

What happens to your information?

What information do we keep about you and why?

We keep computerised and paper records about all children and family members who receive our care and support. This is to ensure that we have the information required to provide and co-ordinate care to meet your identified needs.

Patient information and data held may include personal information such as name, address, contact details, date of birth, gender, ethnicity and religious beliefs, next of kin, information about your health and wellbeing collected by EACH and information received by us from other agencies and health and social care professionals involved in your care, emails, images, audio and video recordings, correspondence, care assessments, plans and records of care and services received, appointments, bookings, incidents, surveys, commendations, complaints and concerns.

We use this information for five key purposes:

- For the purpose of treatment and care
- To make sure we maintain our responsibilities for quality and accountability
- To inform the development of care services for children, young people and families
- To raise awareness of the needs of families and EACH services
- For funding purposes.

For purposes other than treatment or care, the data and information is anonymised in line with the Information Commissioner's Office Anonymisation Code of Practice:

<https://ico.org.uk/media/1061/anonymisation-code.pdf>

There are occasions when we wish to use patient identifiable data or information. For example, for training purposes, raising awareness of family needs or marketing our services, securing funds, service development projects or research.

This could include information about how you and your family use our service, family stories, case studies, images and audio or video recordings. Your consent will always be obtained before we use your information in this way. You have the right to refuse and also to withdraw consent at any time. This will not affect the service you receive in any way.

Our legal responsibilities

EACH is required to comply with the General Data Protection Regulations (EU) 2016 (GDPR), the National Data Opt-Out programme and other legislation which gives you and your family various rights.

All EACH staff have a legal duty of confidentiality.

To help ensure your information is protected and stored securely, EACH complies with the NHS Digital Data Protection & Security toolkit and a range of NHS and NICE Guidance.

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GDPR (EU) 2016

GDPR identifies the following rights for individuals:

- The right to be informed about what information is collected and how it is used
- The right of access to information held about you
- The right to rectification of errors or incomplete records
- The right to erasure (to be forgotten)
- The right to restrict processing
- The right to data portability i.e. obtain and reuse their personal data for their own purposes
- The right to object to the processing of their personal data in certain circumstances
- Rights in relation to automated decision making and profiling.

Further information can be found at <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

The National Data Opt-Out Programme

From May 25th, 2018, any person aged 13 years or over, with an NHS number, can opt out of having their confidential identifiable patient information being used for reasons other than their individual care and treatment. A person with parental responsibility can opt out on behalf of a child under 13 years of age. If you wish to opt out or wish to find out more information about this, please go <https://digital.nhs.uk/services/national-data-opt-out-programme> or ask a member of your local hospice team for a leaflet.

How you can access your records

You or your agreed representative can apply to access your information, known as a subject access request, by letter or e-mail to the EACH Service Manager of your local hospice. If it is an agreed representative, we may confirm this with you before providing the information. They will:

- Deal with your access request
- Request more details from you if necessary
- Comply with your request within 21 working days from receiving the request.

What happens to your information?

How your information is used

- **To provide treatment and care**

Information is collected, used, retained and eventually destroyed in line with legal requirements, and is used to provide and co-ordinate your care and treatment.

We manage our computerised care records in a system called SystemOne – a care records system used in the NHS by many GPs, community nurses, health visitors and other health care staff. The GP is the primary care record holder for all of your care. As such your GP will always be able to see information about you recorded by EACH. If you do not wish your GP to do this, you need to discuss this with the GP Practice directly.

For families whose first language is not English we share information with a secure translation service to provide families with the information they need in a format that they can understand with their consent.

With your consent, we share your information with other health and social care professionals involved in your care. This helps us ensure your care services are co-ordinated and managed to best meet your needs. You have the right to ask that individual entries are marked as private so that only EACH staff can see it. You have the right to refuse to share information with other health care professionals. However, if we believe not sharing this type of information compromises the safety of the care that we provide, we will discuss this with you.

EACH may also engage third party medical or therapeutic professionals or other contractors or agency staff to work on site providing or supporting EACH services. These third parties may be given access to personal information on the same basis as EACH staff and will be contractually bound to the same standards of data protection and confidentiality.

- **To fulfil a legal duty**

There are some circumstances when EACH is required by law to share your information or there is a justified public interest. For example, to safeguard children and adults at risk of harm, in response to a court order, information about certain infectious diseases. In some circumstances this may happen without your prior knowledge or consent.

- **To provide evidence that contracted services have been delivered**

Anonymised service activity information is used as evidence that contracted services have been delivered. Consent is obtained before we share patient identifiable information for this purpose.

- **To monitor the quality of our care and service provision**

Information and data is reported anonymously to monitor the quality of care including, for example, monitoring of commendations, concerns and complaints or incident trends, achievement of service outcomes, clinical audit. Clinical audit reviews current care practice by EACH against accepted best practice.

What happens to your information?

- To provide information to regulatory bodies**
External regulators such as the Care Quality Commission may request information to help inform the inspection of the quality of care services. Consent will be sought before your information is shared with regulators.
- To carry out research**
Research investigates new treatments and procedures so that child/family care and support are continually improved. Whilst auditors audit what has been done, researchers seek to identify new or different ways of doing things. Consent will always be sought before using patient identifiable information for research purposes.
- To help manage and plan services for children, young people and families**
Anonymised caseload, demographic and service activity information is used to inform service development in EACH and externally, including local, regional and national service developments. If we wish to use patient identifiable information for this purpose, consent will always be sought.
- To help educate the EACH team and other professionals involved in providing care and support**
Anonymised case study information may be used to help in the education of professionals. If we would like to use information which could lead to a person being identified we will seek consent before information is used for this purpose.
- To help raise awareness of families' needs and EACH services**
Information could include case studies, family stories, images, audio and video. You will always be asked for consent if the information we would like to use is patient identifiable.

If you would like to discuss any aspect of how we use your information and data, please contact the Service Manager at your local EACH hospice.

Mike Higgins at EACH Milton (Cambridgeshire)	01223 815100, mike.higgins@each.org.uk
Jane Campbell at EACH Quidenham (Norfolk)	01953 888603, jane.campbell@each.org.uk
Nathan Muskett at EACH The Treehouse (Suffolk & Essex)	01473 271334, nathan.muskett@each.org.uk

Alternatively you can contact the EACH Data Protection Officer by email at DataProtectionOfficer@each.org.uk