Patient Experience Data 101

Commissioned and funded by Pfizer Ltd.

PP-UNP-GBR-13772 | November 2025

National Voices

What counts as Patient Experience Data?

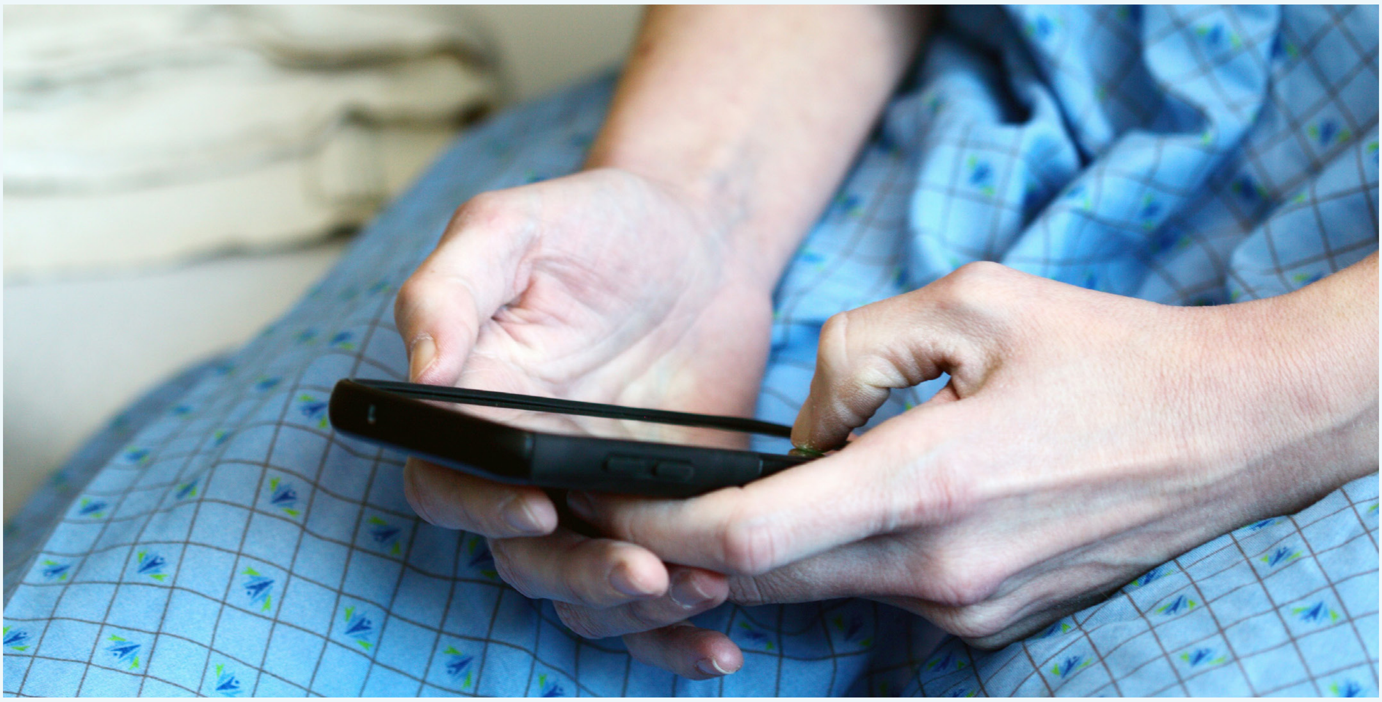
Patient Experience Data is about what care feels like from the patient's point of view.[1, 2]

It includes what people say, write, or show about their care – whether that's through surveys, conversations, complaints, compliments, online posts, or outreach work.[3]

It's not just about clinical outcomes (like test results) or activities (like appointments delivered).[4] Those things are part of the picture, but they don't tell us how patients felt about their care.

There's no single 'right way' to collect this data.[5, 6] It can be formal or informal, written or spoken, structured or spontaneous — what matters is that it helps us understand care from people's perspectives.

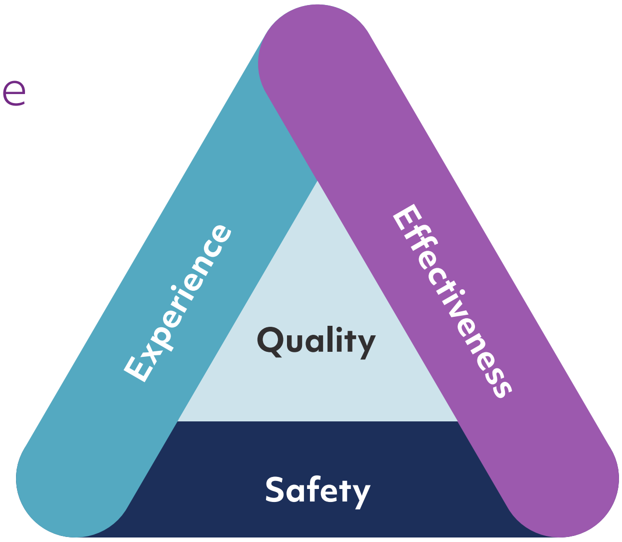
- Surveys and feedback forms
- Spoken or written feedback
- Helplines and online forums
- Photos, videos, and social media posts
- Complaints and compliments



Why does Patient Experience Data matter?

