

# 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 has been recently diagnosed, or has been living with a 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 help clinicians and scientists beat this cruel disease.

#### About the app

With your permission, BRIAN 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 will be able to add information to BRIAN through a pioneering 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 BRIAN to access your child's medical records from sources such as NHS Trusts, NHS Digital Public Health England, NHS Scotland and NHS Wales. 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, date of birth and address are stored separately from their health 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 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 by signing the form?**

By completing the parent /guardian consent form either online or in paper copy, you are giving permission for BRIAN to access and store your child's medical records in a secret or anonymised format. The information in this form will be used together with our *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](mailto: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 leaflet, 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](mailto:enquiries@thebraintumourcharity.org) or writing to us at the address at the end of this leaflet. We will then delete their information. Deleted information will remain hidden in BRIAN's historical records but will 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 opted out of your child's information being shared or used for any purpose beyond providing care, we will not be able to extract any medical records from the NHS, even if you have given us consent to share your child's information with BRIAN. This applies to the two types of opt-out available (<http://content.digital.nhs.uk/yourinfo>). If you would still like to share your child's information with BRIAN, then you will need to let the NHS know that you would like to change your opt-out requirements by contacting the NHS on 0300 3035678 or email [enquiries@nhsdigital.nhs.uk](mailto:enquiries@nhsdigital.nhs.uk).

If you have opted out of your child's information being shared outside the NHS, we will inform you that we have not been able to access your child's medical records.

## **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. Once they have been safely received we will then apply a key to unscramble the information so that it can be read again. For example, John Smith could look like ^Y\*HmA!w£e.

The information is stored in line with the principles defined in the Data Protection Act 1998 and the EU's General Data Protection Regulation from May 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, date of birth and NHS Number, which link them to the information we collect about your child, is stored separately from their health records and not normally shared with any users outside of The Brain Tumour Charity.

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 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?**

As a Charity, we are bound by the Data Protection Act 1998. This regulates the use of any held 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.

Please note that the Data Protection Act will be updated in May 2018 to the GDPR. (General Data Protection Regulation). The Charity will then comply with this new act the principles of which can be found by following this link: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/>

## **SECTION 4: Future Contact**

### **Future Contact by the Charity**

In addition to storing your child's information in BRIAN, we would also like to keep your contact details as the 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](mailto:enquiries@thebraintumourcharity.org), call us on 01252 749990 or write to us at the address at the bottom of this leaflet.

### **Thank you for reading this leaflet.**

If you have any questions, please call us on 01252 413164, email us at [brian@thebraintumourcharity.org](mailto: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 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's BRIAN to be able to see your child's medical records, which are kept by the National Health Service in England, Wales, Scotland and Northern Ireland.

**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 (eg: 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](#). The law changes next year to take account of the increase in the use of technology as the original law has now become outdated. We will continue to abide by the new regulations.

**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 your child can be held in various places, including your GP practice, any hospital where your child has had treatment, your dentist practice, and so on. It should contain all the clinical information about the care your child has received.

**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** – this could include alternative therapies that your healthcare professional has not prescribed, such as diet, over the counter medicines, alternative therapies etc

**Personalised, identifiable information** - This is information that identifies your child. Identifiers include: name, address, full postcode, date of birth or NHS number.

**Prescribed treatments** – the medicine that your healthcare professionals have recommended

**Public Health England (PHE)**-an executive agency of the Department of Health which is the expert national public health agency which fulfils the Secretary of State for Health'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 well-being, 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 created, 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.

# Patient Information Sheet

## (for a young person aged 12 – 15)

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

We're asking whether you would like to share some information about your brain that we will keep safely in our new secure database called BRIAN. Your parents will use a web app on their mobile phone or computer to share with BRIAN how you're feeling or your 'quality of life' information and to find out information about what you can expect.

BRIAN will also pass your information onto scientists and doctors, with information from lots of others with the same brain tumour, to help with their research or work.

Before you decide if you'd like to take part and share your information with BRIAN, it's really important that you understand what we are doing, why we are doing it and what it will mean if you take part. Please read this leaflet carefully with your parents and speak to your doctor, nurse, family or friends about it.

