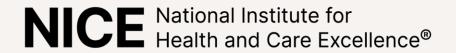# Working alongside People and Communities at NICE

A three-year strategy for involvement and engagement

Progress report:
July 2024 - November 2025

NICE National Institute for
Health and Care Excellence®

Executive summary

> "[working with] NICE gave me the confidence to look elsewhere, pick myself up […] now I've got a purpose" – NICE lay member

In July 2024, the NICE Board approved NICE's strategy for working alongside people and communities. The three-year strategy (2024-27) set out the 5 core areas of focus that NICE would prioritise to achieve the vision of having a 'best-practice approach to involvement and engagement, to improve the impact of our guidance and ensure the best care for people and communities'.

The priorities were informed and shaped by people with lived experience, voluntary and community sector organisations, colleagues, and experts in the field to ensure NICE focused its involvement and engagement approaches on the areas that mattered most to people and communities.

This report provides an update on progress in the foundational year for the strategy (July 2024 – November 2025), our people and communities involvement work in guidance development, and outlines the priority areas of focus for 2026.

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2024/2025 facts and figures – involvement in guidance development

Recruited 58 new lay members to participate in NICE committees

Identified and supported 119 patient experts to share their lived experience with NICE committees

Identified and supported 38 people to share their lived experience at NICE ADVICE meetings

Ran 9 induction sessions for 67 people and organisations participating in medicines evaluations

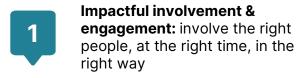Ran a training program for new lay members of guideline committees

Supported 83 lay committee members through their involvement in NICE committees

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A reminder: Our five core areas of focus

Core Areas of Focus

How will these core areas help us achieve our vision?

1 **Impactful involvement & engagement:** involve the right people, at the right time, in the right way

There is no one-size-fits-all solution to involving and engaging people and communities. Our approach will be meaningful, appropriate and targeted on a case-by-case basis. This considered approach will ensure we maximise the input and impact of the people and communities contributing to our work.

2 **Tailored approaches:** tailor the way in which people and communities can engage with NICE

We will break down barriers that restrict engagement with NICE, such as complex committee structures or heavily bureaucratic processes. A tailored approach to involvement and engagement will remove barriers that alienate or discourage involvement. We will seek out more diverse experiences from people from wider communities and ensure we listen and learn.

3 **An innovative culture:** test with, and learn from, new and innovative ways to work alongside people and communities

Established ways of working aren't always the most effective. We will help everyone feel safe to speak up, to disagree openly and test innovative ways to involve and engage people and communities. We will learn from feedback and use this to influence developments in our methods and processes. This will ensure involvement and engagement remains meaningful and is informed by feedback, best practice and the health and care environment.

4 **Productive partnerships:** transform our approach and ways of working with people and communities

The expertise of people and communities is vital for us to realise our vision. We will build on our established relationships and work with partners, particularly those who can help us work with those who often excluded or marginalised, to ensure their involvement and engagement with NICE increases the impact of our guidance.

5 **Focus on people first:** embed an ethos of curiosity for involvement and engagement across NICE

Aligned to NICE values, we will nurture an ethos of curiosity for championing and seeking out involvement and engagement opportunities. Actively seeking out and understanding what matters to people and communities and how and where our work has impact. This commitment will be led by our Executive Team and Board and adopted by everyone.

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Measuring the success of our strategy – summary of July 2024 – November 2025

