



My voice matters



A guide for people who
want to share their
lived experience



This is a guide to help you get involved with organisations and researchers and share your views to help shape services, research and policy.

Shaping Our Lives is a non-profit organisation led by Disabled people and service users. We've got over 20 years' experience in enabling people to have a stronger voice, helping Disabled people and those from other marginalised communities to have their say.

We call this “involvement”, but you may also hear other terms, like engagement, participation, co-production, and co-design. These refer to different ways of working with people with lived experience of using health and social care services or experiencing discrimination and disadvantage.

Shaping Our Lives believes that it's vital for people with lived experience – survivors, Disabled people, those with impairments and health conditions, service users and people from marginalised communities - to join and work with user-led groups and Disabled people's organisations. These collective and inclusive movements make sure our stories can be heard, our experiences valued and our knowledge is used to change policy and practice.

However, you may also want to get directly involved with policy change or research projects and this guide is to help you to have a meaningful and fulfilling experience.

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Why get involved?

In order for services, research and policy to be truly inclusive and represent everyone, organisations need to hear from a wide range of people. That could include you!

What things could I do?

Here's a few examples of how an organisation may involve people to hear their experiences:

- One to one interviews
- Surveys
- Focus groups and/or workshops
- Reference, advisory, or steering committees
- Patient groups and forums
- User testing of products, websites, apps
- Reviewing research proposals or funding applications



What types of organisations want people involved?

User-led and Disabled people's organisations



Groups that are led by and for the people they support, like Shaping Our Lives. User-led organisations offer vital safe spaces for people to share their stories, and access inclusive support and services. They are crucial for building movements to create positive change, and for ensuring the voices of people with lived experience are acknowledged and acted on.

Service providers like local authorities or care homes



For example, your local authority may want to get people involved with helping to improve their housing or social care services.

Health services



The NHS has a duty to listen to patients to improve their services and develop new ones.

Universities



They often involve members of the public in research projects or to give input into the content and teaching of degrees like social work.

Charities



Lots of charities have advisory groups and forums made up of people that the charity is hoping to support or represent. If you have experience of a specific condition or impairment, or lived through a specific life experience, there may be a non-profit organisation that could use your input.

Companies



Some companies may involve the public to inform how they provide their services or products.

Am I an expert by experience?

Organisations have different ways of referring to people that they work with. A few examples:

- Participants
- Service user representatives
- Patient representatives
- Experts by experience
- People with lived experience
- Lay members
- Public contributors



This can be a bit confusing, but usually these terms simply refer to people who have relevant lived experience and are getting involved because the organisation wants to hear their views.

You might not think any of these terms describe you, but don't let that put you off applying for opportunities.

How much will I have to do?

This really depends on the organisation and the opportunity you apply for. Some activities may be a one-off interview or focus group which may only last an hour. Other opportunities may run over several months or years and require travel or in-person attendance at meetings. Make sure you read the application carefully to find out what commitment is required and if this suits you.

What about expenses and payment?

All organisations should meet any expenses you have to take part such as travel, access, support or subsistence costs.

A payment is often offered for your time and expertise, but it is optional to accept this. You should be sure that any payment you accept does not affect your tax liability, pension credits or welfare benefits if you receive them.

There is no national standard for recognising the contribution of people who share their lived experience. However, there are guidelines produced by the National Institute for Health and Care Research (NIHR) that you may find helpful. Sometimes other rewards are offered instead of an involvement payment.

Here are some of the things that may be offered and/or you may want to ask about:

- Payment for your time and lived experience expertise.
- Provision of food and refreshments for meetings.
- Recognition of the contribution service users make, for example, an annual event for service user representatives, a thank you in the annual reports or an award for contributions.
- Opportunities for professional development, studying for qualifications and training.
- Opportunity to talk to other people about your experiences of being a service user representative.
- Accreditation on published reports and papers.
- Routes into voluntary or paid employment.
- A personal reference for involvement activities you complete.



What's in it for me?

You may be asking yourself if getting involved is a good thing to do. Here are some of the benefits:

- It can be empowering to help shape services for the better.
- It can give you a real sense of making a positive difference.
- You can gain new knowledge, skills, and meet new people.
- It can increase your confidence.
- It can lead to other involvement opportunities and events.
- It can be a pathway to new roles – both paid and voluntary.
- It can be helpful and informative to hear other people's stories.
- Some people find that it benefits their health and wellbeing.

I wanted to empower and influence people and make sure that people are heard and able to make changes. That's why I got involved.

I wanted to get involved because I like to help people with learning disabilities to stand up for themselves and take control of their own lives.

For me it was a start to getting back out into the world and a step on the journey to being well again.

There are lots of good reasons to get involved. We can't promise that every involvement opportunity will be beneficial to you. But we do know that your voice, your opinions, your lived experience, are valuable, and there are many benefits you could gain from sharing them.

Alex's story

We worked with Alex* as part of a project run by Shaping Our Lives. Here's what they had to say about the positive impact of sharing their lived experience:

"Shaping Our Lives makes you aware that you can have a voice and that you are not isolated, and that your voice can be heard and you can do good out there.

It can positively impact your confidence and self-esteem. It is across the board, the way it changes your outlook on things – it impacts all aspects of your life.

Being involved with other people does make you realise that others have their own challenges, and it can make you step outside of the chaos that can be in your own head/on the inside.

If you look at service user involvement in mental health services particularly, you can realise the changes that have been made and the improvements that have resulted from that, it is easy to see positives that come out of it."

“ You need to latch on to the victories and be aware of them, and stay strong – it is easy to give up and fall into the trap of thinking that one person cannot change anything. ”

***not their real name**

What are the downsides?

