## **Privacy Notice**

## Electronic Palliative Care Co-ordination System (EPaCCS) in Humber and North Yorkshire

## Why we need to process your personal data?

Patients who are at the end of life come into contact with many health and care professionals. The challenge has been in enabling different care providers to share information about an individual patient's care and end-of-life preferences in a safe, up-to-date and efficient way.

Treatment choices, how and where care is delivered and the preferred place of death are at the heart of end-of-life care. Patient choices are not static and often change during the last weeks and months of life. Typically, preferences for end-of-life care are collected by GPs and inputted into their GP system. However, this may not always reflect the latest wishes of the patient and may not be available to all of a patient's health and care providers.

EPaCCS enables the recording and sharing of a patient's care preferences and key details about their care at the end-of-life. As it is electronic it can easily be shared 24/7 between all of the clinicians and carers involved in the patient's care across organisational and geographical boundaries.

An EPaCCS record can be created, updated and shared by any member of a patient's health and care team, subject to locally-determined pathway and user administration settings. The EPaCCS record is a summary record, intended to provide an easily accessible view of the information that carers need in an end-of-life setting.

We process personal information because it is necessary to comply with our legal obligations and perform our public duty.

## **Data Controllers**

Health and social care organisations involved in delivering end-of-life care to patients are Joint for the purpose of using the shared EPaCCS system.

To find out more about EPaCCS and how it supports end-of-life care in Humber, Coast and Vale go to: https://humberandnorthyorkshire.org.uk/our-work/digital-technology/

If you have any queries please contact: hnf-tr.yhcrhcv.carerecord@nhs.net

How do we collect information about you?	Personal information relating to you will be received from a number of areas. Some of the information about your medical history, such as medications and conditions, will come from your GP record. Information about your preferences for how and where you receive care at the end-of-life will be provided by you when you share this information with the different health and care professionals who care for you.
	We only collect the personal information necessary about you in order to help us deliver the right service or meet legal obligations.
What information will we share about you?	We will share information about you that will help the health and care professionals who provide your care make the best decisions about your treatment and ensure that your preferences and wishes are respected.
	This includes: your demographic details (name, contact details, NHS number, gender), your medications, diagnoses and problems, CPR decision, preferred placed of care and preferred place of death.
How do we use your information?	Your information will be used to ensure that the health and care providers that care for you have the information they need to provide the best care for you and to ensure that your wishes and preferences at the end-of-life are known, shared and respected.
Who will we share your personal information with?	The information within EPaCCS will only be shared with health and care professionals that are directly involved in delivering your care. These organisations include: GP practices, hospitals, hospices, care homes, Out-of-Hours services, NHS 111, community service providers and social care providers.
What is the reason for processing your personal information?	As health and social care providers we have determined that the appropriate legal justification upon which this information can be shared for the purposes of the EPaCCS end-of-life shared care record is the delivery of direct care. This is in line with the recommendations of Caldicott Reviews of 1997, 2013, the provisions of the Data Protection Act (DPA) 2018 and the General Data Protection Regulation (EU) 2016/679 (GDPR) as retained by the UK under the UK GDPR
	The appropriate articles in GDPR are:  • Article 6 (1) – "processing is necessary for the performance of a task carried out in the <u>public interest</u> or in the exercise of official authority vested in the controller;"
	Article 9 (2)(H) - "processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the

	employee, medical diagnosis, the provision of health
	or social care or treatment or the management of
	health or social care systems and services on the
	basis of Union or Member State law or pursuant to
	contract with a health professional and subject to the
	conditions and safeguards referred to in paragraph 3;"
	G (1) (D) "proceeding is necessary for the
	6 (1) (B) - "processing is necessary for the
	performance of a contract to which the data subject is
	party or in order to take steps at the request of the
	data subject prior to entering into a contract.
How long will we	We will only keep your personal information for as long as
keep your	we need to, so we can give you the service you need, unless
personal	we must keep it for legal reasons. You have the right to
information for?	remove your approval for us processing your end-of-life
	preferences at any time.
	It will only be hold for the periods stated in our records
	It will only be held for the periods stated in our records management policy and retention schedule, after which it will
	be securely destroyed.
What are my	You have the right to:
rights in relation	• ask to see the personal information we hold about you;
to my personal	ask us to change it if it is wrong;
information?	<ul> <li>ask us to delete the information we hold about you;</li> </ul>
	<ul> <li>ask us to limit the way we use your personal information;</li> </ul>
	<ul> <li>have your information transferred to another Authority;</li> </ul>
	• complain to the Information Commissioner's Office.
	Value on a with draw your approval for the processing of your
	You can withdraw your approval for the processing of your personal information and sharing of your end-of-life
	preferences at any time.
Who can I	You have the right to submit a complaint if you are unhappy
complain to?	with the way your information is handled or disagree with a
	decision made by us regarding your information.
	In the first instance, please contact the service you are
	dealing with to try to resolve the matter.
	If you remain unhappy with the outcome you receive, you
	may wish to contact the Information Commissioner for an
	independent review. <a href="https://ico.org.uk/concerns/">https://ico.org.uk/concerns/</a>
Contact details	Name: Lisa Davies, Head of Legal Service & Information
for our Data	Governance
Protection Officer	Email: Lisa.Davies14@nhs.net
	Telephone: 01482 477854