

BRIAN: Our global brain tumour databank

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.

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 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, 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.