



Safe and inclusive patient involvement: Embedding lived experience in health policy and advocacy

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Date: March 2026



Disclosure Statement

There are no conflicts of interest to declare.

No funding was received for this work.

Involvement in policy – the challenges

Patient and public involvement is essential to credible health policy, and people with lived experience **must** be involved, despite the barriers:



Fatigue.



Communication difficulties.



Cognitive changes.



Visual impairment.



Low confidence in policy or professional spaces.



Involvement in policy – the challenges

Our model for the 10-Year Health Plan consultation prioritised:

- **Accessibility.**
- **Psychological safety.**
- **Participant experience.**

Involvement isn't just about asking – it's about **how** you create the conditions for people to contribute.



Participants and delivery

We delivered **three national virtual workshops** across England, each focused on one of the three 'shifts' of the 10-Year Health Plan:



Focusing on preventing sickness.



Moving health to communities.



Making better use of technology.



Participants and delivery

Typical group size: **10–30 people per session**

Nearly **100 participants in total**, including:



Stroke survivors.



Carers and family members.



Staff.



Health professionals.



Virtual workshops enabled participation regardless of location or effects of stroke, and enabled us to mobilise and respond quickly, **but may have excluded others.**

Accessibility

Preparing the participants was key to the experience.

Our **'What to expect and how to prepare'** document was designed with:

- ✓ Plain language.
 - ✓ Short sentences.
 - ✓ An explanation of what would happen.
 - ✓ Setting out clear expectations.
 - ✓ Reassurance around their knowledge levels.
- ✓ Encouragement to:
 - Take pauses.
 - Ask for repetition.
 - Share lived experience as expertise.
 - Follow up after sessions if needed.

Psychological safety and skilled facilitation

Sessions were led by one of our trainers with a coaching and mental first aid background.

Ground rules and reassurance at the start of each session:

-  Encouraging questions – including use of Chat.
-  The need to respect different views.
-  Leaving space for everyone to speak.
-  Normalising uncertainty and different levels of knowledge.
-  **Reinforcing that all experiences were valid.**

Psychological safety and skilled facilitation

Breakout group facilitators briefed to:

- **Support quieter voices.**
- Use relatable everyday examples to assist with understanding.
- Monitor chat for people who preferred typing.
- Manage group dynamics.
- Keep discussions paced and inclusive.

These discussions were likely to raise some emotional concerns – signposting to the Stroke Support Helpline for further support was essential.

Accountability - closing the loop

After the workshops, we shared a **feedback and insight report** with participants which:

- Summarised what people said.
- Reflected key themes captured in clear language.
- Explained how insights would be used.
- Outlined next steps we would take.

This helped show people **what happened because they took part**.



Impact

For people with lived experience:

- Increased confidence to take part in policy discussions.
- **Feeling heard and respected.**
- Greater sense of agency and dignity.
- Reduced barriers for people often excluded.



Impact

For the Policy and Influencing function:

- Insights informed the Stroke Association's response to government.
- **Lived experience shaped our recommendations on the three 'shifts'.**
- Supported national focus on stroke within cardiovascular disease priorities.



Transferrable learning

Key principles:

- Design for accessibility from the start.
- Build psychological safety into sessions.
- Use aphasia-friendly preparation materials.
- Invest in good facilitation.
- **Share feedback so people see the impact of their involvement.**

These approaches help make patient involvement:



More inclusive



More meaningful



More trusted

Key takeaway

Design workshops around **the experience of participants** – not just around collecting information.

By focusing on accessibility, safety, and confidence, more people are able to take part and influence policy in a **meaningful** way.





Finding **strength** through **support**