

Working for patients:

How improving the experience of patients with long-term conditions can deliver the Government's ten year health plan





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ABOUT THIS REPORT

Future Health and National Voices have worked in partnership on this research project. The work has been kindly commissioned and funded by AbbVie but Future Health and National Voices have full independent editorial control over the work.

The research has included:

- · A literature and evidence review
- A set of interviews with National Voices members
- A roundtable with national policymakers discussing opportunities to improve patient experience and how this feeds into the ten year health plan
- A set of external interviews with national and local NHS leaders

We are very grateful for all those who have given up time to provide insights, case studies and examples for the report.

ABOUT FUTURE HEALTH

Future Health is a public policy research centre focused on creating healthier, wealthier people, communities and nations.

Future Health publishes regular research papers across its three policy research programmes of health prevention, health technology and the links between improvements in health and economic growth.

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ABOUT NATIONAL VOICES

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

www.nationalvoices.org.uk



EXECUTIVE SUMMARY

On his first day in office the Secretary of State for Health and Social Care, Wes Streeting labelled the NHS 'broken but not beaten'.¹ Whilst the NHS is undertaking record volumes of activity, there are long backlogs for treatment and patient satisfaction has fallen sharply.² Streeting has been clear that the Government's forthcoming Ten Year Health Plan to repair the system will be co-designed with the public, partner organisations and healthcare staff.³

Since last autumn the Government has run an extensive engagement exercise gathering feedback across these groups and many others. By the end of the exercise, the aim is to have had the biggest conversation on the future of the NHS ever held. At the heart of the plan are three shifts: moving care from hospital to community, shifting from sickness to prevention, and re-designing services from analogue to digital.

An ageing population and rises in multi-morbidity mean that 25 million people in England now have a long-term condition (LTC) such as blood pressure, diabetes, rheumatoid arthritis and back pain. Over the coming years this number is set to rise significantly.

This research argues that understanding the experience of people with LTCs needs to be at the heart of the Government's plan. People with LTCs account for 70% of GP appointments and 50% of hospital activity. Understanding if these patients are feeling supported to manage their condition, able to access the care in the community they need, are avoiding complications with their condition, alongside their views on the usability and quality digital services, will be integral to assessing whether the three shifts are working in practice.

The experience of patients within the NHS is captured through a wide range of national and local surveys. But measuring and acting on the experience of patients has been de-prioritised in recent years with a far greater emphasis placed on improving access to services and waiting times for treatment. This is despite there being extensive evidence that improving patient experience can improve the quality of care and reduce more expensive healthcare use.⁵

The lack of prioritisation of patients with LTCs, which worsened during the COVID-19 pandemic and after, coupled with fragmented data collection methods and other structural challenges means the current system is not set-up for success.

This paper proposes a new nationally and locally blended policy model, based on the Core20PLUS5 health inequalities programme, to help embed the experience of

¹ https://labour.org.uk/updates/press-releases/wes-streeting-speech-at-labour-party-conference-2024/

² https://natcen.ac.uk/publications/public-attitudes-nhs-and-social-care

³ https://www.gov.uk/government/publications/working-group-tasks-10-year-health-plan/tasking-statements-for-the-10-year-health-plan-working-groups

⁴ https://www.futurehealth-research.com/site/wp-content/uploads/2023/12/Long-Term-Conditions-Report-FINAL-DECEMBER-2023.pdf

⁵ https://assets.publishing.service.gov.uk/media/5a7c3a5b40f0b67d0b11fbaf/7432.pdf

patients with LTCs at the heart of delivering and monitoring the Government's three policy shifts.⁶

To do so requires a four stage approach. Beginning with auditing what is currently being collected and using this to then inform and build a small number of more effective national experience measures aligned to the three shifts. It involves working with local systems to embed processes and support effective public and patient engagement alongside utilising new technologies to gather and analyse the feedback of patients and reporting back on progress.

In taking such actions the Government will be able to see whether the shifts in the Ten Year Plan are working for those with LTCs.

The latest NHS restructure, announced in March 2025, creates concerns that knowledge and expertise will flow out of the system in how patient experience is collected, analysed and acted upon.⁷ These fears are live and happening in real time as highlighted in National Voices' recent report for the Health and Social Care Committee.⁸

De-prioritising patient experience at this point (framed as part of cuts to bureaucracy) would be completely counter-productive, not only for patients but for the Government itself.

Recording improvements in patient experience will support the Government's aim of improving very low patient satisfaction rates – just one in five people say they are 'satisfied' with the way the NHS runs – bringing not only obvious direct patient but also political benefits.

Instead this restructure needs to be seen as an opportunity to finally embed patients and patient experience at the heart of the new health system.

This is an opportunity that must now be taken.

⁶ https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/

⁷ https://www.hsj.co.uk/integrated-care/revealed-the-icb-staff-targeted-for-redundancy/7039077.article

⁸ https://www.nationalvoices.org.uk/publication/covering-the-fall-out-national-voices-members-concerns-surrounding-the-decision-to-abolish-nhs-england-and-cut-icb-running-costs-by-50/

Summary of findings

On most measures the experience of patients with LTCs has declined in recent years with millions of people not receiving the care and support they need. Our analysis of the most recent, 2024, GP Patient Survey found the following:9

Fewer patients feeling supported to manage their condition

Nearly four in five patients (78%) with an LTC said they were either 'very' or 'fairly' confident of being able to manage their condition. 22% however said they were either 'not very confident' or 'not at all confident'. Projecting these findings across all people with an LTC results in a potential 5.5 million people not feeling confident to manage issues caused by their illness or condition.

