

BRIAN: OUR GLOBAL BRAIN



TUMOUR DATABANK

Parent/Guardian Patient Information Sheet (for a young person aged 12-15)

A Jargon Buster is included for any terms that you may be unfamiliar with.

Section 1: Introducing BRIAN

Whether your child or legal ward (which will be referred to as child in this document) has been recently diagnosed, or has been living with a primary brain tumour for a while, we know your world will have been turned upside down. Parents often have lots of questions about what to expect. How will my child cope with their treatment? What can I do to help them? What does the future hold?

'BRIAN', or the 'Brain tumouR Information and Analysis Network', is a secure database and web app that helps answer your questions. It is a tool that collects and shares information from those affected by brain tumours so they can benefit from others' knowledge and experience, and helps clinicians and scientists beat this cruel disease by providing them with a wider source of data for the work they do.

About the web app

With your permission, The Brain Tumour Charity collects and stores a copy of your child's medical records in a secure database. It links these to information that you tell BRIAN about your child's symptoms, and the impact that their tumour and treatment (both prescribed and non-prescribed) has on their quality of life.

You can ask BRIAN to compare your child's progress and experiences with anonymised groups of other children that have the same brain tumour. It helps you ask the right questions, know where to go next, find out about new research trials, and help you make better-informed decisions about your child's treatment to get the best possible outcome.

Doctors and scientists can also access reports on groups of patients from BRIAN to help improve outcomes and speed up research into brain tumours.

You or your child will be able to add information to BRIAN through a web app which aims to improve the availability and use of brain tumour information worldwide. Your involvement will make a significant contribution to helping other parents make better-informed decisions for their child and will help speed up research to find a cure.

How do I share my child's information?

Sharing information with BRIAN is simple. You or your child can do it either from your computer or any mobile device via the interactive web app, from anywhere and at any time. Similarly, you will be able to access your child's records from BRIAN.

SECTION 2: The consent form

What does the consent form cover?

The consent form (including your child's NHS number) allows The Brain Tumour Charity to request your child's medical records from sources such as the NHS and Public Health England. We can personally identify your child from their records. With your consent, and their NHS number, BRIAN stores your child's medical records safely and securely. Identifiers such as your child's name, address and NHS number, as well as your contact details, are stored separately from their NHS medical records to give added security. We can then link these to information that you and your child tell BRIAN about your child's quality of life, other treatments that they are taking and their experience of living with a primary brain tumour.

You can only use BRIAN after you have registered and submitted your consent form.

What am I consenting to on behalf of my child/ward by signing the form?

By completing the parent/guardian consent form either online or in paper copy, you are giving permission for The Brain Tumour Charity to access and store your child's medical records in a secret or anonymised format. When your child turns 16 you will receive an email advising you that the current consent form has expired and your child will need to consent to BRIAN themselves if you think they are cognitively able. Alternatively you may be able to consent on their behalf. Options will be outlined in the email.

The information in this form will be used together with our **Privacy Policy: thebraintumourcharity.org/privacy-policy**. We ask you to read both documents.

What if I don't agree with one or more of the questions in the consent form?

If you don't agree with one or more of the questions in the consent form and require further information please contact **brian@thebraintumourcharity.org** for help.

We consider that we have your consent if you a) give us your child's NHS number and b) either sign the form and send it to us at the address listed at the end of this information sheet, or submit it online. Your child's NHS number can be found on any letter from your GP or hospital. It has ten digits in a three, three, four format. If you can't find the number, please contact your GP as it is not available online.

Can I still access BRIAN if I do not consent to share my child's medical records?

No, your consent is needed for you to use BRIAN. Providing consent is part of the registration process when you sign up to the web app.

How do I withdraw my consent for my child if I've changed my mind?

If you decide that you would no longer like to share your child's information with BRIAN, you can contact us directly by either emailing us on **enquiries@thebraintumourcharity.org** or writing to us at the address at the end of this information sheet. We will then delete their information. Deleted information will remain hidden in BRIAN's historical records and would only be accessed for legal reasons or future Data Protection issues.

Please note there will also be an option to withdraw your consent on the web app.

What if I have told the NHS I don't want my child's medical records to be shared?

If you have provided consent to share your child's information with BRIAN this will override any requests that you have made to opt out of your child's information being shared or used for any

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purpose beyond providing care. This applies to the national data opt-out programme: nhs.uk/your-nhs-data-matters.

SECTION 3: Protecting my child's information

How will my child's medical records be copied from the NHS; where will they be stored and is it secure?

When we receive your consent and your child's NHS number we will apply for a copy of their medical records from the NHS. The records will be scrambled and sent to us securely for loading into BRIAN. For example, John Smith could look like ^Y*HmA!w£e. Once they have been safely received we will then apply a key to unscramble the information so that it can be read again.

It should be noted we store their date of birth for statistical purposes in BRIAN. On its own it is not identifiable.

The information is stored in line with the principles defined in the Data Protection Act 2018.

