

patient  
advisory  
group

yorkshire's  
brain tumour  
charity!

**Patient, carer and family involvement is really important to Yorkshire's Brain Tumour Charity. Everyone can have the opportunity to be a driving force behind the development of our support services across Yorkshire and Humber.**

Our YBTC Patient Advisory Group (PAG) members represent the views and experiences of people affected by brain tumours. They are influential and instrumental in our work. We value their contribution and views; they are always our first port of call when we are seeking a public or patient opinion.

It is crucial that we attract new members; patient involvement ensures our plans deliver the service that you need and want. You don't need any experience or knowledge of medical research, we just want to hear your views. We will provide any training or guidance you needed so that you can make the most of your time volunteering with us.

If you join our PAG you can get involved as little or as much as you like and help to influence real change in our services, as well as having the opportunity to support clinicians and researchers to give feedback on potential new clinical trials.

Your involvement could mean answering an online survey or poll, attending a focus group (online or face to face), reading new patient information and giving feedback or having a telephone conversation.

We are really keen to hear from patients, carers and family members of all ages, including young people. Getting involved not only means you are helping to improve services but the commitment to your local community could help with job or university applications.

**If you have any questions, please get in touch via email to: [pag@yorksbt.org.uk](mailto:pag@yorksbt.org.uk) or call us on 0113 340 0111.**

## **your involvement**

As a Patient Advisory Group member you will be asked to objectively represent the wider views of people affected by a primary brain tumour, ensuring discussions always consider the patient, carer or family member perspective. You will help us to ensure that patient benefit is central to everything we do.

There are a number of things you may be asked to get involved in, these include:

**Clinical Trial Feedback:** There are many challenges around designing clinical trials that make it difficult to decide where to focus efforts and resources. Listening to patients, carers and family members can improve clinical trials greatly.

**Support service feedback:** We want to ensure that YBTC are providing the services that patients and family members need and want. You can help contribute to decision making and strategic direction of the charity, ensuring quality.

**Identify opportunities for wider involvement:** You can tell us where you think we can ask for patient, carer and family involvement and help deliver activities.

### **How you get involved may include:**

- Online survey or poll
- Attend a workshop or focus group
- Give feedback on a potential new clinical trial
- Complete a telephone survey or interview
- Read new leaflets and information and give feedback
- Review proposed support events and give feedback and ideas
- Constructively contribute to discussions, providing your opinion, advice and feedback

### **Your commitment**

How much you contribute and how much time you give is entirely up to you. You are under no obligation to participate in any activities you are invited to.

## expectations

### **As a member of our Patient Advisory Group we expect you to:**

- Always act respectfully to other members of the group
- Be realistic about what you can achieve and inform us of any change in circumstances and support you may need.
- Take time to undertake any required pre-reading before a workshop or focus group
- Ask questions if you need clarification
- Support and listen respectfully to your fellow Patient Advisory Group members
- Give us plenty of notice if you are unable to attend meetings or meet commitments
- Promote a culture of honesty and sharing by raising concerns, issues or suggestions at the time they arise with your key contact at YBTC
- Maintain confidential information of the organisation and anything discussed within the course of your volunteering.

### **In return, you can expect us to:**

- Ensure you have a named key contact at the charity to answer any questions and support
- Provide a thorough induction on the work of YBTC, our staff and your role.
- To do our best to help you to develop your volunteering role with us, ensuring relevant training is provided as appropriate.
- Cover the cost of reasonable expenses for your PAG volunteering duties and provide any specialist clothing or equipment where this is required.
- To ensure all volunteers are dealt with in accordance with our equal opportunities policy.
- Provide information and support in advance where possible, including dates, details of activities and summaries.
- Always give you the option to not take part in an activity
- Provide feedback to you when necessary or requested and encourage two-way communication
- To be respectful to you, to listen and learn from what you have to say and, where appropriate, feedback on how your views have influenced our work

## YBTC patient advisory group – registration form

If you are interested in being a part of our Patient Advisory Group (PAG) please complete this registration form.

Name:

Date of birth:

Address:

Postcode:

Telephone:

Email:

### Your brain tumour experience:

I have/have had a brain tumour

A family member has/has had a brain tumour

I am/have been a carer for a someone with a brain tumour

I am a parent of a child who has/has had a brain tumour

No one close to me has/has had a brain tumour

Other, please specify:

I would like to be a part of the Patient Advisory Group because:

Signed:

Date:

**Please return this completed form to us at [pag@yorksbtc.org.uk](mailto:pag@yorksbtc.org.uk)  
or post to Yorkshire's Brain Tumour Charity, 31 Otley Road,  
Headingley, Leeds LS6 3AA**