

National Voices Strategy 2024 – 2029



Foreword

Big strategic shifts are often driven by the smaller, more day-to-day changes that fundamentally shape culture and ways of working.

When it comes to the health sector, this can be best summed up by the need for the NHS and social care services to focus more on getting the basics right in partnership with the VCSE.

From understanding the different reasons why people struggle to access primary care, to improving the experience of waiting for hospital treatment, it is getting the basics of person-centred care right that makes services more compassionate and equitable.

As a coalition of charities, representing a vast range of conditions and communities, we are uniquely placed to push for these incremental improvements in every single aspect of health and care. This means, for example, we can challenge services to consistently meet the access needs of Disabled people, whilst also ensuring they address systemic racism. This strategy aims to make the work of our members more than the sum of its parts.

By putting people with lived experience at the heart of everything we do, we can be relentlessly focused on what matters most to them. We can explore ways to build on their skills and capabilities to help patients become partners in designing services and in managing their care.

We know our coalition cannot make this happen on our own, and we are committed to collaborating with system partners to drive change together. But where progress stalls and inequalities persist, we will not be afraid to speak out. What's more, we want to make patient experiences, outcomes and tackling inequalities the core measures of success for services, so that systems challenge themselves to do better.

The ultimate prize of this strategy is a health and care service that better meets the needs of all neighbourhoods and communities across England.

Jacob Lant, Chief Executive



Our history

National Voices formed in 2008 to campaign for more person-centred care, to put people more in control of the decisions about their treatment and support. Today, we are the largest coalition of independent charities in England, putting people at the heart of the biggest conversations on the design and delivery of health and social care.

We began life with a particular focus on long-term conditions, and this continues to matter deeply to us, particularly those who are experiencing life with multiple health needs and intersectional inequalities.

We have played an integral role in major NHS strategies, such as the [Five Year Forward View](#). And we are perhaps best known across the sector for the development of the “[I Statements](#)”, a co-produced set of expectations which set out clearly and concisely what people and communities want from health and care services.

Our new five-year strategy is about building on this rich history, increasingly targeting our efforts, but also being bold in our ambitions, to achieve the maximum impact for our communities. This will involve championing a wider movement of professional development that sees the NHS and social care services working more in partnership with the people they serve to tackle challenges together.

The context we are working in

In its first few days in power, the new Labour government declared that **the NHS is “broken”**. For many of those we work with, this statement reflects the reality of their experience in recent years.

This is not to say that the doctors, nurses and other professionals who make up the NHS and social care sector aren't working hard. We see this every day in the conflicting feedback patients and carers share with our members, that staff are “doing their best” but that fundamentally too many people are not getting the help they need:

- **People repeatedly struggle to access services like their GP**, dentist or A&E when they need – these services are the very front door of the NHS.
- Long waiting times for planned care are likely to be with us for many years to come – **creating a growing need for more support whilst people wait**.
- We hear too often about services failing to get the basics right – from people's **communication needs, such as British Sign Language, being forgotten** to the **lack of good admin** and coordination between services for those on multiple pathways.
- Big social changes like **the cost of living crisis** and **the shift to digital services** are creating new barriers – these risk making the NHS no longer free at the point of need for some of the most marginalised groups.

Some of these issues are of course well known to system leaders, others are invisible because they simply don't appear in how the sector judges performance. It is our job to give these issues visibility and hold services to account for meeting the needs of everyone.

What makes us unique

National Voices is part of a rich landscape of voluntary sector and statutory organisations gathering insights from patients and communities, all of us championing the role that people can play in designing services to be better.

We are therefore increasingly working together to try and make patient and community voices more than the sum of their parts.

But there are some things that make us unique and different to our friends and partners. These qualities will be important for the NHS, the social care sector and the Government to understand as we all seek to tackle the challenges ahead.



Our reach: We are England's largest coalition of independent voluntary, community and social enterprise (VCSE) organisations working in health and care. We bring together a unique combination of over 200 condition-focused charities and community centred organisations who provide services and support to millions of people (both alongside and beyond the NHS/social care) every year.



