

# Electronic Palliative Care Records

Information for  
patients and carers

**This leaflet explains how  
the Electronic Palliative  
Care Record can be  
used to support your  
preferences about your  
care**

All GP practices have records of your medical care and treatment. These are confidential electronic patient records. They are referred to and updated as your care, medication and treatment alters.

Your Electronic Palliative Care Record is a part of your electronic patient record. It is where information about your preferences for future care can be recorded.

Thinking about and considering what is important to you in the future may be helpful. This may be discussed with you, if you are diagnosed with a life-limiting illness or approaching the end of your life.

Your preferences will be included within your electronic patient record.

## What sort of information will be recorded?

You may have views about your care, what you would like to happen, where you want to receive care and your experiences of care. There may be aspects of treatment or care that you wish to decline. Your Electronic Palliative Care Record is a record of your views and preferences about your care. Throughout your care, doctors or nurses you meet will give you the opportunity to talk about your illness, treatment and care preferences. These specific details can be recorded on your Electronic Palliative Care Record.

Talking about the future or your preferences is important but not everyone wants to have this discussion. Doctors and nurses will make every effort to discuss your care and wishes in a sensitive manner. However if you find the discussion upsetting you can decline the conversation. If you do decline, then this will be recorded to ensure your choices are respected and other involved professionals are aware of your choices.

What are the benefits of having information recorded on an Electronic Palliative Care record?

Having this information recorded reduces the need to repeat conversations that can be tiring and upsetting for some people.

Knowing what is or may become important to you in the future, helps professionals and carers who are looking after you to follow your wishes and preferences as far as possible. This helps to direct your care and support your family or those important to you.

Who can see the recorded information?

The record can be seen by your GP. You will be asked if you give your consent to allow other professionals involved in your care to see the record too. Over a period of time this could be community nurses, members of the hospital team, specialist nurses, hospice staff, ambulance service and out of hours medical service professionals. Being able to see this information will enable those looking after you to follow your wishes and avoid you having to repeat and re-explain everything in full if you are unwell or if others need to make decisions for you.

The Electronic Palliative Care Record is part of the Cheshire Care Record. This is a summary care record that gives care providers an overall view of your care from all health and social care services in Cheshire

## Is my Electronic Palliative Care record confidential?

All your electronic patient records are confidential and protected by the Data Protection Act. Only professionals involved in your care and trained to use the system will be able to see your record. Access to all records is monitored and restrictions apply to who can see, add or alter information. To ensure that information in electronic records is of a high quality, care and data managers employed by the NHS will be able to view your record for monitoring purposes only. They will have secure user names and passwords.

## For further information

**End of Life Partnership** <http://eolp.co.uk/>

**Cheshire Care Record** <https://www.cheshirecarerecord.co.uk/>

**NHS Choices** [www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead](http://www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead)

**Dying Matters** [www.dyingmatters.org/page/planning-ahead](http://www.dyingmatters.org/page/planning-ahead)

**Age UK** [www.ageuk.org.uk/health-wellbeing/relationships-and-family/end-of-life/](http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/end-of-life/)

*Electronic Palliative Care Record is another name for a the Electronic Palliative Care Coordination System (EPaCCS)*