**This version of the survey is relevant to CCGs at the planning stage of implementing an EPaCCS**

Electronic Palliative Care Co-ordination Systems (EPaCCS):

Evaluating their implementation & optimising future service provision

This survey aims to capture progress towards implementing EPaCCS across England. It will help to understand how they are being used and identify how local implementation can be best supported. It will also support future development of the national information standard and national guidance.

This research is being undertaken by researchers at the University of Leeds, Kings College London and the Hull York Medical School. We are working in partnership with NHS England and Improvement and Public Health England.

The survey takes up to **10 minutes** to complete and should be completed by a CCG end of life care lead or a nominated representative.

If you have any questions, please contact:

Matthew Allsop (Chief Investigator): m.j.allsop@leeds.ac.uk

Jakki Birtwistle (Research Fellow): j.birtwistle@leeds.ac.uk

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| **Your participation will enable us to provide you with a report of benchmarking data describing models of implementation and reported levels of uptake, and comparing local data with anonymised data from other CCGs that complete the survey.**   |

This study has been approved by University of Leeds School of Medicine Ethics committee: MREC-20- 008.

IRAS project number: 288296. Dated: 13.11.2020 Version 1

**Section 1: Respondent details**

*Your details will remain confidential within the research tea*

Please click the box to indicate you have read the Participant Information Sheet:[ ]

1. About you

|  |  |
| --- | --- |
|  |  |
| Respondent name |  |
| Your job title |  |
| Your organisation (CCG) *Optional* |  |
| Telephone contact no. *Optional* |  |
| Email address *Optional* |  |

**Section 2: EPaCCS in your CCG**

1. Will your EPaCCS be limited to your own CCG geography?

Yes**:** [ ]  No**:** [ ]

1. If **No**, Please list the other CCGs it will cover

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1. What type of organisation will host the planned EPaCCS in your CCG?

|  |  |
| --- | --- |
|  |  |
| Ambulance service | [ ]  |
| CCG Commissioning support unit (CSU) | [ ]  |
| GP Community services provider | [ ]  |
| Hospice | [ ]  |
| Informatics service | [ ]  |
| NHS Trust | [ ]  |
| Out of hours service | [ ]  |
| Urgent care services | [ ]  |
| Unknown | [ ]  |
| Other please specify |  |

**Section 2: EPaCCS in your CCG** (Continued)

1. What (approximately) is the anticipated start date? (*if known*)

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1. Which clinical software system/s will be used?

|  |  |  |
| --- | --- | --- |
|  | LEADclinical software system/s | OTHER system/sthat information is shared with |
| Adastra | [ ]  | [ ]  |
| Black Pear | [ ]  | [ ]  |
| Cerner | [ ]  | [ ]  |
| Cleo | [ ]  | [ ]  |
| Co-ordinate My Care | [ ]  | [ ]  |
| EMIS | [ ]  | [ ]  |
| Graphnet | [ ]  | [ ]  |
| Health Analytics | [ ]  | [ ]  |
| MIG | [ ]  | [ ]  |
| SCR | [ ]  | [ ]  |
| SystemC | [ ]  | [ ]  |
| SystmOne | [ ]  | [ ]  |
| Vision | [ ]  | [ ]  |
| To be confirmed | [ ]  | [ ]  |
| Don't know | [ ]  | [ ]  |
| Other please specify |  |  |

1. Will this be first attempt at implementation?

Yes**:** [ ]  No**:** [ ]  Don’t know**:** [ ]

1. If **No** - what hindered previous attempts at implementation?

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**Section 2: EPaCCS in your CCG (Continued)**

1. What is the intended impact for patients of using EPaCCS?

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1. How will you measure the impact for patients?

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*Section 3 & 4 is for CCGs with an EPaCCS in place and this version of the survey bypasses these parts.*

**Section 5: Barriers & facilitators to EPaCCS development & implementation**

1. What clinical challenges have been experienced in the planning and/or implementation of EPaCCS?

|  |  |
| --- | --- |
| Hard to engage stakeholders (GPs) | [ ]  |
| Hard to engage stakeholders (other) | [ ]  |
| Administration rights (who can add/administer/ has responsibility) | [ ]  |
| Patient consent | [ ]  |
| Clinical leadership | [ ]  |
| IT leadership | [ ]  |
| IT support | [ ]  |
| Training support | [ ]  |
| Other, please specify  |  |

1. Please outline any planned activities that target clinical staff use and uptake of EPaCCS (e.g. training, personalised engagement with services?

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1. Do you have any needs in your role to support the implementation, monitoring or development of EPaCCS?

Yes**:** [ ]  No**:** [ ]

* 1. If **Yes**, What are your needs and what could be provided to support you in meeting these needs?

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**Section 6: Looking ahead**

The national information standard ISB1580 currently defines core content held in EPaCCS or other end of life care co-ordination systems and specifies requirements for its implementation. The standard is due to be revised and information you provide will contribute to its revision.

1. Have you experienced any issues with implementing standard ISB1580?

Yes**:** [ ]  No**:** [ ]

1. If **Yes**, what issues have you experienced? e.g. *difficulty implementing the existing standards, development of an EPaCCS in line with SNOMED codes, limited fields available for some items*

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1. Are you planning to implement any other information standards for end of life care services, including any that are locally developed?

Yes**:** [ ]  No**:** [ ]  Don't know**:** [ ]

1. If **Yes**, would you be happy to share these with us?

|  |  |
| --- | --- |
| [ ]  | Yes - *Please check your details are entered on page 2 and we’ll contact you with a request* |
| [ ]  | No |

**The revised standard aims to:**

* Reflect clear definitions of what is and is not an EPaCCS
* Clarify data ownership, management and control
* Place the person receiving care and support at the centre of the standards intentions
* Ensure inter-operability and equity of access for all direct care providers and the person receiving care and support
* Require systems to be accessible in a timely manner appropriate to role, circumstance and environment
* Clarify terminology and coding standards
* Determine minimum data set requirements
1. What do you think would be useful to include in the revised standard to achieve the above aims?

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**Section 6: Looking ahead (continued)**

1. Do you have a ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form in use in your CCG?

Yes**:** [ ]  No**:** [ ]  Partial (some settings)**:** [ ]

* 1. If **YES**, Are you planning to adapt the ReSPECT form to an electronic version within your patient record system?

Yes**:** [ ]  No**:** [ ]  Don't know**:** [ ]

1. If known, how will your ReSPECT form align with your EPaCCS record?

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Apart from ReSPECT and EPaCCS, do you use any other end of life forms in your CCG?

Yes**:** [ ]  No**:** [ ]  Don't know**:** [ ]

1. Which form/s do you use?

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1. Will you adapt the form/s to an electronic version within your patient record system?

Yes**:** [ ]  No**:** [ ]  Don't know**:** [ ]

**Section 7: Feedback**

Your feedback is important and we invite you to give any comments you may have about the implementation of an EPaCCS; examples of things that are going well, impact for staff, for people and their families and examples of any difficulties or barriers to implementation encountered. We are also interested in hearing about your future plans or developments.

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**And finally:** We want to invite key stakeholder groups to **a future workshop** to build consensus about how EPaCCS should be used nationally and where there are opportunities to improve how they are used. This will take place towards the end of the project in Autumn/Winter 2022-3.

If you are interested in being contacted about this workshop please indicate here: [ ]  and ensure you have entered your email address on page 2.

**Thank you for completing this survey**

**Please email it to: j.birtwistle@leeds.ac.uk**