



Volunteer Role Description

Expert by Experience (EBE)

At Guts UK, our Experts by Experience (EBEs) Panel ensures that people with digestive conditions are at the heart of everything we do and the decisions we make as a charity.

The panel is made up of people from our community who have lived experience of a digestive condition or are a carer/family member of someone living with a condition. We try to make sure our panel represents all the conditions we cover at Guts UK*.

We are proud that our EBEs are involved in all aspects of our work, including assessing new projects and initiatives, informing our strategy, and helping us to determine which research projects to fund. It's important to us that the patient voice is heard in every decision that we make and so all of our services, across the charity, will seek input from our EBEs at some point.

Why we want you?

- It is crucial that we represent, and listen to, the lived experience voice in everything we do at Guts UK
- We want to make sure that the concerns of people affected by digestive conditions are factored in throughout all of our services and activities
- We need people who are comfortable sharing their personal, lived experience and who are passionate about making a difference for others living with digestive health conditions
- We need ambassadors for our charity who are proud to support us and represent Guts UK openly and unashamedly

What you will be doing?

- Sharing your lived experience of a digestive condition to inform projects and services as they develop, across all areas of the charity
- Reviewing and sharing your opinion of applications for our research grants and awards (as part of a wider group including medical and research specialists)
- Taking part in meetings, focus, groups, events (and other activities) to represent and share the voice of people affected by digestive conditions

- Commenting on charity plans, such as our strategy, policies, or proposals to ensure they are relevant and impactful
- Proudly joining Guts UK led campaigns and initiatives including sharing your own story and experience

Where and when

- As a minimum, our EBEs meet on a monthly basis for one hour. There will often be some preparation and reading required ahead of this
- All of our EBEs perform their role remotely with meetings held virtually
- On occasion there may be discussions or opinions required outside of these meetings for different services across the charity. These are notified in advance and are not mandatory
- Selected EBEs also take part in our Research Awards Committee meetings which can take up more time, involving a half day's committee meeting and appropriate review and preparation time in advance. This is not mandatory and EBEs must volunteer and be selected for this extra responsibility

The skills/experience you need

- Direct or indirect personal experience of a digestive condition* – whether that is having a condition yourself, supporting or caring for someone who has, or has had, a condition.
- Willing to be bold and brave and openly share your personal experience of living with (or supporting someone with) a digestive health condition
- Prepared and available to devote the necessary time and effort to the role

Alongside this we are looking for;

- Strong communication skills; comfortable airing your viewpoint in a group setting and explaining your thinking
- A team player who works collaboratively with others and respects, and values, differences of opinion
- Sound independent judgement with an open mind to new, creative ideas
- Excited and energised by the potential of a small national charity with huge opportunities and ambition

No scientific, research or clinical knowledge is required. We welcome everyone regardless of their educational level. We prioritise diversity and inclusion and encourage individuals from all backgrounds and experiences to apply.

The benefits for you

- Your involvement will make a difference to improving the future for people affected by digestive conditions
- You will meet others with lived experience of different digestive conditions and create new connections within the wider community
- You will have the opportunity to learn about other digestive conditions and the landscape for digestive health care across the UK, including research and innovation
- You will have the opportunity to gain volunteering experience and new skills
- You will be a valued member of the Guts team where your opinions and ideas will shape the way the charity moves forward

What we will provide

- A thorough induction process to ensure you are up to speed on the charity, understand what is expected from this role and have been through appropriate training.
- Information (and training if required) for each specific opportunity or activity
- A dedicated employee contact to liaise with throughout your time volunteering with us
- We will reimburse reasonable expenses (eg travel) as outlined in our Volunteer Expenses Policy
- We will keep you informed about relevant news, events, and changes in both the charity and our volunteering community.

* Note:

We recruit EBEs for specific digestive conditions. At any point we will only be looking for volunteers with certain conditions. Our website will be kept up to date with the specific conditions we are looking for at any point. We cannot accept (and will not retain) applications that are not aligned to those conditions.