Over the last five years, coinciding with the start of the COVID-19 pandemic – the numbers of people saying that they are either 'very' or 'fairly' confident of being able to manage their condition has fallen by 5.4% (from 83.6% in 2019).

Mixed support from local services

Nearly a third of patients, surveyed through the GP Patient Survey felt they had not had enough support from local services in helping them manage their condition. 37% said they had had enough support 'to some extent', with 30% saying they had 'definitely' had enough support. Projecting these findings across all people with a LTC results in 7.5 million people saying they have not had enough help from local services to manage their condition.

The number of people saying that they have not had enough support from local services to help them manage their condition has risen by over 10% in the last five years from 21.6% in 2019 to 32.2% in 2024.

50% of patients are not having a conversation about how to best manage their condition with a healthcare professional

Over 50% of patients, surveyed through the GP Patient Survey, said they had not had a conversation with a healthcare professional to discuss what was important to them in managing their condition. 42% by comparison said they had had such a discussion. Projecting these findings across all people with a LTC results in 12.5 million people not having a conversation about what is important to them in managing their condition.

The number of people saying that they had had a conversation with a GP practice professional to discuss what is important to them in managing their condition has risen slightly in the last five years, from 39.5% in 2019 to 41.5% in 2024.

Crucially while we know how many conversations were had, we do not know the value these conversations specifically had for patients in making them more able to manage their own health.

⁹ https://www.gp-patient.co.uk/

There are a lack of patient-healthcare professional care plans in place to support patients

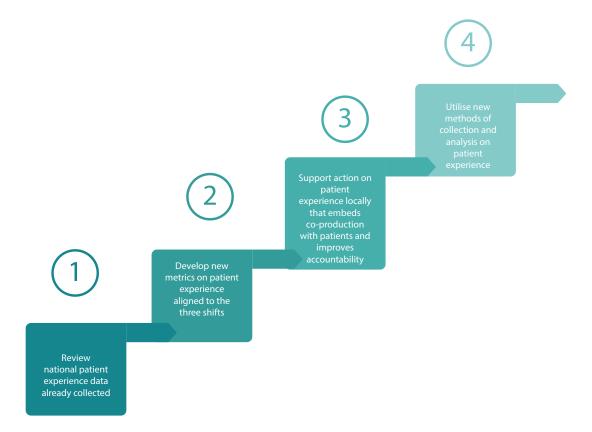
Respondents were split on whether they had agreed a plan to help them manage their condition. 45% said they had agreed a plan, whilst 46% said they had not. Of those who had agreed a plan 94% felt that it had been helpful to them in managing their condition. Projecting these findings across all people with a LTC results in 11.5 million people not having an agreed plan from their GP practice to manage their condition.

The number of people agreeing a plan with a healthcare professional to help them manage their condition has fallen sharply since 2019. In 2019 60.3% of patients said that they had such a plan, but this has fallen by a quarter in the last five years.

Action plan for change

This report proposes a four part action plan for prioritising and improving the experience of patients with LTCs within the NHS.

Figure 1: Four part action plan for improving the experience of patients within the NHS



Review and refresh national patient experience data already collected

As part of the Ten Year Plan the Government should commit to a rapid audit of existing patient experience surveys and measures (see Chapter 2 for an explanation of current national surveys). The audit should be used as a foundation for a clear approach for tracking and acting on the experience of patients with LTCs that more closely aligns to the three shifts in the Ten Year Plan, and to develop ways to bring together insights from the different surveys to create an overview of LTC experience data.

2. Recognise the importance of patient experience for those with LTCs in delivering the three shifts in the Ten Year Plan

Introducing an overarching national metric assessing how well supported people are to manage their LTC would help provide an assessment of whether the plan and its three shifts are working for patients. This could be supplemented with specific metrics for each shift such as:

Hospital to community: A measure focused on people's access to care in the
community and the quality of support they are receiving. This could also include
an assessment of unnecessary hospitalisations and help develop a picture of
whether the new enhanced community offer is working

 Sickness to prevention: A measure focused on patients with LTCs developing other conditions/experiencing complications. This would be a good way to watch performance on secondary prevention

Analogue to digital: A measure focused on whether digital services and support
are effective in helping people with LTCs in managing their condition(s). The
aim being to keep improving both the proportion of people who say their
condition(s) are well managed and the proportion using digital services and
support

3. Support action on patient experience locally that embeds co-production with patients and improves accountability

As part of their responsibilities, Integrated Care Boards (ICBs) should have a named board officer responsible for patient experience. In light of the announced cuts to ICBs there is a danger that patient experience and engagement roles are lost. Given the changes planned as part of the reforms, we argue that it is more important than ever that there is clear accountability for patient and public engagement locally regarding the experience of patients. Indeed it would be odd to run the largest public engagement exercise on the future of the NHS and then disengage from the public as the plan is then rolled out following such engagement.

ICBs working with others in their area such as primary care networks, Trusts and the voluntary sector should publish plans on how they intend to use patient experience data to drive improvements in patient experience and care for those with LTCs. ICBs should be expected to report back on progress on this regularly across both national and locally selected measures.

In undertaking such activities, ICBs should set out how they are ensuring representation from all communities within their area as part of efforts to address health inequalities. Potential resource released from the patient experience survey audit (see above) should be redeployed to local systems to engage patients and the public on their experiences and priorities. This patient feedback should then be used to inform local service design and to make service improvements. Such an approach can help build on the wider positive public engagement exercise undertaken on the Ten Year Plan.