Our focus: We dedicate ourselves to improving care for those who have the worst access, experiences and outcomes. By working with these groups, we can address inequalities head on and find solutions that benefit us all. We are able to do this precisely because of our members, who act as a trusted link into the communities who are so often ignored or poorly listened to.



Our methods: We pioneer new ways of putting people and communities in the driving seat in all our work, and we challenge others to do the same by embedding meaningful citizen involvement in decision making through co-production and co-design. This is underpinned by the National Voices [I Statements](#) which set out what people want from a comprehensive and forward-thinking health and care system in their neighbourhood.

Our Vision:



People shaping their health and care.

Our Mission:



We advocate 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 cause 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.

Developing our new strategy:

As a coalition of organisations, and a champion of co-production more broadly, we recognise the importance of developing our strategic priorities together with those we work with.

Between June 2023 and March 2024, we engaged our networks in a variety of ways to help us identify three interconnected strategic priorities.

This included:

- Analysis of our annual membership survey (83 organisations responded).
- Analysis of CEO roundtables and 1-2-1 meetings engaging a total of 43 members.
- Dedicated workshops with staff, the board and our Lived Experience Partners.

This helped us develop the three proposed areas of focus:

1. End unequal access



2. Transfer power to people and communities



3. Shift the measures of success



We then conducted further engagement in April 2024 to test out if these were the right areas of focus and to finesse them where needed. This included:

- An online session with 30+ members to explore how we might work on these priorities together as a coalition.
- And an in-person session attended by a mix of 40+ staff, trustees, Lived Experience Partners, member representatives, our strategic partners and key stakeholders from across the sector.

Key messages from the engagement:

- Those we engaged with agreed that it was essential for National Voices to continue its focus on health inequalities and to champion working with people with lived experience.
- They felt that the priorities we identified were the right areas to do this and that tangible improvements were possible in all three.
- Participants could also see how the priorities linked together and how activity in each could reinforce the others.
- People cautioned that the three areas were still quite broad and would need us to make tough decisions where we focus to remain financially sustainable as a charity and achieve the most impact.
- Lastly, we heard participants call for us to be bolder in our expectations of the system and to be persistent in our efforts holding decision makers to account.

1. End unequal access

A key aspiration of our NHS is that everyone can access high quality treatment and care, in a timely manner and in a way that works for them. This means services should have a strong focus on health literacy, understanding how to cater to a range of individual needs to help people understand how to access care. This also means listening hard to what communities have to say to actively address wider barriers to access.

Sadly, over the last decade NHS performance statistics have shown growing issues with access. Our members too regularly share how access issues are affecting their beneficiaries, in particular how the challenges are not felt equally across different neighbourhoods and communities. Access is therefore a key driver of inequality, because it doesn't matter how high quality the care is if people cannot access it in the first place.

Access issues are driven in part by macro pressures, like the lack of resources in the NHS and social care, and key workforce shortages in areas of deprivation and rural areas. Stigma and prejudice, such as systemic racism, sexism and transphobia also play a massive part, compounded by a lack of consistent and high-quality demographic data meaning health inequalities often go unnoticed by systems.

Many of the common barriers to access could be overcome if services better understood the context of how people live their lives, and proactively worked with communities who experience unequal access to redesign services.



Our strategic focus

In line with what our engagement exercise told us about focusing our efforts, we will concentrate on how we can help and challenge the system to address the common access barriers faced by those currently experiencing the worst outcomes.

This means we will address health inequalities head on, but by working with people to develop solutions, we aim to find ideas that improve access to care for everyone.

What do we mean by common barriers:

- **Information about services** – e.g. people often don't know which service to use and when, or what to expect. Similarly, services don't consistently meet communication needs, such as those of people with sensory or learning disabilities.
- **Admin processes** – e.g. the system lacks good consistent data on the people it serves, making it incredibly hard to design and deliver proactive and personalised services tailored to people's needs. Likewise, services create admin barriers to care, such as refusing GP registration for those who don't have an address.
- **Challenges with new technology** – e.g. the rapid move to digital systems and services risks excluding those without the right skills, technological confidence or resources.
- **Costs of accessing care** – e.g. people are struggling to afford things like travel to appointments, cost of prescriptions, running medical devices at home.
- **Damage caused by previous bad experiences** – e.g. previous/current bad experiences, particularly around racism, misogyny, homophobia, transphobia and stigma around weight are impacting on people's decisions to seek care and treatment. For example, Black people are more than twice as likely to have to attend three or more GP appointments with symptoms of cancer before getting a referral.

