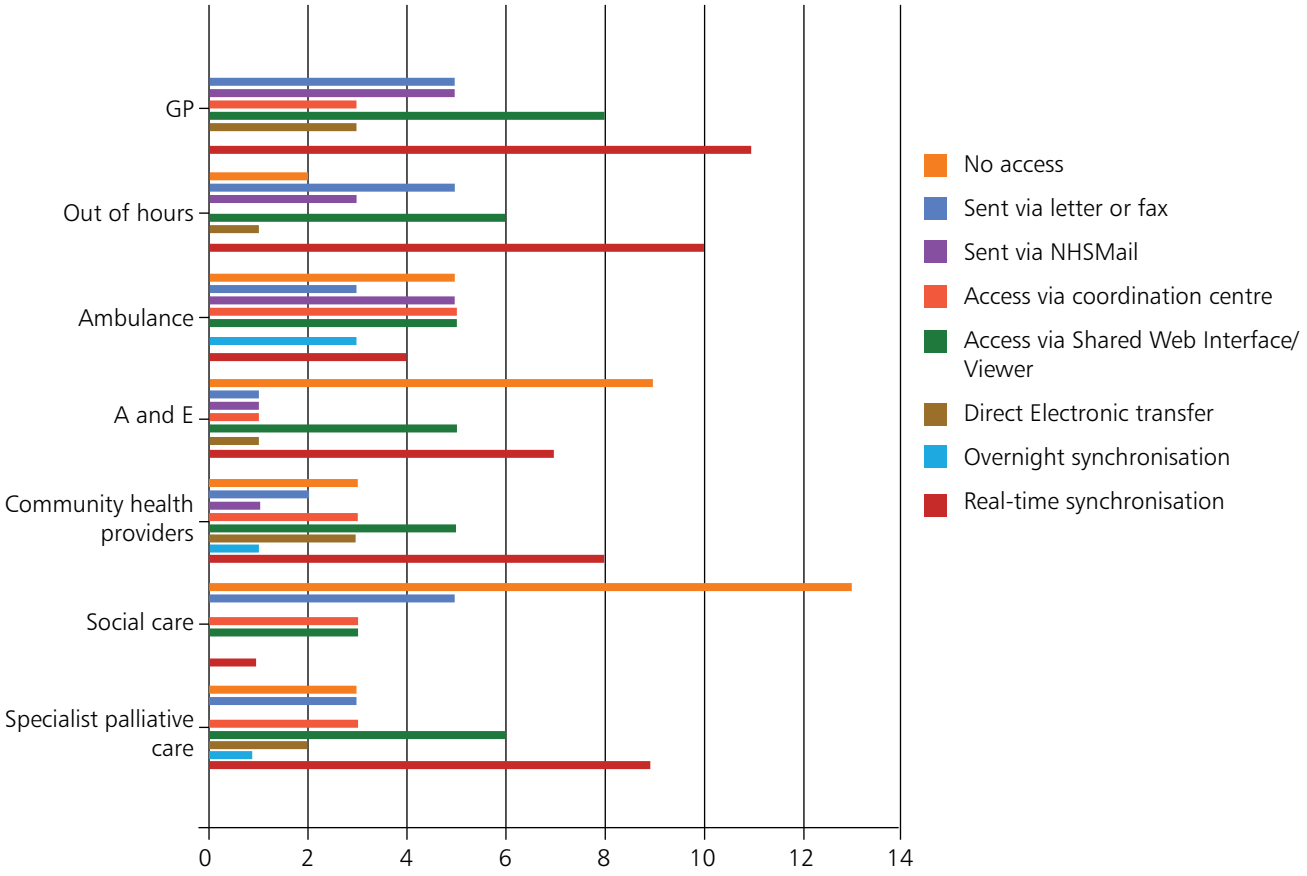


Access arrangements

Access is broken down for all respondents, and then for those using prominent systems.