4. Utilise new methods of collection and analysis on patient experience

The transformation of digital services in the coming years presents new opportunities to capture and act on the experience of patients with LTCs. Examples include:

- Digitising surveys and feedback and providing more real time and actionable data and information to services to respond to
- More easily integrating patient feedback mechanisms across care pathways.
 For patients with LTCs who are often in contact with multiple different services;
 a more integrated and co-ordinated approach to feedback and service improvement would be welcome

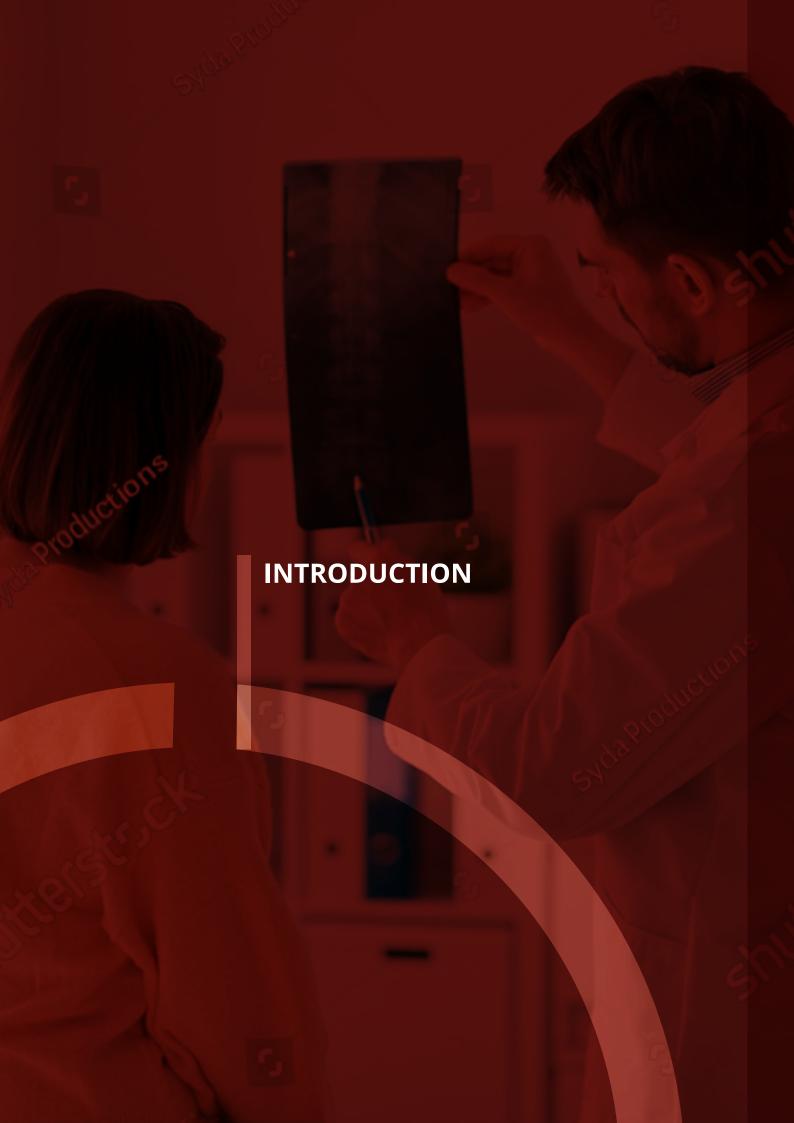
 Using new patient tools such as the NHS App to engage with patients on their experiences of care

 The use of AI and other data technologies can help more quickly process patient feedback and information. It also has the potential to support analysis of free text responses and identify trends

Any such moves will need to be coupled with the continuing use of other non-digital channels aimed at supporting engagement with groups who may not have easy access to digital tools and devices. Al software will also need to be carefully deployed so that it is relevant for analysing and assessing the feedback across the UK's diverse population.

Timeline for delivery

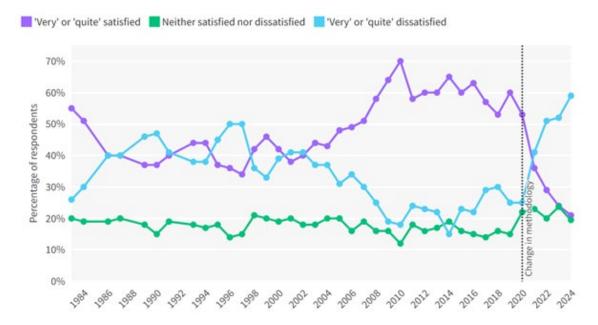
- **Ten Year Plan publication (2025)** sets out the importance of improving patient experience for those with LTCs and how this will be used to measure the success of the Ten Year Plan; commits to audit what is currently collected and to build a new approach aligned to the shifts in the plan
- Ten Year Plan plus six-twelve months (2026) patient experience audit completed, new approach to capturing the experience of patients with LTCs set out along with resource and high level national metrics; metrics to then be embedded in NHS planning guidance and accountability frameworks; local NHS areas begin building their local patient experience measures based on local patient engagement, feedback and priorities
- Ten Year Plan plus twenty four months (2027) first annual report on experience of patients with LTCs and assessment of three shifts across ICBs; local areas publish plans on local actions and priorities based on local patient feedback
- Ten Year Plan plus thirty six to forty eight months (2028/2029) tracking of
 patient experience over time for those with LTCs demonstrates improvements
 in care on the national and local measures



Patient satisfaction with the NHS – measured through the British Social Attitudes Survey – has fallen sharply in recent years.

Figure 2: British Social Attitudes Survey, Public satisfaction with the NHS, 1983 to 2024¹⁰

Question asked: 'All in all, how satisfied or dissatisfied would you say you are with the way in which the National Health Service runs nowadays?'