1. End unequal access

Incremental improvements:

In five years' time, our work will have led to significant changes in the way the NHS and social care services understand “access” from the patient point of view and why addressing common barriers is critical to supporting a more person-centred and prevention-focused health and care service.

For example:

- We will support the system to maximise the potential of new technologies, but we will have also ensured that systems recognise the needs of those who struggle with digital access. This will result in services offering enhanced support to those who need it to access digital services, and continuing to offer analogue options for those who cannot or would prefer not to use technology.
- Management of elective waiting lists will routinely consider social factors alongside clinical need to ensure people get equitable access to treatment and appropriate additional support whilst they are waiting for care. This will include proactive recognition of the impact of waiting on both mental and physical health, and providing “pre-hab” support to ensure people are in the best place possible for their treatment when the time comes.
- By gathering better quality demographic data and routinely segmenting it, Integrated Care Systems (ICSs) will have a much better understanding of who is and who isn't accessing care. This will enable them to undertake targeted and tailored outreach to communities to understand why access is poor and to co-produce the tweaks needed to make care more accessible, from addressing issues with transport to pre-empting communication barriers that might be preventing uptake of services.



Strategic shift:

All health and care leaders will no longer think about their services in terms of who is accessing care, but in terms of who isn't.

They will be equipped with the skills to ask why and will be routinely involving the communities who are missing in designing the solutions.



The nature of health has fundamentally changed. People are living significantly longer than they were when the NHS was established in 1948, but they are not necessarily living those extra years in good health. Indeed **25 million people are currently living with a long-term condition**, and 13 million have more than one.

It is also clear that this is not spread evenly across our country. Those living in the most affluent neighbourhoods can expect to enjoy up to **18 more years of healthy life** than those living in the poorest neighbourhoods.

In response, subsequent governments have promised an increased emphasis on prevention, and a greater focus on helping people better manage their own conditions. But achieving this will require a radical cultural change in the NHS, moving away from the traditional paternalistic model of care. We need a system that provides people with better information, involves them in decision-making processes and respects their wishes.

Where community input is needed to shape services more effectively, at either national or ICS level, this must be sufficiently resourced with health and care leaders working with the needs of communities, respecting the time and energy that people put into making the system better. The system also needs to be open to not just hearing, but also taking action based on the insights generated through community involvement.



Our strategic focus

National Voices is a leader in co-production, bringing people together with decision makers on a regular basis to fix problems collaboratively. Through our strategy we will explore how this approach can be used to democratise decision making in health and care. Ultimately, we want to demonstrate what a new power-sharing model of care would look like if it was spread through every level of the NHS and social care.

On a practical level, we will work to create a world where the capabilities and support networks of patients, people accessing social care, unpaid carers, citizens and the VCSE organisations working with them, are recognised as a powerful piece of the puzzle – both in supporting direct care and in the design and delivery of services overall.

Examples of how we might stimulate this transfer of power include:

- **Supporting better co-design of services**

We will seek to improve both when the system involves patients and the public, as well as the quality of that engagement. Alongside this, we will help to equip system partners to listen better to what they have heard and take action. We will also support partners to improve the diversity of those involved in such activities.

- **Advocating for more support to be provided at key points in the patient journey**

For example, by encouraging more support at the point of diagnosis we can help patients, carers and communities build the knowledge, skills and capacity to support much greater understanding and self-management of conditions, especially during times of change or crisis in a patient's life.

- **Building capacity within communities to prevent the onset of health conditions**

Huge power and energy currently resides within the VCSE sector that can be harnessed to both tackle inequalities, and support communities more broadly to be healthier. Working in partnership with our membership, we will advocate for greater strategic investment of the VCSE sector at national and local level to support the NHS and social care on primary and secondary prevention.



Incremental improvements:

In five years' time, services and communities will have different expectations of the role that patients and the public can play, both in terms of managing their own care and what, and how, they can meaningfully influence decisions about policy and service improvement.

