

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 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.

Where can I access further information?

For more information about EPaCCS, how your data is used, and who has access to your data then please visit:

www.hdft.nhs.uk/services/palliative-care/epaccs/

If you require this information in an alternative language or format (such as Braille, audiotape or large print), please ask the staff who are looking after you.

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NHS

Harrogate and District
NHS Foundation Trust

Electronic Palliative Care Coordination System (EPaCCS) / Palliative Care Register



NHS
Harrogate and Rural District
Clinical Commissioning Group



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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 an electronic record that can then be viewed by health care professionals.

How will this benefit me?

EPaCCS can be accessed by 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 or a wish not to have artificial ventilation
- 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 a computer system called 'SystemOne'. 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 for Harrogate District. If data is used in this way it will be made anonymous.