From 2003 to 2020 more people said that they were 'very' or' quite' satisfied with the way in which the NHS was being run, than said they were very or quite dissatisfied. But in 2021 these numbers reached a cross over point with five per cent more people saying they were more dissatisfied than satisfied. The latest data from 2024 has seen this gap grow to 38%. Just 21% of people surveyed said they were 'very' or 'quite' satisfied – this was the lowest satisfaction figure ever recorded. By contrast 59% of people said they were 'very' or 'quite' dissatisfied – this was the highest figure ever recorded.¹¹

The top three reasons for rising dissatisfaction with the NHS have been fairly consistent since 2015, with the public saying:

- There are not enough NHS staff
- The Government does not spend enough money on the NHS
- It takes too long to get a GP or hospital appointment¹²

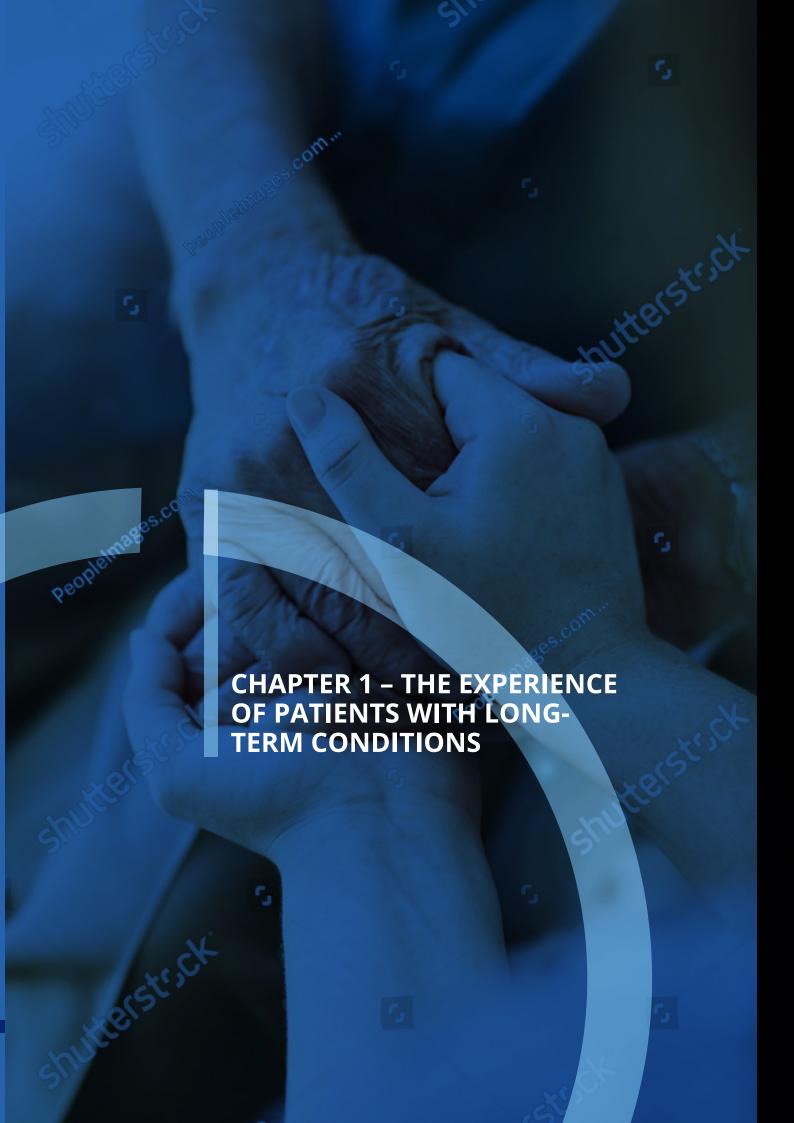
Satisfaction in GP services has seen a particularly sharp fall in recent years. Levels of waste, unpopular Government reforms, the quality of care and the attitudes of NHS staff are some of the other reasons cited for rising public dissatisfaction.¹³

¹⁰ https://www.nuffieldtrust.org.uk/research/public-satisfaction-with-the-NHS-and-social-care-in-2024-Results-from-the-British-Social-Attitudes-survey

¹¹ https://www.nuffieldtrust.org.uk/research/public-satisfaction-with-the-NHS-and-social-care-in-2024-Results-from-the-British-Social-Attitudes-survey

¹² https://www.kingsfund.org.uk/insight-and-analysis/reports/public-satisfaction-nhs-social-care-2023

¹³ https://www.kingsfund.org.uk/insight-and-analysis/reports/public-satisfaction-nhs-social-care-2023



An LTC is a health problem that requires ongoing management over a period of years or decades. It refers to conditions that cannot currently be cured but can seek to be controlled and managed with the use of medication and/or other therapies. Learn Examples of such conditions include high blood pressure, diabetes, rheumatoid arthritis, COPD and visual impairment right through to less common conditions such as cystic fibrosis, Parkinson's disease, and epilepsy. 15

25 million people in England are currently estimated to be living with a LTC and 13.4 million of these have two or more.¹⁶

LTCs increase with age. 86% of those aged over 85 have an LTC, compared with 58% of over 60s and 14% of under 40s. There is also higher prevalence amongst more deprived groups. People experiencing the highest levels of socio-economic inequality have a 60% higher prevalence than those in the least deprived groups and 30% more severity of disease. Across England the higher impact amongst older and more deprived groups sees the prevalence of LTCs being nearly 20% higher in parts of the South West and West of England in comparison to London.

