

# BRIAN: Our global brain tumour databank

## Patient Information Sheet (Person 16 years and over)

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

### Section 1: Introducing BRIAN

Whether you or a loved one 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. People often have lots of questions about what to expect. How will I cope with the treatment? What can I do to help myself? 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 medical records in a secure database. It links these to information that you tell BRIAN about your symptoms and the impact that your tumour and treatment (both prescribed and non-prescribed) has on your quality of life.

You can ask BRIAN to compare your progress and experiences with anonymised groups of other individuals 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 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 patients make better-informed decisions and will help speed up research to find a cure.

#### How do I share my information?

Sharing information with BRIAN is simple. You 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 own records from BRIAN.

### SECTION 2: The Consent Form

#### What does the consent form cover?

The consent form (including your NHS number) allows BRIAN to access your medical records from sources such as NHS Trusts, Public Health England, NHS Scotland and NHS Wales. We can personally identify you from your records. With your consent and NHS number, BRIAN stores your medical records safely and securely. Identifiers such as your name, date of birth and address are stored separately from your health records to give added security. We can then link these to information that you tell BRIAN about your quality of life, other treatments that you are taking and your experience of living with a brain tumour.

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

The information in this form is used together with our *Privacy Policy*. We ask you to read both documents.

### **Can someone complete the consent form for me?**

If you would like to nominate a carer to fill in the information on your behalf please add their details to the consent form. If you are a parent and are happy to consent to the use of your child's data then please read our parent / guardian patient information sheet and complete our parent/child consent form.

### **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 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 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 it then please do call your GP as it is not available online.

### **Can I still access BRIAN if I do not consent to share my 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 if I've changed my mind?**

If you decide that you would no longer like to share your 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 your 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 consent on the web app.

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

If you have opted out of your information being shared or used for any purpose beyond providing care, we will not be able to extract your medical records from the NHS, even if you have given us consent to share your 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 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 information being shared outside the NHS, we will inform you that we have not been able to access your medical records.

## **SECTION 3: Protecting My Information**

### **How will my medical records be copied from the NHS; where will they be stored and is it secure?**

When we receive your consent and your NHS number we will apply for a copy of your 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. We will store your personal details such as name, date of birth and contact details separately from your medical records to provide an additional level of data security.

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 medical records will only be released to us when the organisations holding them, 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 personally identifiable information?**

Personally identifiable information, such as your name, date of birth, address and NHS Number, which link you to the information we collect, is 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 access 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 you. 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 will also include patient representatives and the Charity's Caldicott Guardian. Together, they are responsible for keeping your information safe and ensuring that it is shared at an appropriate level.

#### **Am I protected by the Data Protection Act?**

As a Charity, we are bound by the Data Protection Act 1998. This regulates the use of digitally held information under six key principles ensuring your information is obtained only for one or more specified and lawful purposes. The principles also ensure your child's information is not 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 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 information in BRIAN we would also like to keep your contact details so we can provide you 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 you cannot be identified from the information provided. For example if your 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 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 to fulfil this role.

**Consent** -the permission you 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** –the unedited facts about you. 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 your 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 care.

**Information** – a combination of your medical records and self-reported facts that you have shared with BRIAN

**Medical records** – a record is created on each visit that you make to an NHS service. This means medical information about you 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.

**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 you. 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 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.

**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 yourself, and to extract information.

# BRIAN: Our global brain tumour databank

## Consent Form (Person 16 years and over)

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

1. I have read and understood the patient information sheet
2. I have been given the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that taking part is voluntary. I can withdraw from BRIAN or change my contact preferences at any time without stating my reason, and without my medical care or legal rights being affected.
4. I understand that withdrawal of consent means my information will be deleted\* from BRIAN and a record will be kept that I withdrew my consent.
5. I understand I can re-consent to my information being included in BRIAN at any time and because my history has already been deleted, I will be considered to be a new addition.
6. I understand that my personally identifiable information (such as NHS number and date of birth) will be used to access my medical records from existing sources (including NHS Trusts, Public Health England, NHS Scotland and NHS Wales) in order for them to identify me correctly and share my medical records with BRIAN.
7. I understand that my information, apart from my personally identifiable information, will be shared with other people affected. It will also be shared with scientists, doctors and other organisations who have been approved for such use by The Brain Tumour Charity’s Data Management Board.
8. I understand that, in very specific circumstances, my personally identifiable information such as my 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 Brain Tumour 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 me.
9. I understand if I have a rare tumour, there is a small risk I could be personally identified.
10. I consent to my information being used after I pass away. Or, in the event that I pass away and I want my information subsequently deleted from BRIAN, I understand that my carer or a family member will need to notify The Brain Tumour Charity of my death.
11. 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 information.
12. I agree for the information I provide to be stored for 25 years.
13. If the time arises that I become too unwell to contribute to BRIAN, I consent that a carer can input information on my behalf or from their perspective.
14. I understand however that my contact details 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 for BRIAN and for us to contact you about BRIAN if we need to.

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**

### Your contact details

Please complete the details requested below. Type/write your name in the signature field. If completed online we will accept your typed signature as an e-signature. Please fill in all of the fields, as we do not have your consent until you provide us with your NHS number. This can be found on any letter from your GP or by contacting your GP's surgery.

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

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

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

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

\_\_\_\_\_

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

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

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

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

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

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

## Carer / Family Member contact details

If you are nominating your carer or a family member to input your information on your behalf, or you are a carer or family member, please complete the form 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.