



Shaping independent voice in the Health Bill

Seven principles for what comes next

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Sponsorship

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Introduction

The 10 Year Health Plan promises to put patients and their voices at the heart of decision-making. At the Health Bill Commons Report stage on 7th September 2026, the Minister committed to review the provisions around independent patient voice to make sure the new approach “sufficiently empowers and devolves to local populations.” The future of the independent patient voice is still to be determined and the decisions made as the Health Bill passes through the House of Lords will shape it for years to come. As the Bill changes how independent patient voice is organised, there is a real risk that independence, local reach and statutory powers could be lost. The new arrangements must protect what works and go further.

An independent patient voice is essential to ensuring that experiences, priorities and concerns held by patients are heard in decisions about health and care. Research by [The King's Fund](#) found that independence was a key strength of Healthwatch, building credibility and trust with communities. It also builds trust with those patient organisations that play a pivotal role in bringing together individual experiences, identifying issues that may otherwise go unheard.

On 8th October 2026, the Patients Association brought together patients, carers and national, local and community organisations to ask what independent voice means in practice and what needs to work. What we heard very strongly was that patients need an independent voice that reaches the people who make decisions and leads to the change they want to see.

The report sets out:

- A definition of the independent patient voice
- Seven principles that any future arrangements should meet
- The key messages we want decision-makers to hear

“Patients’ voices should be meaningfully included, not excluded.”

Patient representative

What independent patient voice means

Independent patient voice means patients, carers and the organisations representing them, working in partnership with health and care services to shape decisions and hold decision-makers to account, not just give feedback. They stay free to gather their own evidence, say what people need and suggest solutions, including challenging government, the NHS and social care. It puts power in the hands of patients, as the 10 Year Health Plan promises, and goes out to reach people least likely to get the chance to be heard.

For it to work:

- It has secure funding, is independently run and is open to outside scrutiny
- Patients' voices reach the right decision-makers at the right time
- Decision-makers do not just listen but act. They set out publicly, within an agreed timeframe, what they will do and what has changed as a result, and there is a clear way to take it further if they do not
- Patients can see the impact of their voice, now and in the future, and changes are evaluated to see if they have genuine impact.

"If you're heard and nothing happens, what was the point in being involved?"

Roundtable participant

Principles for independent patient voice

These principles were tested and refined by roundtable participants. They are a practical test that decision-makers can apply to any future arrangements for patient voice.

- 1. Independent and free to speak.** The body that listens to patients is separate from the organisations that run, pay for or check on services, nationally and locally. It can publish what it finds without permission from government, the NHS or anyone it reports on. It has its own independent checks to make sure what it publishes is accurate. Patients can trust that what they say reaches decision-makers in full, and problems are not hidden.
- 2. Partnership and co-production.** Patient voice is part of how government, the NHS and local services work. It is not left to one team, and takes a whole system approach. Decision-makers treat patients and charities as real partners, not a box to tick. People with lived experience, from a range of backgrounds, help run it and are involved from start to finish. This means decisions reflect what matters to patients.
- 3. Impact and accountability.** Success is measured by the difference made to patients, rather than the system-focused targets, such as measuring activity. What people share is used, not just collected. Better and more inclusive data is collected on what matters to patients, such as outcomes and experience, not only on how services are performing. The body should report patient experience publicly at least annually. There must be a statutory commitment for Government and the NHS to say publicly what they have heard and what they will do, then shows it has done it. Changes are

evaluated to see if they have genuine impact. Patients should be able to see that their voice has made a difference.

4. **Equal voices, equal say.** Views are gathered in every area, and from groups who share an identity or experience, not just from where people live. Local work can build trust, and a national body should ensure problems are dealt with everywhere. The body goes to organisations that people already trust, hears from new people and makes sure people know it exists. People can be involved in ways that suit them, not only online. It uses plain language, gives people enough time and remunerates them for their participation. It has a duty to reach people who are least likely to be heard, and their views must count equally. It should record who takes part, and what voices are not engaged as much, so gaps can be addressed and health inequalities can be narrowed.
5. **Clear powers and responsibilities.** The body has a legal right to ask for information and visit services. This covers all health and social care, whether run by the NHS, a local council or a private company. It is clear about what it looks at and why, so people do not confuse it with regulators such as the Care Quality Commission (CQC). Any group, however small, has a right to a public reply within an agreed time. Decision-makers must explain changes being made based on feedback in plain English, even when the answer is no. If concerns are ignored, there is a clear way to take them further. This means concerns lead to action.
6. **Protected, fair funding.** Funding is secure, reflective of health inequalities, lasts several years and cannot be cut by the organisations it criticises. Money is shared out according to need, so areas and communities that need more support to engage get more. This means people have the same chance to be heard, and to see change, wherever they live.
7. **Built with community organisations.** Charities and community groups that patients already trust are recognised and paid for their work as part of health and social care. They stay independent and free to challenge the system. This means trusted relationships lead to better care.

