

BRIAN: OUR GLOBAL BRAIN TUMOUR DATABANK

Patient Information Sheet (for a person aged 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 primary 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 primary 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 NHS hospital 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) have 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 helps 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 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 The Brain Tumour Charity to request your medical records from sources like the NHS and Public Health England. We can personally identify you from your records. Identifiers such as your name, address and NHS number are stored separately from your NHS medical records to give added security. We can then link the information that you tell BRIAN about your quality of life, other treatments that you are undergoing and your experience of living with a primary brain tumour.

You can only use BRIAN after you have consented and received your BRIAN identification number.

The information in this form is used together with our Privacy Policy: thebraintumourcharity.org/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 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 information sheet 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 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 or writing to us at the address at the end of this information sheet. We will then delete your 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 consent on the web app. However, we will keep a record of your contact details and the fact that you withdrew from BRIAN to ensure we don't contact you in future about BRIAN.

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

If you have provided consent to share your information with BRIAN this will override any requests that you have made to opt out of your information being shared or used for any purpose beyond providing care. This applies to the National Data opt-out programme: nhs.uk/your-nhs-data-matters.

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 organisations like the NHS and Public Health England. 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. We will store your personal details such as name and address, separately from your NHS medical records to provide an additional level of data security.

It should be noted that we store your 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 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, 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.

If we are worried about your safety or the safety of someone else then we may need to let people know who you are so we can make sure you are fully supported.

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 Brain Tumour 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?

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 personal information under six key principles ensuring your information is obtained only for one or more specified and lawful purposes. The principles also ensure your 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.

SECTION 4: Future contact

Future contact by The Brain Tumour 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, call us on 01252 749990 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 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 to be able to see your medical records which are kept by the National Health Services and Public Health England.

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 (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 your best interest. You can read more about this law online: legislation.gov.uk/ukpga/2018/12/contents

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 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 your healthcare professional has not prescribed such as diet, over the counter medicines or alternative therapies.

Personalised Identifiable Information – this is information (combined) that identifies you such as name, address, full postcode, date of birth and NHS number.

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

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 general wellbeing including tiredness, response to treatments, headaches and daily feelings.

Research – activity undertaken by both clinical and academic scientists at universities or with industry partners 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.