People with LTCs account for 50% of GP appointments and 70% of hospital beds.¹⁹ As well as having a significant impact on a person's quality and, possibly length of life, Future Health's previous research estimated the overall cost of LTCs to health and care services as £115.2 billion.²⁰ There is also a wider economic cost too. The number of working-age adults who are out of the labour market, economically inactive because of long-term sickness has been rising since 2019 and has reached as high as 2.8 million.²¹

¹⁴ https://www.datadictionary.nhs.uk/nhs business definitions/long term physical health condition.html

¹⁵ https://www.gp-patient.co.uk/surveysandreports

¹⁶ https://www.futurehealth-research.com/site/wp-content/uploads/2023/12/Long-Term-Conditions-Report-FINAL-DECEMBER-2023.pdf

¹⁷ https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity

¹⁸ https://www.futurehealth-research.com/site/wp-content/uploads/2023/12/Long-Term-Conditions-Report-FINAL-DECEMBER-2023.pdf

¹⁹ https://www.futurehealth-research.com/site/wp-content/uploads/2023/12/Long-Term-Conditions-Report-FINAL-DECEMBER-2023.pdf

²⁰ https://www.futurehealth-research.com/site/wp-content/uploads/2023/12/Long-Term-Conditions-Report-FINAL-DECEMBER-2023.pdf

²¹ https://www.statista.com/statistics/1388245/uk-sick-leave-figures/

COVID-19 and people with long-term conditions

During the COVID-19 pandemic, people with LTCs faced severe disruptions to their healthcare access and overall wellbeing. Services were either withdrawn or shifted to remote delivery, which proved inadequate for many conditions and with most people unused to using such technology. A Versus Arthritis survey revealed the scale of impact; 40% reported difficulties accessing care, while half of respondents couldn't perform basic household tasks due to pain. Similarly, 50% had their physiotherapy and podiatry appointments cancelled.²²

Treatment delays were widespread, with routine procedures like joint replacements suspended for months, creating persistent backlogs. Poor communication compounded patient stress. Some avoided seeking care due to infection fears, leading to delayed diagnoses of life-threatening conditions like cancer. Remote consultations presented additional challenges, exemplified by a patient struggling to photograph a suspected melanoma, resulting in missed diagnosis.

Similar findings were highlighted in a March 2022 research paper, which found the pandemic resulted in poorer management of LTCs in children. For example, increased seizure severity was experienced by children with epilepsy from limited access to care and increase in acute hyperglycaemia in children with diabetes. The research also highlighted an increase in delayed or missed diagnosis of common mental health problems, cardiovascular and cerebrovascular disease, type 2 diabetes, and cancer in both adults and children "which could have a clinically significant impact on long-term health and mortality."²³

These challenges exacerbated existing inequalities. People with LTCs, already disadvantaged in employment, often lost jobs or had to stop working. The pandemic particularly impacted those facing socio-economic inequality, who typically develop multiple conditions earlier.

It was initially thought that COVID-19 brought welcome attention to the issue of health inequalities and the quality of care, creating a unique opportunity for concerns to be addressed. However, when the World Health Organisation declared the pandemic emergency over in 2023, this momentum was quickly lost, having the greatest effect on those living with health inequalities and long-term conditions.

Looking ahead, the ageing population is set to see the numbers of LTCs increase further. The Health Foundation has estimated that four-fifths of the total rise in population morbidity to 2040 will be due to the increase in the number of older people, rather than an expansion of morbidity. Almost 1 in 5 of the population are projected to be living with major illness by 2040, an increase of more than a third.²⁴

²² https://www.health.org.uk/sites/default/files/2021-08/VERSUS%20ARTHRITIS%20response.pdf

²³ https://journals.sagepub.com/doi/full/10.1177/00469580221081445

²⁴ https://www.health.org.uk/reports-and-analysis/reports/health-in-2040-projected-patterns-of-illness-inengland

Patient case study: Angela, 41, London

"I have multiple long-term conditions which all require strict daily medication and monitoring, one through remote technology monitoring for my respiratory condition, and one using fairly new sensor technology for my diabetes.

"I am under the care of three different specialist healthcare teams which are based across different parts of London and I use my GP to deal with smaller complications arising from my health conditions. I also use three apps – a bespoke one for a hospital trust, the NHS app and one for my GP surgery, plus a separate online portal for booking in community blood tests that I need regularly to monitor medication levels in my blood.

"This year alone – I have had to chase three referrals. I had to cancel a diagnostic test for one of my conditions as I was on holiday on the date given – I am now back at the end of the queue so from first consultation to test I will have waited 10 months. Via my GP I had booked a physiotherapy appointment in my local hospital to manage my deteriorating condition while waiting for this test. However, I got a letter saying the appointment had been cancelled - no reason was given and I have not yet heard whether an another appointment will be scheduled.

"My mental health care is non-existent despite many attempts over many years to access support. Last year I was referred to a peer support programme but this programme is still yet to be set up one year on. I have also been part of group therapy but once I joined I realised it was about managing long-term pain, which is a symptom I don't experience. I have now given up seeking NHS care as its more depressing to keep having my needs ignored.

"I have also had some good experiences – I am well known by my named GP who listens to what care I feel I need. I use the online triage form to select appointments with her as often my long-term condition needs do not need sameday care and can be dealt within a 2-3 week wait. I also have had some serious health issues flare up and have found the hospital specialist team really supportive and proactive in helping me get better."

Patient case study: Ed, 31, rural Lincolnshire

"I have multiple long-term conditions; mainly Multiple Sclerosis, plus respiratory issues, a hiatus hernia, and mental health challenges. In the past year, I've had medical appointments across four English counties. While my MS care is always in Cambridge, I have to travel elsewhere for my other conditions.