For example:

- Individuals will have an understanding of and the power to make trade-offs between speed of access and continuity of care depending on their clinical and non-clinical needs. This includes the choice of professional they see and whether the appointment is in-person or managed remotely.
- Services will be providing wrap-around support at the point of diagnosis, facilitated by the VCSE and peer support. This means patients, their families and carers will have a better understanding of their condition from the start, their treatment options and how to manage their ongoing needs.
- People and communities will be able to actively and continually engage with their local services and ICS, putting forward ideas for improvement, influencing decision making and understanding how the system is acting on their input.



Strategic shift:

We will have effectively democratised decision making in health and care. Individuals will be routinely offered meaningful choice and control over the support they receive to help them stay well and manage conditions when they arise. Communities, and the VCSE organisations supporting them, will be energised and activated as a key part of the local and national infrastructure on prevention and wellbeing.

3. Shift the measures of success



At the moment, the success of the NHS is primarily judged on process measures and volumes of activity.

For example, media and political narratives are almost entirely focused on three key performance indicators (KPIs):

- The size of the elective backlog and whether the number is going up or down.
- The numbers of people waiting more than four hours in A&E.
- The overall number of GP appointments being delivered.

From a public perspective, performance against these KPIs is important, because we know that no one wants to wait a long time to receive care when they are in need.

However, the current metrics are not particularly helpful in enabling individuals to understand whether they will be able to access care in a timely manner, or whether the care they receive will actually meet their particular set of needs.

Part of the problem is that the current KPIs reflect only a very narrow part of the care pathway, rather than assessing the outcomes and experiences of care. Only by asking patients about their experiences, can we really understand if the NHS is truly meeting the health needs of the population.



Our strategic focus

We will seek to raise the importance that government and system leaders place on user-reported experiences and outcomes as a key indicator of performance.

This will help to drive up the importance of engaging with people and communities as NHS and social care services seek to understand how well they are performing and how to improve.

We will seek to do this by growing the use of the National Voices “[I Statements](#)” as a basis for understanding what matters most to people.

These eight statements are:



1. I am listened to and what I say is acted on.
2. I make decisions that are respected, and I have rights that are protected.
3. I am given information that is relevant to me, in a way I understand.
4. I am supported to understand risks and uncertainties in my life.
5. I know how to talk to the person or team in charge of my care when I need to.
6. I know what to expect and that I am safe when I have treatment and care.
7. I am supported and kept informed while I wait for treatment and care.
8. I am not forgotten.



3. Shift the measures of success



Incremental improvements:

In five years' time, the NHS and social care will be using a whole suite of additional performance metrics to understand how well it is meeting the needs of the population. This will include better use of existing data, in particular broken down by key demographics to highlight performance against health inequalities. This could also include new core metrics around areas of performance that are co-designed with patients to ensure they focus on things that matter most to them, like experiences and outcomes in relation to the management of long-term conditions.

Examples of how this might be different include:

- GPs will be judged not on the number of appointments they deliver but on the proportion of their patients who got the help they needed and their experience of the process. This will take into account the complexity of the local community served by the practice.
- Hospitals will be judged not on the size of their waiting list, but on the outcomes they are helping people to achieve such as how many patients have successfully seen an improvement in their quality of life post-treatment.
- ICSs will be judged on how they have engaged with people and communities and the impact of that engagement on tackling key challenges around access and inequalities. A key success measure for this will be how successfully each ICs has helped to close the gap in healthy life expectancy between key demographic groups and postcodes.



Strategic shift:

The measures of patient experience and outcomes will sit side-by-side in terms of importance with productivity measures and financial reporting. This will be reflected in NHS Planning Guidance, the ICS Oversight Framework and in any financial incentives offered to providers in secondary, primary or community services. Political stakeholders and the media will also be routinely questioning/reporting on how well the NHS is meeting patient needs, rather than the size of waiting lists or the number of appointments.

National Voices

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

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info@nationalvoices.org.uk
www.nationalvoices.org.uk
[@NVTweeting](https://twitter.com/NVTweeting)

020 3176 0738
The Foundry, 17 Oval Way, London SE11 5RR