If you have any questions please call us or ask your parents to do so on the details at the bottom of this leaflet and we will discuss it with you.

### **1. What are you doing?**

We're asking anyone with a brain tumour like yourself, to let us have a copy of your medical records, or the information that the doctors and hospitals have about you and your brain. We will hold a copy of it safely in our new secure database called BRIAN. We're also asking you, or your parents, to let us know how you're feeling - for example whilst you're going through chemotherapy, radiotherapy or after an operation - by entering the information through a web app on your (or your parents') mobile or computer.

BRIAN will keep all of this information about you and your brain and will store it safely. When other people want to find out more about brain tumours, they will be able to ask BRIAN to share your information, along with information from others with the same tumour

### **2. Who will want to see my information?**

Scientists carrying out research into brain tumours may need access to your information from BRIAN. Our hope is that it will help them find a cure for brain tumours.

It will also help the doctors and nurses know what to recommend to other people with the same tumour as you. Finally, it will help other children and their parents know what to expect.

### **3. Why do you want me to help?**

You have been asked because you have a brain tumour.

By sharing your information with BRIAN you will be able to help other young people and their parents know what to expect. It will also help the doctors and nurses know what to recommend to other people with the same brain tumour as you.

Lastly, scientists will be able to ask BRIAN for information about yourself and others as quickly as possible, so that they can carry out the best research and hopefully find a cure for brain tumours faster.

#### **4. Will anyone know the information is about me?**

When we collect your information BRIAN will store it safely and will only share it with people who need to see it. Your name and address and will be kept separately so that you are less likely to be identified from your information, unless a scientist needs to access details that will identify you personally. Should this be the case, the Charity has a group of experts that are part of something called the 'Data Management Board' and it is their job to decide whether or not it is absolutely necessary to share your personal details.

#### **5. Do I have to take part?**

No. It is entirely up to you. If you do decide to take part your parents will be asked to sign a consent form to give permission for BRIAN to access your medical records. When you turn 16, you will be asked to sign your own consent form. Don't worry though, we'll be in touch when that happens and we will keep your records for up to one year. If we don't hear from you within 12 months, the law says we have to delete your information.

You are free to stop taking part at any time without giving a reason. If you decide to stop, this will not affect the care you receive.

#### **6. What if I change my mind after I've said 'yes'?**

Just tell your parents or guardian at any time and they will contact us at the details included at the bottom of this leaflet. You will still have the same care and you won't upset anybody.

#### **7. How can I find out more about BRIAN?**

Your parents, guardian or other adult you trust may be able to answer your questions. The doctors and nurses looking after you can also help you find out more. Or you can ask your parents to contact us by phone on 01252 413164 or email at [brian@thebraintumourcharity.org](mailto:brian@thebraintumourcharity.org).

If at any stage you do not want to hear from The Brain Tumour Charity, you can email [enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org), call us on 01252 749990 or write to us at the address below.

**Thank you for taking the time to read this – please ask any questions you have.**

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

## *Jargon Buster*

**Anonymous** – this is a way of keeping your personal details (your name, address, date of birth etc) secret so that people can't tell that the information is about you.

**Consent** -the permission your parents give to The Brain Tumour Charity's BRIAN to be able to see your medical records which are kept by The National Health Service in England, Wales, Scotland and Northern Ireland.

**Data Management Board** – a group of professional people who look at requests from the scientists and doctors and decide if the information they ask for will help defeat brain tumours. It is their job to decide whether or not it is absolutely necessary to share your personal details

**Information** – a combination of your medical records and the information that you share with BRIAN about your symptoms

**Medical records** – a record is created every time you go to an NHS service. This means medical information can be held in various places, including your GP practice, any hospital where you have had treatment, your dentist practice, and so on. It should contain all the clinical information about the care you have received.

**Quality of Life** – your general well -being including tiredness, response to treatments, headaches and daily feelings

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

**Web App** – this is something that you can add to your mobile or computer. You can both add your own information to an app and get useful information out of it.

## Parent/ Guardian Consent Form

Please read the following statements and tick the “accept” box if you agree with them.

