Managing care for people in community hospitals

by enhancing care processes and outcomes

**Patient Information Sheet**

We’d like to invite you to take part in our research study seeking to inform how we provide care in community hospitals. Joining the study is up to you. Before you decide, we would like you to understand why the research is being done and what taking-part would involve. One of our team will go through this information sheet with you, to help you decide if you would like to take-part (or not) and answer any questions you may have. We'd suggest this should take about 15 minutes. Please feel free to talk to others about the study if you wish.

The first part of the information sheet details the purpose of the study and what taking-part will involve. We then give detailed information about how the study will be undertaken. Do ask if anything is unclear. Thank you for taking the time to read this sheet.



The study is led by Dr Catherine Evans

HEE/NIHR Senior Clinical Lecturer & Honorary Nurse Consultant

King’s College London and Sussex Community NHS

Foundation Trust

# What is the study about?

**Improving how we deliver care in community hospitals**

We want to understand if we can help to improve care and outcomes of care by using a set of key documents during a person’s admission to a community hospital. The set of documents is called SPACE, which means Symptom and Psychosocial Assessment and Communication Evaluation. We want to help both you (the patient) and those close to you, i.e. your family. The documents will be used from admission to discharge. The documents will aim to improve comfort and reduce distress by improving for key areas of care:

1. Assessment – we want to understand ‘what matters to you’ and try to enhance your independence in the community hospital
2. Priorities and preferences – we want to understand your priorities and preferences for care to help us to improve your care and enable you to pursue your goals
3. Involvement – we want to understand how best to involve you in decisions about your care
4. Discharge – we want to make sure that you have enough information about your care and how it is planned to continue.

**We want to understand**:

* How to support people in a community hospital if their health gets worse and how to support those close to them
* If people can benefit from assessments of ‘what matters to you’ and enhancing independence
* If the SPACE documents could support communication and ensure people have enough information when discharged about what to expect now and in the future
* The important information to share with other services when discharged to make sure care continues as planned
* If these documents could improve our understanding of people’s priorities and preferences for care and how to tailor care better

**What would taking part involve?**

**Completing questions about how you are in yourself and the care you receive**

Taking part in the study would mean a research nurse, or a researcher from King’s College London, visiting you in the community hospital and talking to you about the study. They will ask if you are willing to provide your consent for them to complete a questionnaire with you. The questionnaire asks you questions about how you are feeling in yourself, how you feel about the care you receive, and how you feel about being involved in the research study. It will take about 30-40 minutes. We will ask you to complete another shorter questionnaire before you are discharged. We will ask you if we can post a final questionnaire to you after you are discharged. We can support you to complete the questionnaire over the phone or visit you at home if you prefer. The questionnaire is returned to the research team in the FREEPOST envelope. We would send you two reminders to complete the questionnaire by telephone and posting a letter. You can tell us you don’t want to complete the questionnaire by posting the reply slip to the research team, or phoning or emailing the team.

We will also ask if the research nurse or researcher can look at your clinical notes in the community hospital. This helps us to understand more about the reason for your admission and the planned treatment and care, and how the staff are using the new documents. The researcher may also observe the care you receive from the staff at the community hospital and make notes about this care. Researchers may observe you more than once during your stay at the community hospital, with a maximum of 5 observations. You will only be asked to consent to these observations once.

To thank you for taking part, you will receive a £5 gift voucher once you have finished taking part in the study.

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

**Being a part of improving care in community hospitals for others**

We hope you will find it helpful to talk in confidence about what is happening to you. We know that patients can benefit from knowing that their contributions can help to improve care in hospitals.

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

**The questionnaire may be tiring to complete**

Completing the questions will take some of your time. We appreciate this. Telling us about what is happening to you can be a relief or a challenge. Some people may find the questions we ask difficult. This is because we are asking about symptoms you might be experiencing and how you feel in yourself. If you find it hard to complete the questions, please ask the research nurse to pause or stop. Our research nurses are experienced and able to support you if you find completing the questions difficult. If needed and with your permission, they will refer you to a colleague who can help you more. If you decide to withdraw from the study, this will not affect your care in any way.

**How can I take part?**

Please tell a member of staff in the community hospital that you would like to know more about the study.

**Why have I been invited?**

We are approaching you as you are a patient in a community hospital that is participating in the study. The staff in the community hospital thought that you may be interested in the study. They have not passed on your details to King’s College London.

