

What happens to your information?

What information do we keep about you and why?

EACH keep electronic and paper clinical records for lead children, young people who receive our care and support. We also keep electronic clinical records for family members, including siblings, who receive wellbeing and mental health support from one of our counsellors or therapists. This is because we are required by law to keep clinical records of the individual care and treatment we provide to both children and adults.

Patient information and data held may include personal information (such as name, address, contact details, date of birth, persons with parental responsibility) and information about your child's or your health and wellbeing. This includes information received from other agencies such as health and social care professionals who are involved in your care.

We use this information for five key purposes:

- For treatment and care
- To maintain our responsibilities for quality and accountability
- To help us to develop the care services for children, young people and families
- To raise awareness of the needs of families and EACH services
- To support sources of funding.

Where information is used for reasons 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 times when we wish to use patient identifiable data or information for example, for training, 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. We will always ask your permission before we use your information in this way. You have the right to refuse and to change your mind at any time. This will not affect the service you receive in any way.

Our legal responsibilities

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This leaflet fulfils the function of the privacy statement for service user information in EACH.
East Anglia's Children's Hospices (EACH) – www.each.org.uk – Royal Patron: HRH The Duchess of Cambridge

EACH is a registered charity (no. 1069284) and relies on voluntary donations for the majority of its income.
Leaflet available in other formats on request (including other languages, braille and Easy Read).

V6. Sept. 2021

What happens to your information?

EACH is required to comply with the Data Protection Act (2018) and the National Data Opt-Out programme and other legislation which gives you and your family various rights.

All EACH staff and volunteers 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.

The Data Protection Act 2018 (DPA 18)

EACH will ensure that the principles of the DPA 18 are met. These are that:

- data is processed lawfully, fairly and transparently (lawful, fair and transparent)
- a legal authority (legal base) exists for processing for specified, explicit and legitimate purposes (purpose limitation)
- data is adequate, relevant, limited to what is necessary and related to the purpose declared (data minimisation)
- data is accurate and where necessary kept up to date (accuracy)
- data is kept only for the time period necessary (time limited)
- data is held securely without unauthorised access or unauthorised processing (integrity and confidentiality).

Further information can be found at [Guide to the UK General Data Protection Regulation \(UK GDPR\) | ICO](#)

The National Data Opt-Out Programme

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 to <https://digital.nhs.uk/services/national-data-opt-out-programme> or ask a member of your local hospice team for a leaflet.

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How you can see your child's or your clinical 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 at your local hospice. If it is an agreed representative, we may confirm this with you before providing the information.

The EACH Service Manager 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.

The information from the record can be sent to you by post, email or uploaded to a secure 'cloud' location for you to download.

If your young person is aged 16 or over, and has capacity, we must seek their permission for you to access their records, before sharing their information with you.

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 either your child's or your care and treatment.

We manage our computerised care records in a system called SystmOne – 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.

With your consent, we share information with other health and social care professionals involved in your care. This helps us ensure care services are co-ordinated and managed to best meet your child's or 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,

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however, in line with national procedures, EACH is unable to mark safeguarding information as private. If we believe not sharing information compromises the safety of the care that we provide, we will discuss this with you.

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.

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 or 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 for example, monitoring of commendations, concerns and complaints or incident trends, achievement of service outcomes or clinical audits.

- **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.

What happens to your information?

- **To carry out research**

Research investigates new treatments and procedures so that child/family care and support is 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**

We use anonymised information for education and training purposes. If the information is identifiable we will gain your consent before it 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 EACH Milton 01223 815100

mike.higgins@each.org.uk

Michelle Briggs EACH The Nook 01603 967596 michelle.briggs@each.org.uk

Nathan Muskett EACH The Treehouse 01473 271334 nathan.muskett@each.org.uk

Alternatively, you can contact the EACH Data Protection Officer by email at

DataProtectionOfficer@each.org.uk