Access – all respondents (n=26)

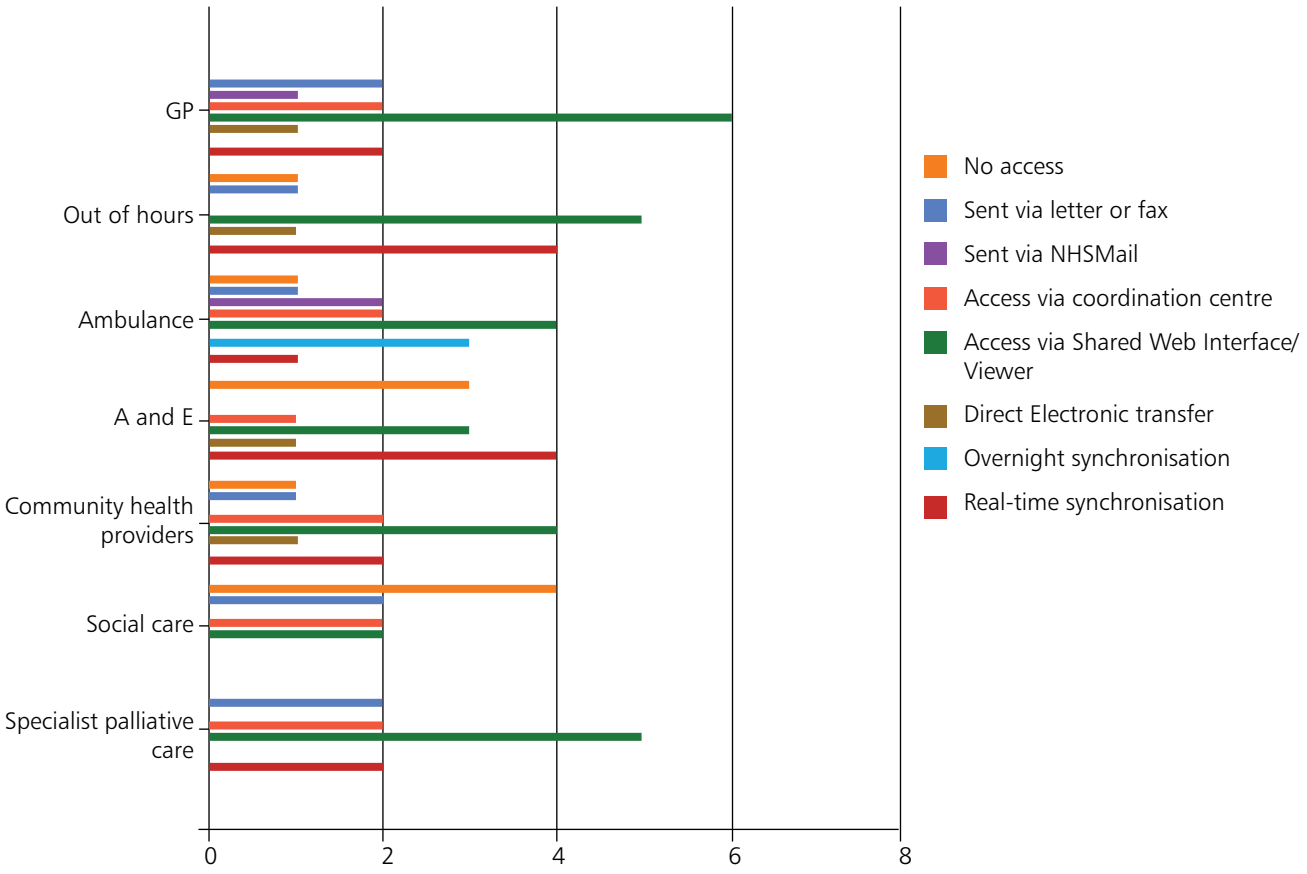
Care setting access and synchronisation arrangements



The project noted that real-time synchronisation for social care was only at the planning stage.