Providing patients with a positive experience isn't optional — it's one of the three aspects of high-quality care.[7, 8]

NHS leaders and statutory guidance are clear: services must aim to deliver care that is not only safe and effective, but also compassionate, kind, and respectful.[9]



By consistently collecting – and using – Patient Experience Data (PED), we can:

Demonstrate good practice

Understanding care from the patient's perspective helps to show what's working – and what isn't.[10]

Explain outcomes

Patient experience insights help to explain why patients may experience different outcomes.[11]

Identify inequalities

Disaggregated patient experience data helps reveal disparities and unmet need.[12, 13]

Drive improvement

Patient feedback helps to identify shortcomings and develop targeted improvements.[14]

Build public trust

Demonstrating a willingness to listen – and act – increases service credibility.[15]

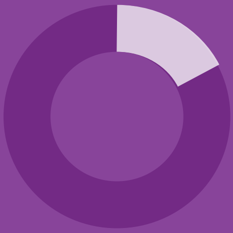
Case study:
Digging deeper into Patient Experience Data

National Voices and Ipsos used disaggregated PED to highlight disparities in the experiences of health and care service users.

Headline figures suggest most people feel confident and supported to manage their health, but disaggregated data shows that people with multiple long-term conditions (i.e., those who use services most) are about twice as likely to lack confidence and feel unsupported.[16]

% "not very"/"not at all" supported to manage their health

18%



People with no long-term health conditions

39%

People with multiple long-term health conditions

% "not at all" treated with dignity and respect when using NHS services

4%

People from white ethnic backgrounds

13%

People from ethnic minority backgrounds

Overall, most people report being treated with respect and dignity when receiving care – but closer examination reveals that ethnic minority respondents are more than three times more likely to report negative experiences than their white peers.[17]

What does the 10-Year Health Plan say about Patient Experience Data?

The NHS 10 Year Health Plan puts patient voice and experience at the heart of how care is measured, assessed, improved, and funded.

By 2029, all services will collect and publish experience data, and feedback will shape everything from local care to national funding flows.

This marks a cultural change as much as a technical one – requiring not just new infrastructure, but new mindsets.[18, 19] Getting it right will depend on meaningful data, inclusive collection, and trust in what people say about their care.

Patient voice is a priority

> *"We will put patient choice, voice and feedback at the heart of how we define and measure quality."*[20]

Incentives will align with experience

> *"It will make NHS funding flows increasingly sensitive to patient voice, choice and feedback."*[23]

Data will be visible and actionable

> *"The app will give patients the option to leave feedback … this will be viewable by others, nationally collated and translated as actionable recommendations."*[21]

Feedback will drive improvement

> *"By 2029, both PROMs and PREMs will be used universally, [and] will be published in the public domain."*[22]

A new leadership role

> *"We will create a new National Director of Patient Experience … responsible for overseeing the collection of more informed feedback … and making it publicly available."*[24]

Collecting data responsibly and effectively

Collecting patient experience data responsibly means knowing why you're collecting it, using the right methods, and respecting the people who share their stories.[25, 26, 27]

Start with 'why'
Be clear about what you're collecting, from whom, and why.[28]

Get meaningful consent
Tell people what you'll do with their feedback, and ask if they'd like to stay involved.[29]

Make it accessible
Offer different ways to give feedback. Avoid digital-only routes.[30]

Pick the right tools
Use a range of methods, tailored to your specific goals.[31]

Protect people's data
Store data securely. Share data only with permission.[32]

Close the loop
Let individuals and communities know what changed ("you said, we did")[33]

Putting equity at the centre

Patient experience data should help us reduce inequalities – not reinforce them. That means collecting feedback from diverse communities, understanding who's missing, and acting on what we find.

Core principles

Equity ≠ equality
Everyone should get what they need to achieve a fair outcome, not just the same thing.[34]

Proportionate universalism
Support should be universal, but with more help for those who need it most.[35]

Universal design
Design with the most marginalised in mind. If it works for them, it will work for everyone.[36, 37]

Learn more: What is Universal Design?

Break down your data: Report findings by group (e.g., age, ethnicity, deprivation, etc.) to see who's missing – and who's missing out.