Core Areas of Focus	Measuring success	Progress	Status
Impactful involvement & engagement	• The areas that matter most to people and communities are identified, and there is increased guidance uptake in these prioritised areas. • Improved rating and feedback on experience, impact and psychological safety from people & communities involved in guidance development. • Involvement opportunities and communications are accessible for people and communities, measured through quantitative, qualitative and narrative evidence sources. • An updated payment policy fairly and transparently compensates people for their involvement and engagement	• Active lay membership of prioritisation board; VCS Network jointly prioritising areas for collaboration that matter most to them - associated uptake measurement will be considered in 2026-27 • Reduction in lay members experience of working with NICE as 'good or excellent' in 2024/25 – proactively working to understand themes and initiate plans to improve experience and feedback within wider committee improvement plan • Accessibility- improvements to the IT system, communications, and recruitment process ongoing • Payment policy updated and fully implemented	AMBER
Tailored approaches:	• Introduction of a suite of involvement and engagement methods to enable a tailored approach to guidance development • Annual improvements in our reputational research survey results from the voluntary and community sector, across all domains. • Increased participation and improved feedback on experience and impact from groups who experience health inequalities, including carers, advocates, or representatives.	• Work established to test a tailored menu of options and inform involvement and engagement options at topic start • Reputational research survey results due Jan 2026 • Involvement & engagement data and feedback due April 2026	GREEN
An innovative culture	• The impact of any innovative or new ways of working are routinely evaluated and implemented more widely in guidance production • Guidance development methods will be updated to define tailored options and evaluation approaches for impactful involvement and engagement.	• Patient involvement impact project underway to better understand, describe, and measure impact • Harmonised and tailored approaches being tested with guidance teams	GREEN
Productive partnerships	• Increased number of new partnerships formed with voluntary and community sector organisations to increase the uptake and impact of NICE guidance. • Positive rating and feedback on experience and impact of the partnership from voluntary and community sector organisations.	• Partnership with National Voices to explore barriers to uptake and access in women's health topics • 5 VCS organisations contracted to lead the VCS leaders group, setting priorities for the VCS network • VCS data collection initiated, full data set due April 2026	GREEN
Focus on people first	• Designate a NICE Board non-executive director with specific responsibility for people and communities involvement and engagement. • Increase the proportion of NICE staff trained as involvement and engagement leaders, to build an organisational culture for involvement and engagement.	• Non-executive director designated • 76 staff active participants in the NICE involvement and engagement champion's network	GREEN

1. Impactful involvement and engagement: We will identify, involve, and engage the people and communities who will benefit from our guidance, and seek out more diverse experiences. Our involvement and engagement approach will be meaningful, appropriate, and targeted on a case-by-case basis to maximise input and impact.

Progress made:
- To ensure NICE priorities reflect the needs of people and communities, 2 lay members actively participate in the NICE prioritisation board
- To better convey the impact of Tics and Tourette syndrome on people's daily life, social life, education, mental health and wellbeing, for the first time we created a digital story for committee, based on the survey responses of over 1,500 people [HTE25]
- To improve understanding of experiences of people seeking help for anxiety and depression using digital triage, we introduced patient questionnaires into the diagnostic assessment program [HTE30] as there was little evidence available about people's experiences of using digital front door tools
- To more fairly recognise the commitment made by all committee members and introduce more flexibility in our payment offer we launched an updated payment policy.

2. Tailored approaches: We will break down the barriers that restrict engagement and ensure our approaches are tailored to be accessible and inclusive. We will involve and engage with the right people, in the right way at the right time.

Progress made:
- To enable patient experts to have more detailed discussions about their experiences, we tested earlier engagement approaches with some medicine evaluation topics ahead of committee meetings
- To ensure that the outcomes and issues most important to people are reflected in guidance scoping, we have introduced involvement of people with lived experience in the early scoping stages of prioritised guidelines
- To better seek out more diverse experiences from people from wider communities, we have identified guideline topics where diverse populations are most impacted and identified alternative methods of capturing those experiences
- To improve understanding of the needs of people using technologies in practice, we have supported the involvement of people with lived experience in user preference workshops for late-stage health technology assessments.

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3. An innovative culture: We will help people and communities, staff, and our committee members feel safe to speak up and test innovative ways to involve and engage people and communities meaningfully. This will be, informed and inspired by evidence where possible and aligned with best practice and the health and care environment.

Progress made:

- We have used a continuous quality improvement (CQI) approach to better understand and measure the impact of involvement and engagement in NICE guidance production, developing a feedback loop for people with lived experience and voluntary and community sector organisations. We now have a definition of impact and understand where impactful involvement adds value in NICE processes
- To better understand and learn from people's experiences (positive and negative) of working with NICE, we have used CQI methodologies to explore themes and test solutions. Feedback is now sought throughout the process, via a suite of surveys and structured conversations, enabling more timely responses and actions
- To test the new PIPER (Pathways to Implementation for Public Engagement in Research) toolkit, we collaborated with Keele University, Midlands Partnership University NHS Foundation Trust, and patient representatives to consider how organisations could incorporate health inequality considerations into the uptake of treatments for endometriosis and fibroids.

