

# BRIAN: Our global brain tumour databank

## Parent/ Guardian Patient Information Sheet (for a child aged 0-11 years)

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 child aged 0-11 years)

### To be shown and read by parent/guardian if required

We're asking whether you would like to share some information about your brain that we will keep safely in our new database called BRIAN. Your parents will use a web app on their mobile phone or computer to share with BRIAN how you're feeling, and to help look after you. BRIAN will also pass your information onto scientists and doctors, with information from lots of other children, 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 you can ask your parents to call us 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 the information that the doctors and hospitals have about your brain. We will then hold a copy of it in our databank called BRIAN (a secure computer that stores information). We're also asking your parents to tell BRIAN how you're feeling after you've taken some medicine or been to the hospital. They will use a web app on their computer or phone to do this.

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 lots of other children with the same tumour. They won't be able to see your name or any details about just you.

### 2. Why do you want me to help?

You have been asked because you have a little lump inside your brain called a brain tumour. It is made up of cells, or building blocks, that have grown when they shouldn't have.

The scientists want to understand why they have grown and how to stop them from growing. The tests, or research, that they do will be much better if they have information from lots and lots of people like you with the same type of brain tumour. That's why we're asking you and anyone else with a brain tumour to share their information with BRIAN.

It will also help the doctors and nurses know what might help other children with the same tumour as you.

And one more thing. It will also help other children with the same tumour and their parents know what to expect.

### 3. So, why are you doing this?

We're collecting as much information from as many children and grown-ups with brain tumours as possible. All of this information will be really useful to help lots of different people.

Your parents might want to see how other children with the same brain tumour feel after a trip to the hospital or taking a particular type of medicine.

Doctors will want to see how other children with brain tumours feel after their treatment or operation so that they can give you the best treatment.

Also, scientists doing research will want to test their questions on everyone's information to help find a cure for brain tumours.

#### 4. Who will see the information about me?

When we collect a copy of your information BRIAN will store it safely and will only share it with people who need to see it. It will be anonymous or secret, so they won't be told your name.

The types of people that might need to see information about your brain are:

Doctors  
Scientists  
Parents

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

No you do not. It is up to you. We would like you to read this leaflet. If you agree to take part, we will also ask your parents or guardian to fill in a form called a "consent form". You can still change your mind later. If you don't want to take part, just say no.

#### 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 get the same care and you won't upset anybody.

Your parents, guardian or another grown-up 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).

**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.

*Why not have a go at our very own word search? Good luck spotting all of the words listed below!*

M M D M C E Y B R A I N	SHARE
N I N F O R M A T I O N	WEBAPP
A B N U H A L R Y V S R	BRIAN
O V P Y U H A W I F D K	BRAIN
R B G H D S T G G B R W	DOCTOR
W M K W W R O T C O D B	HOSPITAL
T E T S I T N E I C S C	INFORMATION
O R B W O R L W A C R T	SCIENTIST
W D G A R B D B R I A N	
I D J O P Y F R E L C J	
J C F U N P V I Y U M I	
L A T I P S O H D G D J	

## 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.