Start with trust: Partner with trusted local groups (VCSE, Healthwatch) to close trust gaps and share power.

Make equity routine: Build equity into every stage of data collection and analysis – it's an obligation, not a 'nice to have'.

Hear from people not in the system: Go to where people are. Keep the agenda broad and open. Listen for what matters to them, not just what's useful to you.

Over-represent under-represented groups: Deliberately oversample people who don't usually take part.

Turning data into impact

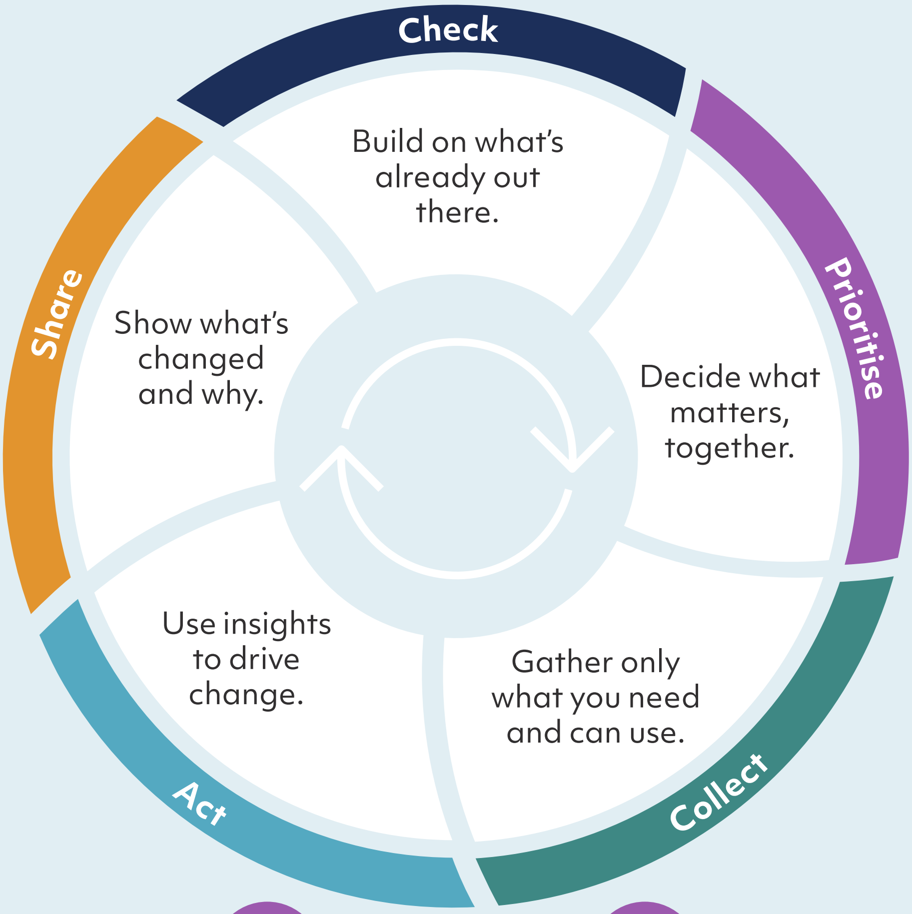
Collecting data is not the same as using it. Patient Experience Data only adds value when it leads to meaningful change.[38]

Use co-production where it adds the most value

Choose the right approach to involve people meaningfully.[39]

Don't drown in data

Focus on the insights you can use; check what already exists before collecting more.[40]



Check

Build on what's already out there.

Prioritise

Decide what matters, together.

Collect

Gather only what you need and can use.

Act

Use insights to drive change.

Share

Show what's changed and why.

Work together

Share data and costs with partner organisations. Joint projects are likely to be seen as more 'credible' and attract more funding.

Use qualitative insights to illustrate quantitative trends

Numbers show **what** is happening; stories explain **why**.[41, 42]

Case study:
From community insights to national guidance

National Voices worked with NHS England and local community groups to understand how people who don't speak English well experience NHS services.

They reviewed existing evidence, held focus groups with six language-minority communities to co-design practical improvements to translation and interpreting, and fed these insights into NHS England's national improvement framework.

Learn more:

- [National Voices project report]
- [NHS England improvement framework]

Check

Reviewed existing reports and research on language barriers and inequalities before designing new engagement.[43]

Prioritise

Targeted engagement with six 'less heard' language communities facing major barriers and worse outcomes.[44]

Collect

Ran focus groups and interviews to hear experiences and co-design practical improvements.[45]

Act

Used findings to shape NHS England's community languages improvement framework and its main areas for action.[46, 47]

Share

Published NV report and NHS guidance showing how community experiences led to chosen priorities and actions.

