

BRIAN: OUR GLOBAL BRAIN



TUMOUR DATABANK

Personal Consultee Information Sheet

A personal consultee is someone who knows the patient well (such as a relative, friend or carer), including those with Lasting/Enduring Power of Attorney

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

Introduction

You have received this information sheet as it is felt that your relative or friend is unable to decide for themselves whether to share their medical information with The Brain Tumour Charity's BRIAN (Brain tumouR Information and Analysis Network). An adult who is either temporarily or permanently unable to make a decision of this kind for themselves, is described as 'lacking capacity' under the Mental Capacity Act 2005.

This law protects the interests of adults aged 16 or over (in England and Wales) who are unable to make their own decisions, including as to whether they should take part in a medical research project. The law also provides that a Consultee can be appointed to give advice as to the likely wishes and feelings of an adult who lacks capacity about taking part in a proposed project.

We'd like to invite you to become a Personal Consultee for your relative/friend who lacks capacity. A Personal Consultee is someone unconnected to the project in question (BRIAN), who personally knows the individual who lacks capacity and who is able to advise on the person's wishes or preferences.

You must decide for yourself whether or not you want to take on this role. You may wish to seek independent advice before deciding. We will understand if you don't want to take on this responsibility. Your relative or friend's standard of care will not be affected if you tell us that you don't want to take on the role of Personal Consultee.

If you decide you would be happy to become your relative/friend's Personal Consultee, please read the following information sheet. We'd like to ask your opinion whether or not your relative or friend would want to be involved and share their information with BRIAN. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions that they may have made about participating in research. These should take precedence.

If you decide your relative or friend would have no objection in taking part, we will ask you to read and sign the consultee declaration form. If you have any concerns after you have signed the form or think your relative or friend should be withdrawn due to fluctuating capacity or any other reason, please don't hesitate to contact us either directly or by email at enquiries@thebraintumourcharity.org. We can talk you through the best approach to stay engaged with BRIAN or withdraw their information from BRIAN, and please be assured that it will not affect the standard of care they receive in any way.

Please note, the following information is the same as would have been provided to your relative or friend.

Section 1: Introducing BRIAN

Whether your relative or friend 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 they cope with the 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 primary brain tumours so they can benefit from others' knowledge and experience, and help 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

If you decide your relative or friend would want to take part, The Brain Tumour Charity will collect and store a copy of their medical records in a secure database. It links these to information that you tell BRIAN about your opinion of your relative or friend'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 their 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 their 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. It is important we receive information from all tumour types so BRIAN is representative of the brain tumour population including those whose mental capacity can fluctuate.

You will be able to add information about your relative or friend to BRIAN through a web app which aims to improve the availability and use of brain tumour information worldwide. Their 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 their information?

Sharing information with BRIAN is simple. You can share your opinion of your friend or relative's information either from your computer or any mobile device via the interactive web app, from anywhere and at any time.

SECTION 2: The Personal Consultee declaration form

What does the declaration form cover?

By signing the declaration form (including your relative or friend's NHS number) you are providing a positive 'opinion' stating you are happy for The Brain Tumour Charity to request their medical records from sources like the NHS and Public Health England. We can personally identify them from their records. With your opinion and your relative or friend's NHS number, BRIAN stores their NHS medical records safely and securely. Identifiers such as their name and address, and your contact details, are stored separately from their NHS medical records to give added security. We can then link these to information that you tell BRIAN regarding other treatments that they are taking and your opinion as a Personal Consultee of their quality of life, and experience of living with a primary brain tumour.

You can only use BRIAN after you have registered and submitted your opinion as a Personal Consultee via the declaration form.

The information in this form is 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 declaration form?

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

We consider that we have your opinion if you a) give us your relative or friend'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 relative or friend's NHS number can be found on any letter from their GP or hospital. It has ten digits in a three, three, four format. If you can't find it then please do call their GP as it is not available online.

Can I still access BRIAN on my relative or friend's behalf if I do not give a positive opinion to share their medical records?

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

How do I withdraw my opinion if I've changed my mind?

If you decide that you would no longer like your relative or friend's information to be shared 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 opinion on the web app. We would recommend that you consider their wishes and feelings and make a decision accordingly. You may notice that their capacity to make decisions may vary due to treatment or side effects and if this happens please do call us or act in the best interest of the patient.

What if my relative or friend has told the NHS they don't want their medical records to be shared?

If you have provided consent to share your relative/friend's information with BRIAN this will override any requests that they have made to opt out of their 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 their information

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

When we receive your positive opinion and your relative or friend'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. We will store their personal details such as name and address separately from their NHS medical records to provide an additional level of data security.

It should be noted we store their date of birth for statistical purpose 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 their 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 relative or friend's personally identifiable information?

Personally identifiable information, such as their name, address and NHS number, which link them 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 your relative or friend. You will not be informed on an individual basis should this be the case.

In rare situations we may have to break confidentiality, for example, if we think the person participating in BRIAN is at risk of harm from themselves or others.

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.

Is my relative or friend 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 relative or friend's information is not processed in any manner incompatible with that purpose or those purposes. As it relates to the declaration 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 relative or friend's 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 relative/friend's medical records which are kept by the National Health Services and Public Health England.

Data – the unedited facts about your relative/friend. When we get lots of data we can combine it and turn it into information that is of value to other groups (for example as 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 might 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 relative/friend's care.

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

Mental Capacity Act – this refers to the Mental Capacity Act 2005. It is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over. You may notice that a person's capacity to make decisions may change from time to time which may be due to treatments or other factors. Please do take this into consideration when using BRIAN and call us if you need to discuss the situation.

Medical Records – a record is created on each visit that your relative/friend makes to an NHS service. This means medical information about your relative/friend can be held in various places, including out patients, accident and emergency and any NHS hospital where they have had treatment. It should contain all the clinical information about the care they 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 a healthcare professional has not prescribed for your relative/friend such as diet, over the counter medicines and alternative therapies.

Opinion – this what you think your relative or friend would say with respect to joining BRIAN.

Personalised Identifiable Information – this is information (combined) that identifies your relative/friend and includes your full name, address, full postcode, date of birth and NHS number.

Personal Consultee – a Personal Consultee is someone unconnected with the BRIAN project. They personally know the person who lacks capacity and are able to advise on the person's wishes or feelings. It could be the person's friend, family member or carer. They must not be someone who is paid to look after the person who lacks capacity.

Prescribed Treatments – the medicine that healthcare professionals have recommended for your relative/friend.

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/her power to promote the health and wellbeing of the nation.

Quality of Life – your relative/friend’s general wellbeing 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 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 relative/friend, and to extract information.