"There is some communication between hospitals, but it gets confusing when one hospital books me in at another. My MS infusions are relatively regular, but MS consultations seem very few and far between. Different doctors handle them differently - they only seem interested if there's a problem. A handful of times I have had consultations moved, or cancelled, with little to no notice given. At the worse point, I have gone two years without a consultation.

"I have also been on a waiting list for hiatus hernia surgery for nearly three years, which flared up following Covid complications. When attending the consultation, I was told the initial diagnostic test I received wasn't the right one. This process then had to start again. After prolonged testing and consultations I was then told the surgery would happen this spring (2025). However, it has now been pushed back another 18 months.

"Being immunocompromised means I get hit harder by illnesses and my MS flares up. This throws me into a state of anxiety, as my health is out of my control, and I do not know where to turn to in order to resolve things quickly. Due to the inaccessibility of mental health services, I have sought private therapy, but it is difficult to account for the impact each of my conditions have on each other in this environment, and how my mental health gets worse as my conditions flare up.

"At one point I was informed that my multidisciplinary team had been disbanded, but this was the first time I heard I had had one. I had no say in this, or clear reasoning given for the decision, making me feel like I am just another number in the system. The lack of joined up care makes managing my health incredibly difficult, as every condition is treated as an isolated problem, rather than in a more holistic manner."

What matters to patients with long-term conditions?

The Department of Health and Social Care through its own public engagement work on LTCs in 2012 noted that patients with LTCs consistently say:

- They want to be involved in decisions about their care they want to be listened to
- They want access to information to help them make those decisions
- They want support to understand their condition and confidence to manage support to self-care
- They want joined up, seamless services
- They want proactive care
- They do not want to be in hospital unless it is absolutely necessary and then only as part of a planned approach
- They want to be treated as a whole person and for the NHS to act as one team²⁵

Work led by National Voices during the pandemic found a similar set of issues that are important to patients with LTCs, which developed into 'I' statements:

- I am listened to and what I say is acted on
- I make decisions that are respected, and I have rights that are protected

²⁵ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf

- I am given information that is relevant to me, in a way I understand
- I am supported to understand risks and uncertainties in my life
- · I know how to talk to the person or team in charge of my care when I need to
- I know what to expect and that I am safe when I have treatment and care
- · I am supported and kept informed while I wait for treatment and care
- I am not forgotten²⁶

What is the experience of patients with long-term conditions?

The GP Patient Survey ask a series of questions about the support patients with LTCs have in managing their condition and their experience of care.

Figure 3: How confident are patients with long-term conditions to manage their condition²⁷



Nearly four in five patients (78%) with a LTC said they were either 'very' or 'fairly' confident of being able to manage their condition. 22% however said they were either 'not very confident' or 'not at all confident'. Projecting these findings across all people with a LTC results in 5.5 million people not feeling confident to manage issues caused by their illness or condition.

Over the last five years the numbers of people saying that they are either very or fairly confident of being able to manage their condition has fallen by 5.4% (from 83.6% in 2019).

²⁶ https://www.nationalvoices.org.uk/publication/what-we-need-now/

²⁷ https://www.gp-patient.co.uk/

Figure 4: Have patients with LTCs had enough support to manage their condition in the last 12 months²⁸



Nearly a third of patients felt they had not had enough support from local services in helping them manage their condition. 37% said they had had enough support 'to some extent', with 30% saying they had 'definitely' had enough support. Projecting these findings across all people with a long-term condition results in 7.5 million people saying they have not had enough help from local services to manage their condition.

The number of people saying that they have not had enough support from local services to help them manage their condition has risen by over 10% in the last five years from 21.6% in 2019 to 32.2% in 2024.

²⁸ https://www.gp-patient.co.uk/

Figure 5: Have patients had a conversation with a healthcare professional to discuss what matters to them²⁹



Over 50% of patients said they had not had a conversation with a healthcare professional to discuss what was important to them in managing their condition. 42% by comparison said they had had such a discussion. Projecting these findings across all people with a LTC results in 12.5 million people not having a conversation about what is important to them in managing their condition.

The number of people saying that they had had a conversation with a GP practice professional to discuss what is important to them in manging their condition has risen slightly in the last five years, from 39.5% in 2019 to 41.5% in 2024.

²⁹ https://www.gp-patient.co.uk/

Figure 6: Have patients with LTCs agreed a plan with a GP practice professional to help them manage their illness³⁰



Respondents were split on whether they had agreed a plan to help them manage their condition. 45% said they had agreed a plan, whilst 46% said they had not. Of those who had agreed a plan 94% felt that it had been helpful to them in managing their condition. Projecting these findings across all people with a long-term condition results in 11.5 million people not having an agreed plan from their GP practice to manage their condition.

The number of people agreeing a plan with a healthcare professional to help them manage their condition has fallen sharply since 2019. In 2019 60.3% of patients said that they had such a plan, but this has fallen by a quarter in the last five years. The pandemic which has clearly created additional pressures in the health and care system is a likely significant factor here.