Resources

Statutory guidance

Patient Experience Improvement Framework (NHS Improvement)

Best practice

Using Patient Feedback: A Practical Guide to Improving Patient Experience (Picker)

Making Sense and Making Use of Patient Experience Data (Civica, InHealth Associates)

Making Better Use of Patient Experience Data for Health Service Improvement (University of Oxford)

Case studies

The Patient Experience Book (NHS Institute for Innovation and Improvement)

Themed Review: Improving Care by Using Patient Feedback (NIHR)

References

What Counts as Patient Experience Data?

[1] Picker Institute, 2009. Using Patient Feedback, 7
[2] National Institute for Health Research, 2019. Improving Care by Using Patient Feedback, 6
[3] Nuffield Department of Primary Care Health Sciences, 2016. Resource book for participating frontline medical ward teams, 10
[4] National Institute for Health Research, 2019: 6
[5] Picker Institute, 2009: 7
[6] National Institute for Health Research, 2019: 8

Why does Patient Experience Data matter?

[7] UK Government, 2025. Fit for the Future: 10 Year Health Plan for England, 86
[8] NHS England, 2025. NHS Oversight Framework 2025/26, n.p.
[9] NHS Improvement, 2018. Patient Experience Improvement Framework, 5
[10] Picker Institute, 2009: 5
[11] Picker Institute, 2009: 5
[12] Picker Institute, 2009: 8
[13] National Institute for Health Research, 2019: 30
[14] Picker Institute, 2009: 7
[15] Picker Institute, 2009: 7

Case study: Digging deeper into Patient Experience Data

[16] Ipsos, 2025. Polling reveals ethnic minorities and people with multiple long term health conditions more likely to express dissatisfaction with NHS care, n.p.
[17] Ipsos, 2025: n.p.

What does the 10-Year Health Plan say about Patient Experience Data?

[18] Neurological Alliance, 2024. How does the NHS use patient experience data as a driver for service improvements?, 4
[19] National Institute for Health Research, 2019: 17
[20] UK Government, 2025. Fit for the Future: 10 Year Health Plan for England, 86
[21] UK Government, 2025: 8
[22] UK Government, 2025: 88
[23] UK Government, 2025:.83
[24] UK Government, 2025: 89

Collecting Data Responsibly and Effectively

[25] National Institute for Health Research, 2019:11
[26] Picker Institute, 2009: 7
[27] UK Research Integrity Office, 2025. Code of Practice for Research, 16-17
[28] National Institute for Health Research, 2019: 11
[29] UK Data Service, 2024. Ethical and legal guidelines in data sharing, 26
[30] Picker Institute, 2009: 15
[31] Picker Institute, 2009: 7
[32] UK Data Service, 2024: 17
[33] Royal Devon University Healthcare, 2022. Patient Experience Strategy, 2022-25, 11

Putting Equity at the Centre

[34] National Voices, 2024. Equality Action Plan 2024-29, 4
[35] Institute of Health Equity, 2020. Health Equity in England: The Marmot Review 10 Years On, 7
[36] Blackwell, A., 2017. The Curb-Cut Effect, n.p.
[37] Daly, N., 2025. What is universal design?, n.p.

Turning Data into Impact

[38] National Institute for Health Research, 2019: 11
[39] Carers Trust, n.d. Understanding co-production, 5
[40] Care Quality Commission, 2025. Addressing health inequalities through engagement with people and communities, p.15
[41] National Institute for Health Research, 2019: 8
[42] Nuffield Department of Primary Care Health Sciences, 2016. Resource book for participating frontline medical ward teams, 8

Case study: From community insights to national guidance

[43] National Voices, 2024. Community Languages, Translation and Interpreting Services, 8
[44] National Voices, 2024: 9-11
[45] National Voices, 2024: 8-9
[46] National Voices, 2025. The impact of real-word experiences in shaping translation and interpreting services, n.p.
[47] NHS England, 2025. Improvement framework: community language translation and interpreting services, n.p.

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.

**National Voices is a registered charity, no. 1057711,
and a company limited by guarantee, no. 3236543.**

info@nationalvoices.org.uk
www.nationalvoices.org.uk
@NVTweeting

020 3176 0738
The Foundry, l7 Oval Way, London SE11 5RR

Non-Promotional Certificate UK

Name UK_PA_National Voices Patient Data Resource

Document Number PP-UNP-GBR-13772

NON-PROMOTIONAL ITEM CERTIFIED FOR USE

The below signatories have examined the electronic final form of this material and in their belief it complies with the Code.

Other Final Country Signatory	Name: Bryan Shapiro Signature Date: 12-Dec-2025 15:35:38 GMT+0000 Reason: Non-Promotional item certified for use