## **Who will know about my involvement in the study?**

Sussex Community NHS Foundation Trust will collect your information from you and your clinical records. They will give this information to the research team at King’s College London. The information will include your name, contact details and health information. We may use this information to contact you and to ensure the quality of the research. We will ask your permission if an issue comes up in your interview that we want to discuss with the ward staff.

We will keep all your information confidentially and follow guidelines to make sure that happens. Your information will be made anonymous to make sure no one can identify you. This will be done by removing your name and address. This anonymous information may be used for educational purposes and to help future research. Staff from King’s College London and monitoring organisations may look at your records to check the accuracy of the study. The information you share will be stored in a safe place at King’s College London. Any information that identifies you, such as your contact information, will be kept separately from your research data. Only staff at King’s College London who need to contact you will have access to information that identifies you. The people who analyse the data will not be able to identify you or find out your name or contact details.

King’s College London is the sponsor for this study, based in England. This means that they take responsibility for the data in this study, looking after your information and using it properly. King’s College London will keep information that identifies you for up to 3 years after the study has finished.

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

We will need to use information from [you] and from your medical records for this research project. This information will include your name, NHS number and contact details. 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.

## **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. If you choose to stop taking part in the study, we would like to continue collecting information about your health from your hospital record. If you do not want this to happen, tell us and we will stop.

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. The data will be held by the research team.

You can find out more about how we use your information by asking one of the research team at the contact details below or at [www.hra.nhs.uk/information-about-patients](http://www.hra.nhs.uk/information-about-patients)

**What will happen if I don’t want to carry on with the study?**

If you do not want to continue with the study we will keep the information you have already given to us. We will always aim to use information that does not identify you.

# Do I have to take part?

No. It is entirely up to you to decide whether or not to take part. We will give you 24 hours to consider if you would like to take part. Your rights and care will not be affected.

# Who is organising and funding the study?

The study is a joint project between King’s College London and Sussex Community NHS Foundation Trust. Dr Catherine Evans leads the study as the chief investigator. The study is funded by Health Education England and the National Institute for Health Research.

The study has been reviewed by an independent group called a Research Ethics Committee to protect your interests. This study has been reviewed and given approval by [INSERT NAME] Research Ethics Committee. To guide and monitor the study the researchers work with two groups:

* A Steering Group including researchers, clinical staff and representatives from the voluntary sector.
* A Lay Project Advisory group comprising older people, carers and voluntary sector representatives

**What happens to the findings of this study?**

The findings of this study will be published in scientific journals. A summary of the findings will be sent to parties such as, clinical colleagues in the trust, the Community Hospital Association, national leads for older people’ services and individual patients and their caregivers. If you wish, we can send you a copy of the results. The findings will be published on the project website at: [**https://tinyurl.com/SPACEtoolkit**](https://tinyurl.com/SPACEtoolkit)**.**

**What happens if something goes wrong?**

We hope that taking part in this study will be a positive experience. However, if you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Please contact Catherine Evans, lead researcher on 020 848 5516 or [Catherine.evans@kcl.ac.uk](mailto:Catherine.evans@kcl.ac.uk). In the event that something does go wrong and you are harmed during the research then you may have grounds for legal action for compensation against King’s College London but you may have to pay your legal costs. King’s College London maintains adequate insurance to cover any liabilities arising from the study.

Alternatively, if you have concerns you can also contact the Patient Advice and Liaison Service (PALS) for the Trust, details below:

PALS Patient Advice and Liaison Service, Sussex Community NHS Foundation Trust, B Block, Brighton General Hospital,

Elm Grove, Brighton BN2 3EW

Tel: 01273 242292 Email: [sc-tr.PALS@nhs.net](mailto:sc-tr.PALS@nhs.net)

**Thank you very much for taking the time to read this sheet**

**Contact details**

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| **Lead Researcher**  **Dr Catherine Evans**  Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation,  King’s College London,  Bessemer Road, SE5 9PJ  **Tel:** 0207 848 5516  **Email:** [catherine.evans@kcl.ac.uk](mailto:catherine.evans@kcl.ac.uk)  <https://tinyurl.com/SPACEtoolkit> | **Research Nurses**  **INSERT names**  Sussex Community NHS Foundation Trust  Research and Innovation Department  Bramber House  Brighton General Hospital  Elm Grove, Brighton  East Sussex BN2 3EW  **Tel:** 01273 696011 ext 1800  **Emails:** INSERT  <https://www.sussexcommunity.nhs.uk/> |