These data reflect Future Health's previous research on trends in patient experience for those with LTCs. Since 2010 fewer patients felt supported to manage their condition, and healthcare-related quality of life for patients with LTCs has fallen.³¹³² This contrasted with progress in the 2000s where a growing number of those surveyed said that they felt supported to manage their condition.³³

Similarly, a Patient's Association survey in the summer of 2024 found that only 41% of respondents agreed that their care has been well coordinated, while under half (45%) agreed they had been kept informed about what was happening with their care.³⁴

³⁰ https://www.gp-patient.co.uk/

³¹ https://www.futurehealth-research.com/site/wp-content/uploads/2023/12/Long-Term-Conditions-Report-FINAL-DECEMBER-2023.pdf

³² https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

³³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215340/dh_130806.pdf

³⁴ https://www.patients-association.org.uk/news/beyond-the-breaking-point-general-election-survey



There is a range of evidence that improving patient experience can improve the quality of care, patient outcomes and service delivery. A study from Bombard et al found that 'patient engagement can inform patient and provider education and policies, as well as enhance service delivery and governance.'35 A National Institute for Health Research review from 2019 noted that 'better patient experience is associated with the efficient use of services. It results in the patient being better able to use the clinical advice given, and to use primary care more effectively.'36 Research from Doyle et al across 55 studies found 'positive associations between patient experience and self-rated and objectively measured health outcomes; adherence to recommended clinical practice and medication; preventive care (such as health-promoting behaviour, use of screening services and immunisation); and resource use (such as hospitalisation, length of stay and primary-care visits).'37

Lord Darzi's *High Quality Care for All* White Paper in 2008 identified patient experience as one of three drivers of high quality care.

Figure 7: Darzi Healthcare quality framework



Darzi defined patient experience as 'how personal care is – the compassion, dignity and respect with which patients are treated. It can only be improved by analysing and understanding patient satisfaction with their own experiences.'38

³⁵ https://link.springer.com/article/10.1186/s13012-018-0784-z

³⁶ https://content.nihr.ac.uk/nihrdc/themedreview-04327-PE/Patient-Feedback-WEB.pdf

³⁷ https://bmjopen.bmj.com/content/3/1/e001570

³⁸ https://assets.publishing.service.gov.uk/media/5a7c3a5b40f0b67d0b11fbaf/7432.pdf

The importance of patient experience and listening to patient feedback was subsequently enshrined within the NHS Constitution. Principle 4 states:

PRINCIPLE 4. THE PATIENT WILL BE AT THE HEART OF EVERYTHING THE NHS DOES

[The NHS] should support individuals to promote and manage their own health. NHS services must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers. As part of this, the NHS will ensure that in line with the Armed Forces Covenant, those in the armed forces, reservists, their families and veterans are not disadvantaged in accessing health services in the area they reside. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve its services.³⁹

However, delivering on these ambitions for patients with LTCs has proven difficult. There are two main challenges to progress: a lack of national prioritisation and a fragmented architecture of data collection and accountability of action.

Challenge 1: A lack of national prioritisation

Despite the importance of patient experience being enshrined within the NHS Constitution, in reality, the main focus for Ministers and NHS leaders in critical national frameworks is on cutting waiting times and improving access to A&E, GPs and elective appointments.

The following summarises the focus of patient experience within national policy documents.

Government Mandate to NHS England

The Government's Mandate to NHS England was published in January 2025 with five objectives:

Objective 1: reform to cut waiting times

Objective 2: reform to improve primary care access

Objective 3: reform to improve urgent and emergency care

Objective 4: reform to the operating model

Objective 5: reform to drive efficiency and productivity⁴⁰

³⁹ https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

⁴⁰ https://www.gov.uk/government/publications/road-to-recovery-the-governments-2025-mandate-to-nhs-england/road-to-recovery-the-governments-2025-mandate-to-nhs-england

Whilst patient experience is not one of the primary objectives in the Government's Mandate, it does feature as a supplementary issue of importance.

Improving patient experience is mentioned six times with four references within objective 1 relating to cutting waiting times. Two of these references focus on improving patient choice. One reference notes the importance of 'shifting culture to focus as much on experience as outcomes and safety, making the most of patient voice and involvement in co-design solutions.'⁴¹ The final reference aligns to the Elective Reform Plan and states that NHS England should 'work with patients and carers to understand their expectations and co-design solutions to improve experience of care.'⁴²⁴³

NHS Planning Guidance 2025/26

Within the NHS Planning Guidance, also published in January 2025, the then NHS Chief Executive Amanda Pritchard noted that the 'timeliness and experience of care is still not good enough.'

The guidance sets out 18 national priorities and success measures for 2025/26. There is just one measure focused on patient experience and this is within General Practice. By comparison there are five measures focused on elective recovery.⁴⁴

NHS Performance Assessment Framework

The NHS Performance Assessment Framework was published in March 2025 and replaces the NHS Oversight Framework. The Framework includes metrics that will be used to hold ICBs and NHS Trusts to account for their performance.

The Framework notes the one direct patient experience measure within the planning guidance (see above). It also includes a section on 'longer term priorities such as patient outcomes, prevention and inequality as well as cultural and experience measures,' within this two metrics which are the responsibility of ICBS are listed on LTCs:

- Percentage of hypertension patients treated to target
- Percentage of diabetes patients to receive all eight care processes

Within table 6 qualities and inequalities metrics are listed, with the following patient experience measures listed across a range of organisations including ICBs, acute trusts, mental health trusts and community services:

- Percentage of patients able to see their preferred primary care professional
- Percentage of standard Continuing Healthcare referrals complete within 28 days

⁴¹ https://www.gov.uk/government/publications/road-to-recovery-the-governments-2025-mandate-to-nhsengland/road-to-recovery-the-governments-2025-mandate-to-nhsengland

⁴² https://www.gov.uk/government/publications/road-to-recovery-the-governments-2025-mandate-to-nhs-england/road-to-recovery-the-governments-2025-mandate-to-nhs-england

⁴³ https://www.england.nhs.uk/publication/reforming-elective-care-for-patients/

⁴⁴ https://www.england.nhs.uk/long-read/2025-26-priorities-and-operational-planning-guidance/

- CQC inpatient survey satisfaction rate
- National maternity survey "looking after you" sub score
- · Rate of restrictive intervention use
- Percentage of patients waiting over 52 weeks for community services
- Annual change in the number of diagnostic tests booked directly by GPs per 100,000 people Percentage of patients referred to crisis care teams to receive face to face contact within 24 hours
- Change in the number of people accessing community mental health services with serious mental illness
- Number of mental health patients spending over 12 hours in A&E
- Percentage of people with suspected autism awaiting contact for over 13 weeks⁴⁵

Whilst some of these measures are clearly patient experience metrics such as the feedback from patients to inpatient care via the CQC survey and the national maternity survey, a number are more focused on access to care rather than experience of care.

