

# About National Voices

## Lived Experience Partner with National Voices

[National Voices](#) is the leading coalition of health and social care charities in England. We have more than 200 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people. We work together to strengthen the voice of people - patients, people who use services, their families, carers and the voluntary organisations that work for them.

National Voices advocates for more equitable and person-centred health and care, shaped by the people who use and need it the most. We do this by:

- Understanding and advocating for what matters to people especially those living with health conditions and groups who experience inequalities
- Finding common causes across communities and conditions by working with member charities and those they support
- Connecting and convening charities, decision makers and citizens to work together to change health and care for good

National Voices has 14 members of staff, who you can read more about [here](#). We are an independent charity, and are self-funded through membership, projects and grants. We work collaboratively with a wide range of stakeholders across the health and care system, from tiny grassroots organisations to government leaders.

## Defining Lived Experience

At National Voices, we use [Baljeet Sandhu's](#) definitions of "Lived Experience" and "Lived Expertise":

- Lived Experience - *'The experience(s) of people on whom a social issue, or combination of issues, has had a direct impact'*
- Lived Expertise - *'Knowledge, insights, understanding and wisdom gathered through lived experience.'*

This means that, in the context of our work influencing the health and care system, when we refer to people with lived experience, we mean:

- A person living with, or a person providing unpaid care to a family member living with:
  - Long-term health conditions and/or disabilities
  - Who experiences health inequalities

When we refer to the expertise of people with lived experience, we mean:

- The knowledge, insights, understanding and wisdom gathered through their experience of being:

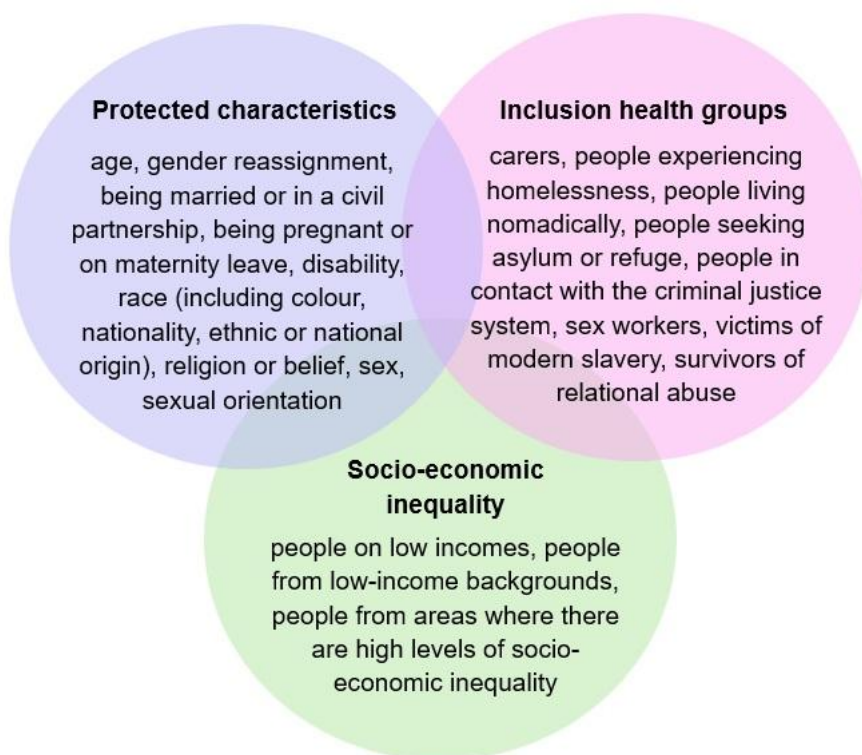
- o A person living with, or a person providing unpaid care to a family member living with:
  - Long-term health conditions and/or disabilities
  - Who experiences health inequalities

## Defining Health Inequalities

Health inequalities are avoidable, unfair and systematic differences in health between different groups of people (Source: [The King's Fund](#)). They are driven by a wide range of social, economic and environmental factors. These are things like: how much money you have to live on, the quality of the education you had or have, the house and the local area you live in, and whether you face discrimination, stigma or social exclusion due to who you are as a person.

People who experience health inequalities are more likely to face barriers in accessing the care and treatment they need. They are also more likely to experience poorer outcomes from the care and treatment that they receive.

In the diagram below, we have outlined the groups of people who experience health inequalities:



## The different groups of people that National Voices connects with

In order to understand people's experiences of health and care, we connect with a wide range of people through our work at National Voices. We learn from people's experiences and amplify their voices to make recommendations that improve the experiences for other people.

The different groups of people that we connect with are broadly summarised as:

- People with experience of using health and care services – we often work with people who have experience of using health and care services in our research and policy influencing work. This is usually focused on a particular type of experience relevant to our work at the time, such as experience of using a medical device, or of receiving a cancer diagnosis. People with experience of using health and care services may be invited to complete a survey or attend an interview or focus group so that we can better understand and learn from their experiences.
- People who experience health inequalities – we regularly work with people who experience health inequalities in our research and policy influencing work. We amplify their voices in decision making in order to improve equitable access and breakdown systemic barriers. People who experience health inequalities may be invited to complete a survey or attend an interview or focus group so that we can better understand and learn from their experiences.
- Lived Experience Partners (sometimes called Experts by Experience) – we work closely with a small team of people known as Lived Experience Partners. Our Lived Experience Partners are people with significant, often long-term, lived experience of using health and care services, who experience health inequalities, and who have either had training in co-production, or have been involved in patient experience and co-production work. Through this training and experience, they have developed knowledge, skills and expertise on both the health and care system and the practice of engagement, co-design and co-production. We work with our Lived Experience Partners in a range of ways to inform and influence our work.
- Advocates from Voluntary, Community, Faith and Social Enterprise (VCFSE) organisations – as a membership organisation for health and care charities, we often work with advocates from VCFSE organisations in our research and policy influencing work. VCFSE organisations are typically focused on a particular mission (e.g. advancement of treatment for a particular condition, or reduction in health inequalities for a particular group). They will often be able to connect us directly into particular communities and share technical knowledge and data on the experiences and preferences of the group they represent.

## Engagement, Co-design and Co-production

We know that health and care systems and services are at their best when they are designed with people with lived experience. People with lived experience hold unique and invaluable expertise (knowledge, insights, understanding and wisdom gathered through their experiences). When this expertise is valued, and people are enabled to meaningfully influence decision making, in collaboration with the expertise of leaders, professionals and staff in health and care systems and services, service design and improvements are more likely to achieve greater impact and better outcomes for people and communities.

Co-production is a word that is often used, and it is often used incorrectly! There are a range of ways that organisations can work with people with lived experience, and co-production is one of those ways. At National Voices, we use the [Peoplehub](#)

Spectrum of Participation to illustrate and describe the different ways that we work with people with lived experience.



In our work with Lived Experience Partners, we focus on the right-hand side of the Spectrum, on “doing with” people. Across our work with the different groups of people that we connect with, we work to ensure that their input is **meaningful**. We do this by:

- Acknowledging and addressing power imbalances
- Supporting and preparing people to participate well
- Enabling genuine influence and being prepared to change our thinking and our ways of working
- Feeding back to people about the impact and the difference that their involvement has made

National Voices engages with people with lived experience through surveys, interviews, focus groups, roundtables and workshops. We aim to co-design and co-produce our strategies and policies, and the projects, processes, methods and outputs of our work with Lived Experience Partners.