



# People Participation for disordered eating

## Help transform disordered eating support

### What is People Participation?

People Participation is the way we work with patients/service users and carers to **improve services** at East London NHS Foundation Trust (ELFT). We can support you to **share your views** based on your personal experiences of disordered eating. We also offer **payment** for your time. To find out more, continue reading or [contact us here](#).

*“I’ve recently joined the People Participation team and I find the experience very rewarding. It gives me a sense of solidarity with my community, helps me realise I wasn’t alone in my struggles and offers me the chance to pick up new skills.”*

*Expert by Experience, East London*

### What is disordered eating?

The term 'disordered eating' is intended to cover a broad range of difficulties associated with **emotional and psychological distress around food or eating**. You (or the person you care for) **may or may not have been diagnosed with an eating disorder**, and may or may not have accessed specialist eating disorder support.

### Do I have the right experience for this role?

‘Professional expertise’ is only one part of what makes a **good mental health service**. If you have **personal experience** of disordered eating or an eating disorder, your **perspective** on what can help people is really **valuable**. This makes you an ‘**expert by experience**’ – your personal understanding can help us **see what no one else can**.

*“Being involved in ‘People Participation’ basically feels like being an expert advisor to the ELFT service. You use your unique insights and personal experience to bring the views of service users to the table. You make sure the service is shaped by the people who actually use it!”*

*Expert by Experience, East London*

## What impact does this make?

Your input influences **how healthcare professionals think** about disordered eating and helps us to develop more **accessible and compassionate treatment** options for local residents.

*“Hearing people’s stories has helped us as a team to be more open when we’re thinking about treatments. We want as few barriers as possible between someone realising that they need support for an eating disorder and accessing treatment.”*

*Dr Brian Sreenan, Consultant Psychological Lead for Disordered Eating*

## What kind of opportunities could I get involved with?

You can choose what you get involved in and how much you want to participate. Some examples of our work include:

- **focus groups** to help inform best practice in disordered eating support
- **co-delivering psychoeducation** sessions for service users
- co-designing and **co-delivering training** on disordered eating to ELFT staff
- co-producing **support resources** and **communications materials** for the service
- participating in **Eating Disorders Awareness Week** campaigns
- **planning meetings** or workshops alongside staff
- sitting on **interview panels** to recruit new staff

## What services would I be working with?

This work is co-ordinated by the **People Participation Lead for Disordered Eating**, who is based within the ELFT **Community Eating Disorder Service**. We also work with other healthcare professionals who are involved in disordered eating support across East London.

## How it works

### Am I eligible to get involved?

You are eligible to join the ‘**disordered eating workstream**’ within the People Participation programme if:

- You (or the person you care for) have **lived experience of disordered eating** or an eating disorder, **and**
- You (or the person you care for) are currently **accessing ELFT mental health services**.

Once you have joined, you can remain involved for **up to 12 months after being discharged** from ELFT services. If you’re not sure whether you are eligible, we would be happy to discuss this with you via the contact details below.

### Do I need to have an eating disorder diagnosis?

People who experience disordered eating or an eating disorder can face many barriers to getting a formal diagnosis and specialist treatment. Our group includes people both **with and without formal diagnoses** – all of whom have experience of the **psychological distress** associated with disordered eating. Our People Participation Lead will be able to discuss any questions about this with you before joining.

### Will I get paid?

As an ‘expert by experience’, you can be **paid for your time**. Our ‘Reward and Recognition’ scheme offers different reward levels for different activities, which will be paid into your **bank account** via BACS. You can also choose not to receive payment, if this would better suit your needs.

### Is this a job?

No – opportunities are **ad hoc** and there is **no minimum time commitment**. Some people choose to participate in several meetings per month, while others get involved occasionally or only once.

### Will I have to share personal details about my experiences?

No. We want to hear your **views and expertise**, but it is not necessary to share your personal experiences if you don’t want to.

## The impact on you

### How do I benefit from this work?

As well as being beneficial for the service, the experience of being involved with People Participation can be **rewarding in many ways**. Holding the NHS to account, contributing to the improvement of services and **discovering the power of your voice** and lived experience **can positively impact on wellbeing**, increase **confidence** and improve a **sense of purpose and identity**. Many people feel that being involved in the People Participation programme has been helpful for their ongoing recovery.

*“I’ve felt empowered by sharing my experiences and giving voice to the frustrating aspects. It has also been exciting to hear about the changes planned. I look forward to the meetings and it is great to be doing something worthwhile with my time outside of my normal job.”*

*Expert by Experience, East London*

### Will I have to travel anywhere to participate?

At the moment, most activity takes place **online via MS Teams**, although there may be future opportunities for face-to-face work.

### How will I access different opportunities?

If you choose to sign up, our People Participation Lead for Disordered Eating will keep you **updated with relevant participation opportunities** and can help **support you to get involved**. This can include:

- **meeting with you individually** to talk through any questions or concerns;
- making sure we know about any **accessibility needs** or **reasonable adjustments** that would help you to participate;
- connecting you with **training sessions** to develop new skills.

### What support will I be offered?

While many people find PP work **empowering and beneficial to their recovery**, we understand that discussing issues to do with disordered eating **may bring up a range of feelings**. Our **People Participation Lead also has lived experience of an eating disorder** and will have an **initial meeting** with you to help decide whether PP work feels right for you at this time. **We will always aim to help you navigate the work in a way that feels safe**, including encouraging you to reflect on your personal boundaries, providing space to debrief where relevant, and signposting to further support if necessary.

### Is this a support group?

PP staff are **not therapists or support workers** and are not trained to provide clinical care. Although we aim to provide a supportive environment for sharing your views and making change, **this is not a support group** or recovery service. **If you are in need of further support with your mental health, it is best to discuss this with your GP or mental health team.**

## Getting in touch

If you want to get involved, ask questions, or find out more information – we'd love to hear from you. You can do this by **contacting our People Participation Lead, Sarah Mann, in any of the following ways:**

- **send an email** directly to Sarah at [sarah.mann27@nhs.net](mailto:sarah.mann27@nhs.net)
- complete this short **contact form**: <https://forms.office.com/e/ti77KvQknF>

Sarah will then get in touch with you to **arrange an initial conversation** and **discuss whether People Participation for Disordered Eating feels right for you**. You **will not be asked to commit to anything** during this conversation.