4. Productive partnerships: We will develop productive partnerships with people and communities to deliver greater impact through increased uptake of guidance

Progress made:
- NICE convenes two external networks with the Voluntary and Community Sector (VCS) and with People and Communities - the network remit has been refreshed and membership has increased to 300 organisations and 424 individuals respectively
- To ensure that these external networks were productive and focussed on topics and priorities which matter most, we established leadership groups for both, with appointed organisations and individuals to co-lead with NICE colleagues
- The VCS network now co-delivers task and finish groups in prioritised areas. The initial priority is health inequalities, with a specific focus on understanding digital exclusion, particularly in the area of digital health technologies
- To understand where there are opportunities for improving uptake of medicines guidance in asthma, migraine, diabetes and endometriosis, we have engaged with VCS organisations representing people living with those conditions
- To help identify barriers to access and uptake of guidance in women's health topics, we have partnered with National Voices to gather community expertise and insight.

5. Focus on people first: We will demonstrate visible Board commitment and develop involvement and engagement leaders who will nurture an organisational culture for championing and seeking out involvement and engagement opportunities with the people we serve

Progress made:
- NICE designated a NICE Board non-executive director to lead on people & communities involvement and engagement – thank you to Jackie Fielding
- To build an organisational culture for involvement and engagement, we established a people and communities champions network for NICE staff. The network has:
  - 76 staff members
  - 11 members recruited to its network leaders group
  - Completed planning to set out the vision and work for the network
- Led contributions from people with lived experience and VCS organisations at 5 NICE all-staff meetings to help colleagues better understand the impact of involvement and engagement in NICE's work
- Delivered a panel session at the 2025 NICE conference, in collaboration with 3 VCS organisations.

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People and communities experience of working with NICE

- Exit survey responses - % of people reporting their overall experience of NICE as 'good or excellent'

Respondent	23/24	24/25	Change
Lay members	95% (n=20)	79% (n=19)	-16%
Patient experts	91% (n=47)	85% (n=60)	-6%

Lay members reported a good experience when:

- They felt heard on the committee, their lived experience was welcomed, and they had lots of opportunity to contribute
- They had good support from fellow committee members, NICE staff and topic advisers
- There was good communication, timekeeping and inclusive chairing
- They saw their impact in the guidance
- They received training to support them on the committee

Lay members reported a poor experience when:

- Review protocols failed to capture important patient outcomes and people were not involved in scoping
- NICE did not consider the right evidence to address patient outcomes and understand health inequalities
- Communication was poor, papers arrived late and were too lengthy and technical
- There was a lack of diversity on committees
- Practitioner voices were perceived as more highly valued than lay members
- Discussions were overly technical or exclusionary

To proactively address issues, we are now collect experience data throughout the guidance development process to understand and respond in a more timely way. We will continue to work with NICE teams and committees to improve experience, including as part of the wider committee improvement plans, and feed back to participants what has changed as a result.

Our focus in 2025/26

As we move into the second full year of implementing our strategy, we will focus on the following areas:

- Embedding findings to build further understanding and improve people's experience of involvement and their impact in working with NICE

- Improving how we involve carers and take carer experience into account in our guidance development

- Bringing together the external and internal networks to operate as a 'network of networks', further enabling the strategy, providing input and expertise to NICE and strengthening the organisational culture of involvement & engagement

- Early involvement in horizon scanning, surveillance and topic prioritisation to ensure NICE is developing guidance which addresses areas which matter most to people and communities

- Improving how we find and use patient experience data, how we incorporate that data into guidance development, and how we re-use that data to prevent duplication across topics - reducing the burden on VCS organisations and individuals

- Wider implementation of digital storytelling to better share and embed narrative data across committees

- Continuing to increase the diversity of committee lay members and people who share their lived experience with us, ensuring we tailor our approaches to involvement.

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