

Patient Information Sheet

NBT National Brain Tumour Study

You are invited to take part in a research study, which is looking at the possible role of inherited factors that may be increasing the risk of brain tumour development. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please talk to your family members or your GP about the study if you wish.

Brain tumours may be caused by changes in DNA, which is the inherited blueprint for your body. We are studying individuals with brain tumours to identify any new genes, or segments of DNA, which may lead to an increased risk of developing this condition.

What is the purpose of the study?

The purpose of this study is to collect information from individuals with brain tumours and from families with a family history of brain tumours, so that we can try to identify new hereditary factors that may increase the risk of brain tumours. This may help us understand why this condition develops and perhaps lead to the development of new drugs for chemotherapy.

Why have I been chosen?

Individuals that have been diagnosed with a primary brain tumour are eligible to take part in the study. As this study is also interested in looking at brain tumours within families, with your consent, we may ask you to consider inviting any family members you may have that have also been affected by a brain tumour. However, we will only ever approach family members if they have contacted us first to tell us they are interested in participating.

What will happen if I decide to take part?

If you would like to participate in this study we will ask for the following:

- A signed consent form stating that you agree to participate.
- A completed questionnaire. In this questionnaire, we will ask you for some details about yourself and your family history, including which of your family members have had cancer.
- Details (provided by your clinician) of your medical history including your diagnosis, information about any tumours you may have had removed, and the hospital where you were treated. With your permission, we may request tumour tissue specimens that are stored in hospital archives.
- A small blood sample (approximately one and a half tablespoons or 18 ml). A research nurse will make arrangements with you to take this blood sample.
- The procedure carries virtually no risks.

What will happen to my samples and the information I provide?

- Your blood samples and samples of previously removed tumours (if available) will be used to extract the genetic material to help us look for new genes predisposing to brain tumours.
- The blood samples you provide will be stored indefinitely and used for research purposes only. Unused tumour samples will be returned to hospital archives.
- No clinical genetic testing will be performed and no information will be published that might identify any individual participant; therefore there will be no insurance implications involved in taking part.
- Only authorised researchers will have access to the information you provide, and your details will never be disclosed to any third party.
- The samples and information you provide will be treated in the strictest confidence, in accordance with the Data Protection Act (1998).

We are not intending to communicate the results of this study to patients or their doctors on an individual basis. This is because the study may take several years to complete and will not provide any information regarding your medical care or the medical care of your family and it will be extremely difficult to assess the importance of these findings without supporting evidence from other studies.

What are the benefits of the study?

Although we cannot promise that this study will benefit you directly, by participating in this study however, you will be helping us to search for genetic risk factors that may be leading to the development of brain tumours. This information may help with the treatment and counselling of brain tumour patients and their families in the future. It may also help us discover why and how brain tumours occur and may eventually lead to the development of new drugs to treat this condition. Your participation in this study would be invaluable to us and our research.

We do, of course, hope that the results of our study will be of benefit to patients with brain tumours, in general. We encourage you to keep in contact with your consultant, where appropriate, and with us to update us with any new information you may have.

Do I have to take part?

No, your participation in this research is entirely voluntary and will not affect the standard of care you or your family receive in any way should you decide to withdraw or not take part. Should you join the study and later wish to change your mind, you are free to withdraw at any time without giving us a reason and your samples will be destroyed at your request.

If you are willing to take part in the study, please let your doctor or research nurse know. If you would like more information please do not hesitate to contact a member of our research team on 020 8722 4431. Thank you very much for your consideration.

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