“It’s not just feedback. It’s about patients being able to shape their services, and not only when things go wrong.”

Roundtable participant

What participants told us

At the close of the roundtable, we asked each participant for the one message they most wanted decision-makers to hear. The word cloud brings together those messages and the words participants used at the start to describe independent patient voice.



“Listen and respond is a little too easy to be a tick-box exercise without an expectation of appropriate review and action.”

Roundtable participant

Key messages for decision-makers

Drawing on the roundtable, these are the messages we want decision-makers, policymakers and commissioners to hear:

1. **Protect independence.** The body that listens to patients must be separate from those that run, pay for or check on services, and free to publish what it finds without permission.
2. **Being heard is not enough.** Decision-makers must respond publicly within an agreed time, explain what they will do, and show what has changed as a result.
3. **Give patient voice real powers.** It needs a legal right to ask for information and visit services across all health and social care, and a clear route to take concerns further when they are ignored.

4. **Reach everyone, not just the easiest to hear.** Funding should follow need and there must be a duty to reach the people least likely to be heard.
5. **Work with the organisations that patients already trust.** Charities and community groups should be recognised and paid for their role, while staying free to challenge the system.

Conclusion

The Minister's commitment to review the provisions on independent patient voice is welcome. The Health Bill now moves through the House of Lords, and the decisions made there will shape how patients are heard for years to come. This is the moment to get it right.

Participants were clear that being listened to is not enough. An independent patient voice must reach the people who make decisions, lead to action, and show patients what has changed as a result. Without that, involvement risks becoming a tick-box exercise, and the trust that patients and communities have placed in independent voice will be lost.

The seven principles in this report offer a practical test for any future arrangements. Decision-makers, policymakers and commissioners should ask of any proposal whether it is:

- independent and free to speak
- built on genuine partnership and co-production
- measured by its impact on patients, with clear accountability
- reaching everyone equally, especially those least likely to be heard
- backed by clear legal powers and a right to a public response
- secured by protected, fair, needs-based funding
- built with the community organisations patients already trust

The 10 Year Health Plan promises to put patients and their voices at the heart of decision making. Meeting that promise means independent patient voice must be designed into the Bill from the start, properly funded and given the powers to make a difference. We urge decision-makers to use the passage of the Health Bill to secure these principles, so that every patient, wherever they live and whoever they are, can be heard and see that their voice has led to change.

The Patients Association will continue to work with patients, carers and partner organisations to make sure this happens.

Acknowledgments

This roundtable was held under Chatham House Rule, so individual contributions are not attributed. The definitions, principles and recommendations in this report were developed by the Patients Association drawing on the discussion. Taking part in the roundtable does not mean that individuals or organisations endorse the contents of this report.

We want to extend our warm thanks to the patients and organisations that took part in the roundtable and wider engagement, for their time and valuable insights. While representatives from individual organisations took part, these representatives spoke on behalf of patients they work with. Their contributions sought to represent patient views, and ensure their voices were reflected in the conversation.

Attendees at the roundtable: Crohn's and Colitis UK, Endometriosis UK, Guts UK, LGBT+ Foundation, Macular Society, the Patients Association, Prostate Cancer UK, Pulmonary Fibrosis Trust, The Richmond Group of Charities, Turning Point, and one patient representative.

External engagement: Communities in Sync, Pumping Marvelous Foundation, Sandwell African Caribbean Mental Health Trust, and one patient representative.

The Patients Association

The Patients Association is an independent charity campaigning for improvements in health and social care for patients.

Our vision is a health and care system where patients get the care they want and need, when they need it, and where their voices shape how that care is designed and delivered. Our mission is to amplify patient voices and ensure they are heard, acted on and embedded in how healthcare is delivered. We listen to patients, translate their experiences into evidence, and use that evidence to influence policy, hold systems to account, and drive real and lasting improvements in care.

Membership of the Patients Association is open to anyone interested in health and social care. If that's you, we'd love you to be a part of our growing community - [Join us today](#).

Our [helpline](#) is free and available to anyone with a question about their care or that of a loved one. You can contact our helpline advisers by email or phone (details below).

To support our work, [visit our website](#).

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