1. I confirm I have parental responsibility for the child.
2. I have read and understood the parent/ guardian patient information sheet.
3. I have been given the opportunity to consider the information, ask questions and have had these answered satisfactorily.
4. I understand that entering my child is voluntary. I can withdraw them from BRIAN or change my contact preferences at any time without reason, and without their medical care or legal rights being affected.
5. I understand that withdrawal of consent means my child's information will be deleted\* from BRIAN and a record will be kept that I withdrew my consent.
6. I understand however that my contact details, as the parent / guardian of the child, will be stored and remain stored on The Brain Tumour Charity's contact management system unless I specifically request for them to be removed. This allows us to record your consent preferences for BRIAN and for us to contact you about BRIAN if we need to.
7. I understand I can re-consent to my child's information being included in BRIAN at any time and because their history has already been deleted, they will be considered a new addition.
8. I understand that their personally identifiable information (such as NHS number and date of birth) will be used to access my child's medical records from existing sources (including NHS Trusts, Public Health England, NHS Scotland and NHS Wales) in order for them to identify my child correctly and share their medical records with BRIAN.
9. I understand that my child's information, apart from their personally identifiable information, will be shared with other people affected. It will also be shared with scientists, doctors and other organisations who have been authorised for such use by The Brain Tumour Charity's Data Management Board.
10. I understand that, in very specific circumstances, my child's personally identifiable information such as their name, date of birth, address and phone number may be shared with scientists or doctors. Permission to access this information will only be given when The BrainTumour Charity's Data Management Board agrees that such access is necessary to achieve the goals of the research, is appropriately beneficial, and will not in any way be detrimental to my child.
11. I understand if my child has a rare tumour there is a small risk they could be personally identified.
12. I consent to my child's information still being used in the event that they pass away. Or, in the event that my child passes away and I want their information deleted from BRIAN, I understand that I will need to notify The Brain Tumour Charity of their death.
13. I understand that data breaches are not completely preventable even if all security and privacy measures are taken, and I am still willing to share my child's information.
14. I agree for my child's information to be stored for 25 years.
15. I have read and understood The Brain Tumour Charity's **Privacy Policy**.

A jargon buster, or glossary, is available at the end of the Patient Information Sheet should any terms in this form need further explanation. If there are any other terms that you would like explained, please contact us using the details listed below.

Tick here to indicate that you have read and agreed to the terms



### Child's details

Please complete the details requested below **on behalf of your child**. All fields are mandatory, as we do not have your consent until you provide us with your child's NHS number. Your child's NHS number can be found on any NHS correspondence you have had, or by contacting your GP.

First name: \_\_\_\_\_

Last name: \_\_\_\_\_

Gender: Male / Female / Other

NHS number: \_\_\_\_\_ (format: xxx xxx xxxx)

Date of birth: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ (dd/mm/yyyy)

### Parent / Guardian details

Please complete your **own contact details below**. Please type/write your name in the signature field. If you complete the form online we will accept your typed signature as an e-signature.

Title: Mr / Mrs / Ms / Miss / Other: \_\_\_\_\_

First name: \_\_\_\_\_

Last name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Postcode: \_\_\_\_\_

Email Address: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Signature: \_\_\_\_\_

### Keeping in touch

The Brain Tumour Charity will keep you updated with all news and information about BRIAN via the email address that you have provided.

In addition, we would like to keep you up to date with our work, which will include information about research breakthroughs, support services and how you can get involved, for example by fundraising or volunteering.

How can we contact you?

By email: Yes / No

By SMS: Yes / No

We will keep your details safe and you can unsubscribe or change your contact preferences at any time through the web app or by emailing [enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org). Please read our [Privacy Policy](#) for more information about how we look after your details.

Project contact details for further information: The Brain Tumour Charity, Hartshead House, 61-65 Victoria Road, Farnborough, GU14 7PA or email [brian@thebraintumourcharity.org](mailto:brian@thebraintumourcharity.org)  
Registered Charity no. 1150054 (England and Wales) SC045081 (Scotland) Company no. 08266522

\*Deleted information will remain hidden in archive but will only be accessed for legal reasons or future Data Protection issues.