A copy of your child's medical records will only be released to us when the organisations holding their records, such as NHS Digital or Public Health England, have concluded that we are operating with an appropriate standard of governance.

What about any of my child's personally identifiable information?

Personally identifiable details, such as your child's name, address and NHS number, which link them to the information we collect about your child, is stored separately from their NHS medical records and not normally shared with any users outside of The Brain Tumour Charity.

In rare situations we may have to break confidentiality, for example, if we think your child is at risk of harm from themselves or others.

In very specific circumstances, a scientist using BRIAN may need access to a greater level of identifiable detail. Permission to use this personalised, identifiable information will only be given if The Brain Tumour Charity's Data Management Board agrees that such access is necessary to do the research, is appropriately beneficial, and will not in any way harm your child. You will not be informed on an individual basis should this be the case.

What does the Data Management Board do?

The Data Management Board is a group of people with a variety of expertise, ranging from research, ethics and data protection. It also includes patient representatives and The Brain Tumour Charity's Caldicott Guardian. Together, they are responsible for keeping your child's information safe and ensuring that they are shared at an appropriate level.

Is my child protected by the Data Protection Act?

The Brain Tumour Charity is bound by the Data Protection Act 2018, the principles of which, and information about your rights, can be found by following this link ico.org.uk/your-data-matters. This regulates the use of any personal information under six key principles ensuring your child's information is obtained only for one or more specified and lawful purposes. The principles also ensure your child's information is not further processed in any manner incompatible with that purpose or those purposes. As it relates to the consent form, the purpose is to improve the lives of people diagnosed with a brain tumour.

SECTION 4: Future contact

Future contact by The Brain Tumour Charity

In addition to storing your child's information in BRIAN, we would also like to keep your contact details as their parent or guardian, so we can provide you and your child with services and information in line

with your needs. When you sign into the web app you will be asked to select your communications preferences as part of the registration process.

If at any stage you do not want to hear from The Brain Tumour Charity, you can email enquiries@thebraintumourcharity.org, call us on 01252 749 990 or write to us at the address at the bottom of this information sheet.

Thank you for reading this information sheet

If you have any questions, please call us on 01252 413164, email us at brian@thebraintumourcharity.org, or write to us at The Brain Tumour Charity, Hartshead House, 61-65 Victoria Road, Farnborough GU14 7PA.

SECTION 5: Jargon Buster

Anonymised – anonymised simply means secret and secure such that your child/ward cannot be identified from the information provided. For example if your child's name was John Smith and you wanted to anonymise it, it may be shown like this ^Y*HmA!w£e. The authorised person receiving this would know how to unlock the code to read your child's name.

Caldicott Guardian – a Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient information and enabling appropriate information-sharing. We have our own Caldicott Guardian at The Brain Tumour Charity.

Consent – the permission you give to The Brain Tumour Charity to be able to see your child's medical records, which are kept by the National Health Services and Public Health England.

Data – the unedited facts about your child. When we get lots of data we can combine it and turn it into information that is of value to other groups (for example doctors, scientists, people affected by brain tumours).

Data Management Board – a group of professional people who look at requests from the scientists and doctors and decide if the information they request will help defeat brain tumours.

Data Protection Act – the law protecting data. It is there to ensure your records are used legally, securely, fairly and in you and your child's best interest. You can read more about this law online at legislation.gov.uk/ukpga/2018/12/contents

Healthcare Professionals – doctors, nurses, surgeons, oncologists, physiotherapists, opticians, dentists and other people who are involved in your child's care.

Information – a combination of your child's medical records and self-reported facts that you or your child have shared with BRIAN.

Medical Records – a record is created on each visit that your child makes to an NHS service. This means medical information about them can be held in various places, including out patients, accident and emergency and any NHS hospital where you have had treatment. It should contain all the clinical information about the care you have received from the NHS (not privately).

NHS Digital – exists to improve health and care by providing national information, data and IT services for patients, clinicians, commissioners and researchers.

Non-Prescribed Treatments – therapies that healthcare professionals have not prescribed for your child, such as diet, over the counter medicines or alternative therapies.

Personalised Identifiable Information – this is information that identifies your child and includes their name, address, full postcode or NHS number.

Prescribed Treatments – the medicine that healthcare professionals have recommended for your child.

Public Health England – an executive agency of the Department of Health which is the expert national public health agency which fulfils the Secretary of State for Health and Social Care's statutory duty to protect health and address inequalities, and executes his power to promote the health and wellbeing of the nation.

Quality of Life – your child's general wellbeing, including tiredness, response to treatments, headaches and daily feelings.

Research – activity undertaken by clinical and academic scientists at universities or pharmaceutical companies in the UK and globally. As part of their job they will investigate different aspects of brain tumours to try and understand how they are caused, what keeps them growing and how they can be controlled or cured. Their work and studies are critical to finding a cure.

Trial – the study that scientists carry out to investigate different aspects of brain tumours.

Web app – an online website you can visit from your computer or mobile device to input information about your child, and to extract information.