We can't promise every involvement activity will be done perfectly, and, like with anything, there can be downsides. Some of the things you could experience might include:

- It can be slow and take a long time to make a difference.
- The process may not be flexible to new ideas.
- Feeling patronised if you are not listened to, the professionals are not committed, or some are listened to more than others.
- Witnessing people with lived experience not being treated as equal partners and their views given equal priority.
- A lack of clear feedback telling you what difference you made.
- Stress, distress and tiredness from sharing personal experiences and listening to the experiences of others.
- Apprehension about the knowledge required to take part and the interaction with professionals.
- Frustration from communication and access barriers.

Many people feel that any negative personal outcomes are generally outweighed by the positive feelings of contributing to improving services, but this is different for everyone.

We can't promise every involvement activity will be done right. But we can make some suggestions to help you choose what to get involved in and things to look out for before you do.

Things to consider

Let's start with the basics - here are some key things to find out:

- Is it clear what the role is?
- What is the time commitment?
- Will you have to travel or can it be done online?
- Is the organisation offering to cover expenses?
- Is the organisation offering a form of involvement payment or thank you?

Other important questions to ask the organisers:

- What are you trying to achieve?
- How are you planning to do it?
- What will my time be spent doing?



Red flags to look out for:

- The time commitment is unclear.
- You feel like you're being included just to "rubber stamp" an idea
- The timings of the project seem rushed.
- There are no plans to feedback to people who get involved.
- There is no support offered such as meeting accessibility requirements or covering expenses.

What to expect

If you've found an opportunity you're interested in, talk to the organisers to make sure they have taken some practical steps to involve you. Here are some things you could reasonably expect:

- An overview of the activity, what it aims to achieve and what the outcomes will be.
- Terms of reference for people taking part in a group that will meet over a longer period.
- Clear guidance on how much time you'll need to commit.
- Payment policy for reimbursing expenses with details of how to claim and how long it takes for a claim to be processed.
- Involvement payment policy with details of how to claim and how long it takes for a claim to be processed.
- A skills audit to see if you have the appropriate skills.
- A clearly established process to share and meet access and support needs.
- An opportunity to discuss meeting venues, meeting times and other practical arrangements to suit everyone involved.
- Confirmation of practical arrangements, such as times and places for meetings.
- A named, single point of contact in case of any concerns.

Depending on the opportunity, you may also want to ask about:

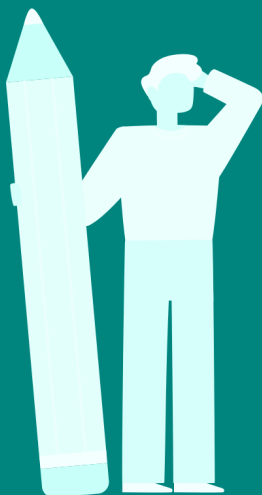
- Inductions.
- Training.
- Support – such as access to a mentor.
- Equipment – do you need any IT equipment? Some organisations may be able to provide this.



Your handy checklist

Use this checklist as a quick reminder of the things covered in the sections above:

<input type="checkbox"/> Role description	<input type="checkbox"/> Payment policy
<input type="checkbox"/> Time commitment	<input type="checkbox"/> Terms of reference
<input type="checkbox"/> Information about what they hope to achieve	<input type="checkbox"/> Access and support needs
<input type="checkbox"/> Travel requirements	<input type="checkbox"/> Training requirements
<input type="checkbox"/> Tech requirements	<input type="checkbox"/> Support and benefits they can offer
<input type="checkbox"/> Expenses policy	<input type="checkbox"/> A named contact



Tools to help you

The People's Involvement Pledge

We've developed a pledge that you can take to the involvement organisers. It outlines 12 simple steps to inclusive involvement that you expect the organisers to meet in order for you to be able to participate fully.

You can download [a free copy of the pledge](#) from the Shaping Our Lives website or ask us to send you one by emailing hello@shapingourlives.org.uk or phoning 0345 241 0383



What about my access and support needs?

You should be asked about what access and support requirements you have and the organisation you apply to should be willing to make adjustments to meet those requirements.

You may also find using the My Involvement Profile helpful. Designed by disabled people, it's a simple template form for writing down all your access and support requirements, and your involvement interests and activities in one place. You can then share this with any involvement opportunity organiser. It means you won't have to repeat your requirements and you can fill it out in your own time and update it as your needs fluctuate or change.

[Download your free copy.](#)

Where can I find opportunities?

Here are some places you can look - where the text is underlined it means there is a link you can click:

- [The Shaping Our Lives Involvement Opportunities Board](#)
- [Local or national user-led and Disabled people's organisations](#)
- Your local GP surgery or your local hospital
- [The Integrated Care Board for your area](#)
- [The Patient's Association](#) often advertise opportunities
- NHS England [Current opportunities to get involved](#)
- [Be Part of Research](#)
- [Your local Healthwatch](#)

If you live with a condition, or have specific life experience, there may be a charity which you can get involved with. Try searching on Google. Here are some examples:

- [Samaritans Lived Experience Panel](#)
- [MS Society Lived experience network](#)
- [Shelter Lived Experience of Housing issues](#)
- [Rethink Experts by experience roles](#)



Find out more

Here's how you can contact us and stay up-to-date with our work:

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- [Follow us on Instagram](#)
- [Visit our website](#)
- [Send us an email](#)
- Call us on 0345 241 0383

We're building a community of people who are committed to truly effective, inclusive involvement. If that sounds like you, [join the free community](#).



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