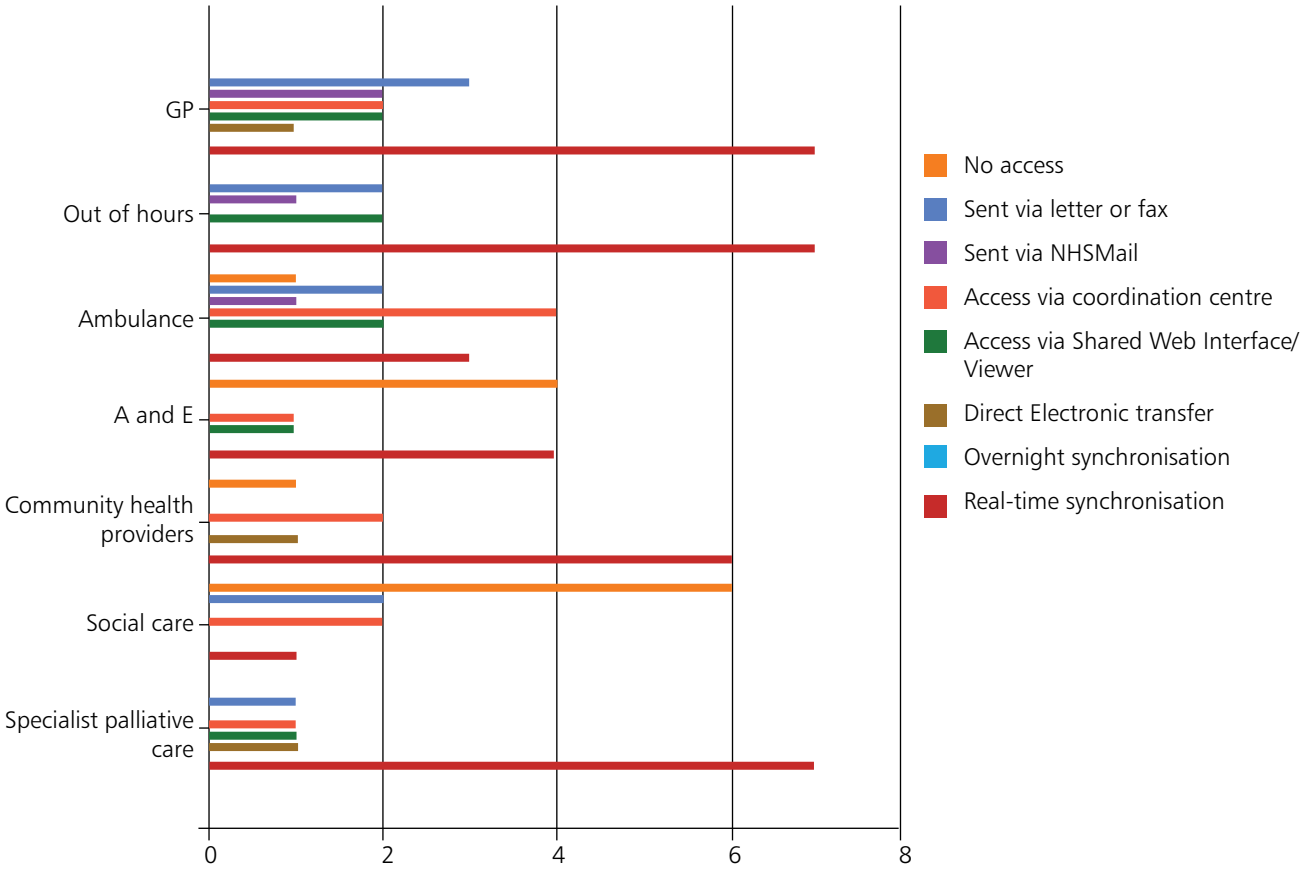
Access – Adastra (n=11)

