



## Participant Information Sheet

**Study title:** Electronic Palliative Care Co-ordination Systems (EPaCCS) in end of life care: evaluating their implementation and optimising future service provision.

### Invitation

You are being invited to participate in this study as an end of life care lead, EPaCCS lead, or representative with knowledge of EPaCCS within your clinical commissioning group.

### Brief summary

We are conducting an online survey of end of life commissioners to understand where and how EPaCCS are being used across England. Your views will contribute to a national picture of current practice which will inform the next phases of our research and help guide the best approaches to using EPaCCS as part of NHS service delivery.

We appreciate that EPaCCS are at different levels of implementation across England. We are keen to learn about the experience of EPaCCS in your clinical commissioning group. If you do not have an EPaCCS, are planning an EPaCCS, have only just implemented an EPaCCS, or have an EPaCCS in place, we are keen to hear about your experience and have you participate in the survey.

### Why have I been approached to take part in the study?

You have been approached as you have been identified as a champion of end of life care.

### Who is organising and funding the study?

This study is funded by National Institute for Health Research and supported by NHS England and [Public Health England]. It is hosted by the University of Leeds with research partners at King's college London and the Hull-York Medical School. Further details can be found on the [NIHR website](#)

### What's involved?

Participation will involve completion of a one-off, brief online questionnaire survey. The survey has been designed to take no longer than 30 minutes to complete. You will be asked about the Clinical Commissioning Group you work within. Questions cover will the CCG's progress towards implementing EPaCCS and factors facilitating and inhibiting uptake.

At the start of the survey you will be asked to tick a box to consent to taking part in the survey. You will not be able to proceed with the survey unless this box has been ticked. All data will be returned to the research team directly, your responses will be identifiable to the research team. All data will be stored securely and will only be accessible to members of the research team.

If you are interested in taking part in the further phases of the study you will be asked to provide a contact email address. These details will be removed from the questionnaire data, stored separately in a password protected file on the University of Leeds secure servers and accessed via password protected University computers.

### **What will happen to the data collected?**

The data will be analysed and will contribute to a national picture of how EPaCCS are currently being used in routine care. Findings will inform the next phases of our research and help guide the best approaches to using EPaCCS as part of NHS service delivery. Your confidentiality will be preserved in all published articles. We will store this research data for 10 years after the study has ended.

### **What are the possible benefits of taking part?**

It is hoped that you will find the survey interesting, stimulating thoughts on documenting and sharing patient preferences and the factors that influence uptake of EPaCCS. In return for your participation you will be offered a confidential personalised report of benchmarking data comparing local data with anonymised data from CCGs completing the survey.

### **What are the possible disadvantages and risks of taking part?**

We do not anticipate that completing the questionnaire will cause you any distress. You will not be asked to provide any information about individual patients or staff.

### **How will we use information about you?**

We will need to use information from NHS England for this research project. This information will include your name and email address. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. We will store information will (your name and email address) for 3 months after the study has ended.

### **What are your choices about how your information is used?**

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

### **Transparency statement**

The University of Leeds is the sponsor for this study based in the United Kingdom. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, you may request that we remove the information we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. If you have any concerns with regard to the way your personal data is being processed or have a query with regard to this Notice, please contact the research team on the details below or our Data Protection Officer at: [dpo@leeds.ac.uk](mailto:dpo@leeds.ac.uk). You can find out more about how we use your information here <https://dataprotection.leeds.ac.uk/research-participant-privacy-notice/>.

### **How do I access the survey?**

The survey is available at the following secure link: [End of life care commissioners' survey](#)

If you agree to participate we would value receiving your completed questionnaire by: **31<sup>st</sup> March 2021**

If you would prefer a paper copy (with stamped addressed return envelope), please contact the research team directly on the details below.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- by asking one of the research team (details below)
- by contacting the University of Leeds Data Protection Officer at: [dpo@leeds.ac.uk](mailto:dpo@leeds.ac.uk).
- by ringing us on 0113 343 6907

**Research contacts:**

Dr Matthew Allsop: [m.j.allsop@leeds.ac.uk](mailto:m.j.allsop@leeds.ac.uk) or

Jakki Birtwistle: [j.birtwistle@leeds.ac.uk](mailto:j.birtwistle@leeds.ac.uk)

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