

# Electronic Palliative Care Coordination System

## (EPaCCS)/Palliative Care Register

### What is EPaCCS?

Communication and coordination between health care professionals is key to providing high quality care for patients with life limiting and long term conditions. As a patient you may well have views about your care: what you would like to happen, where you want to receive care, and even things you wish to avoid. This is known as Advance Care Planning (ACP). It may help to include your family and carers when making these plans. The Electronic Palliative Care Coordination System (EPaCCS) records and shares this information in a template in an electronic record that can then be viewed by health care professionals who use the same IT system.

### How will this benefit me?

EPaCCS information can be accessed by users of the IT system which may include many professionals who may be caring for you including GP, district nurses, specialist nurses, palliative care nurses, hospices and some social care staff and hospital services. It can be particularly useful for professionals such as out of hours doctors and night nursing services who are less familiar with you to know what type of care they should provide.

Patients on EPaCCS form a register at your GP practice. Regular meetings called 'Gold Standards Framework' (GSF) or 'Palliative Care' meetings allow the professionals caring for you to meet together to help plan your care and if necessary to update any information on EPaCCS according to your wishes and preferences or changes in your condition. This approach is widely used throughout the country in many different settings to enable people to receive a 'gold standard' of care and to help them live as well as possible until they die.

### Do you need my permission to include my details on EPaCCS?

You will be asked by one of the health care professionals caring for you for permission to include your details on EPaCCS and for consent to share this information with other professionals looking after you. If you are not in a position to provide consent and do not have a legally appointed advocate then a professional may decide that it is in your best interests to record information about you in an EPaCCS record.

### What information will be shared?

EPaCCS will include a record of:

- Your diagnosis.
- A summary of the treatment you have had for your illness and any significant past medical history.
- Where you would prefer to be cared for
- Decisions you have made about your care, including resuscitation decisions.
- Next of kin details and who you would wish to speak for you if you are unable to make decisions for yourself in the future.

Your health care team will regularly discuss your condition with you and update your EPaCCS record if your condition or wishes change.

### Who will have access to my information?

Your information will be held securely on an electronic (computer) patient record. Every professional who has access to this information is employed by an organisation that understands and respects the need for patient confidentiality. The system itself is secure and has the same level

of protection as your normal NHS record. There is a function which shows who has put your information on the system and when they did so.

Data from combined EPaCCS records will be used for statistical analysis in order to review the effectiveness of end of life care and plan the best services Barnsley. If data is used in this way it will be made anonymous.

## Can I have a copy of my information?

It can be helpful for you to have a printed paper copy of your EPaCCS record. You may want to show it to your family and carers and other health care professionals who do not use the same electronic records e.g. at the hospital. If your wishes change, let a health care professional know so the electronic record can be updated and a new copy printed for you.

## What other methods can be used to share EPaCCS information?

If you are registered with a GP practice in England you will have a Summary Care Record (SCR), unless you have previously chosen not to have one. It includes important information about your health:

- Medicines you are taking
- Allergies you suffer from
- Any bad reactions to medicines

You can choose to have additional information included in your Summary Care Record. This includes the information that is recorded on your EPaCCS record. By consenting to this the information can be shared with health care professionals who are caring for you who may be using different IT systems. Consent for this must be recorded by your GP Practice.

Further information is available:

<https://digital.nhs.uk/services/summary-care-records-scr>

## What happens if I do not want to have an EPaCCS record?

You will still be able to receive the best possible care and support from individual professionals but it may be more difficult for them to communicate and coordinate the care they provide. You can also change your mind at any time. Let one of your health care professionals know and they will close down your record so that professionals can no longer share information. ■

Developed in partnership