Care setting access and synchronisation arrangements

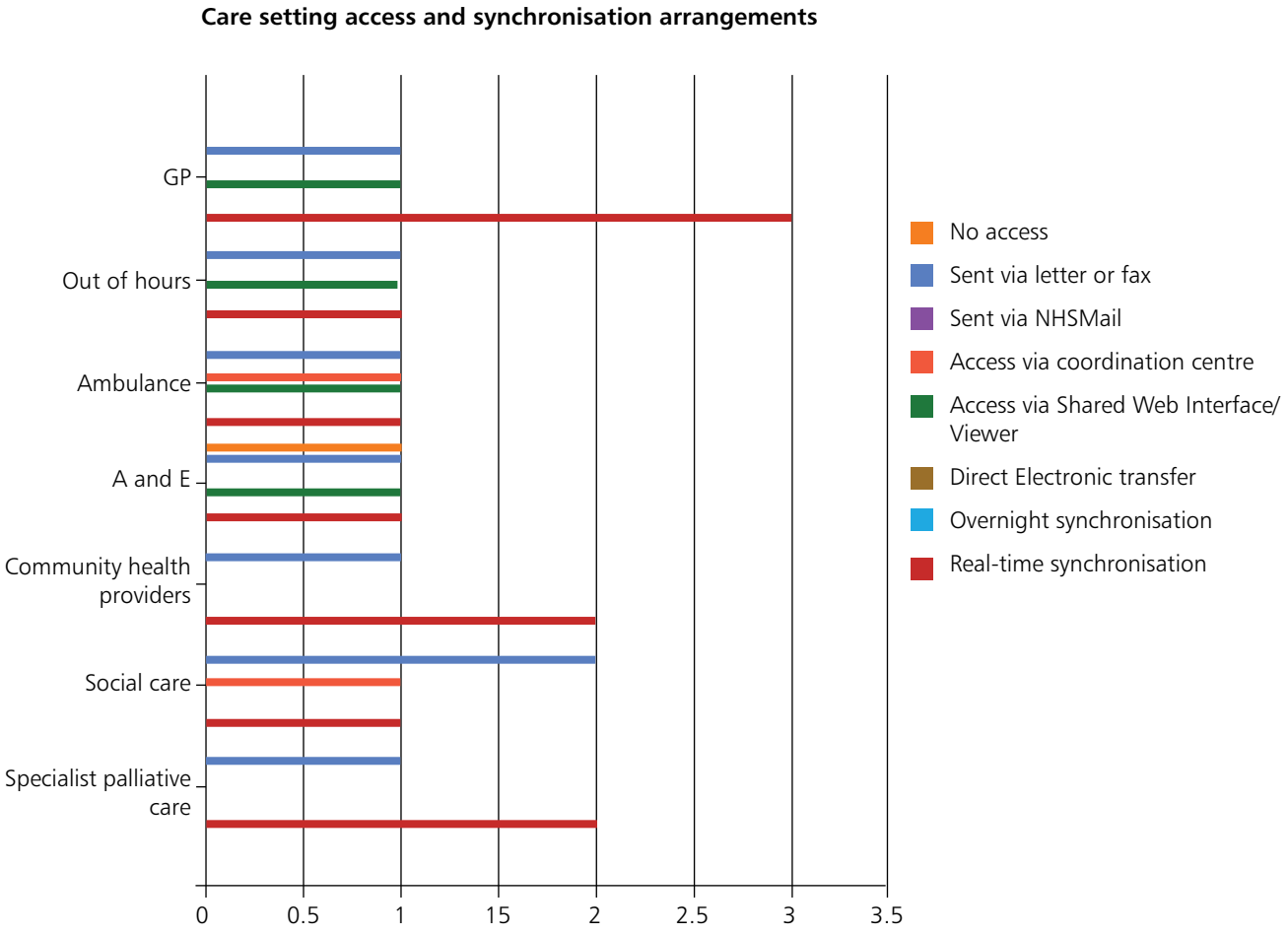


Access – SystmOne (n=10)

Care setting access and synchronisation arrangements



Access – SCR (n=3)



Willingness to share contact details and responses

The following responses were gathered from the respondents.

Are you happy to share contact details with others?	Number
No	11
Not sure	6
Yes	56
(blank)	4
Total	**77**

Are you happy to share responses?	Number
No	7
Not sure	5
Yes	49
Yes, but without my contact details	12
(blank)	4
Total	**77**

Sustainability

Respondents will be contacted towards the end of 2012 to answer an update survey.

Can you answer in six months' time?	Number
I am not sure - if you have any problem, please use the contact details below	9
I doubt so - please send any further enquiries to the contact details below	2
Yes I should be able to complete in six months time	63
(blank)	3
Total	**77**

Lessons learned

Although data gathering is at an early stage, EPaCCS implementations show that they are having a positive effect on quality and productivity.

PCT contacts are disappearing due to system reconfiguration changes; it is therefore important to maintain contact with survey respondents over the coming weeks and months.

The survey questions need further definition, especially around performance data. The following headings are suggested:

- Timeframe – should be determined in advance
- Eligible (total adult) population
- Total numbers on EPaCCS for given period (broken down by alive and dead)
- Total numbers of deaths (to identify proportion of deaths on EPaCCS) Alternatively ask: What percentage of all deaths in your district were on a register
- PPD stated (from total numbers on EPaCCS)
- Proportion with PPD stated (from total numbers on EPaCCS)
- Preference for Place of Death 1 (broken down by setting)
- Preference for Place of Death 2
- Proportion with Actual Place of Death recorded (from total numbers on EPaCCS)
- Numbers Achieving Place of Death 1
- Numbers Achieving Place of Death 2
- Reasons for variance

Recommendations

- **Revise data requested – potentially through national reporting framework**
- **Encourage co-working between users of similar systems**
- **Provide guidance on use of SCR as EPaCCS**
- **Identify and share good practice in providing access for social care**

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