NHS Outcomes Framework

The NHS Outcomes Framework is similarly under review with a consultation on the framework's future direction held between December 2023 and March 2024. The original framework included domain 4 focused on patient experience. Indicators included:

- 4a.i Patient experience of GP services
- 4a.iii Patient experience of NHS dental services
- 4b Patient experience of hospital care
- 4.2 Responsiveness to inpatients' personal needs
- 4.3 Patient experience of A&E services
- 4.4.i Access to GP services
- 4.4.ii Access to NHS dental services

These indicators were drawn from the GP Patient Survey and the CQC surveys. 46

⁴⁵ https://www.england.nhs.uk/wp-content/uploads/2025/03/6-the-nhs-performance-assessment-framework-annex.pdf

⁴⁶ https://files.digital.nhs.uk/47/737BBB/NHSOF_Domain_4_S.pdf

NHS Elective Reform Plan

The NHS Elective Reform Plan sets out the path to meeting the constitutional standard which would see 92% of patients receiving treatment within 18 weeks of a referral.

The Plan places empowering patients and improving patient experience at its heart. Making a series of commitments summarised below.

ELECTIVE REFORM PLAN: EMPOWERING PATIENTS BY GIVING THEM MORE CHOICE AND CONTROL

Empowering patients by giving them more choice and control and establishing expected standards for making their experience of planned NHS care as smooth, supportive and convenient as possible.

- 1. NHS England will: i. work with patients, carers and their representatives to publish the minimum standards patients should expect to experience in elective care September 2025 ii. actively promote and monitor patients' right to choose when and where they receive care iii. collate and publish data to help improve the uptake of national health inequalities initiatives, throughout 2025/26 iv. expand the NHS App and Manage Your Referral website to improve information and appointment management on elective care for patients, as well as parents and carers through proxy access March 2027 Reforming elective care for patients January 2025 9 v. work with providers to make the NHS App and Manage Your Referral website the default route so patients can choose their elective provider or decide not to make that choice themselves
- **2. Integrated care boards will:** i. ensure patients and their carers are aware of the new experience expectations for elective care and their right to choose their care September 2025 ii. set a clear local vision for how health inequalities will be reduced as part of elective care reform, and ensure interventions are in place to reduce disparities for groups who face additional waiting list challenges March 2025
- 3. NHS elective care providers will: i. name an existing director who is responsible for improving experience of care in each ICB and provider April 2025 ii. make customer care training available to non-clinical staff with patient-facing roles, as well as ensure take up of the training already available on the eReferral Service (e-RS) to support effective referral, booking and waiting list management processes iii. implement agreed local interventions to reduce disparities for groups who face additional challenges accessing healthcare iv. by the end of March 2025, 85% of acute trusts will enable patients to view appointment information via the NHS App v. by March 2027, the NHS App will be significantly expanded to improve information for patients in elective care, as well as their parents and carers through proxy access vi. make the NHS App and Manage Your Referral website the default route so patients can choose their elective provider or decide not to make that choice themselves

GP contract

The most recent GP contract includes a range of incentives to improve the quality and outcomes for patients in primary care. These are captured in the Quality and Outcomes Framework (QOF) which has five domains: clinical, public health, public health – additional services, public health – vaccination and immunisation and quality improvement.⁴⁷

At the end of February 2025 the Government, NHS England the BMA agreed a revised GP contract for 2025/2026. The National Director for Primary Care and Community Services Amanda Doyle's letter setting out the terms for the new 2025/2026 GP contract notes that 'the government and NHS England are determined to improve people's access to, and experience of, GP services'.⁴⁸ The main levers for this are in promoting continuity of care for patients and improving the experience of patients in booking appointments. The new contract reduces the number of indicators within the QOF from 76 to 44.⁴⁹ There are no specific indicators on patient experience and patient feedback.

Challenge 2: Fragmented data collection

The NIHR evidence review of patient experience notes that 'large amounts of patient feedback are currently collected in the NHS.'50 The experience of patients with LTCs is captured in a range of different ways as summarised below

Figure 8: How the experience of patients with LTCs is captured in the NHS



⁴⁷ https://qof.digital.nhs.uk/

⁴⁸ https://www.england.nhs.uk/long-read/changes-to-the-gp-contract-in-2025-26/

⁴⁹ https://www.england.nhs.uk/long-read/changes-to-the-gp-contract-in-2025-26/

⁵⁰ https://www.nihr.ac.uk/news/nhs-use-patient-experience-data-growing-imperfect

National surveys

There is no central national survey capturing the experience of patients with LTCs. Instead, this experience is captured across a number of different national surveys including:

The GP Patient Survey – This includes a specific question on the overall GP experience of patients as well asking patients whether they have an LTC and then subsequently:

- Q41. Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?
- Q42. How confident are you that you can manage any issues caused by your conditions or illnesses?
- Q43. In the last 12 months, have you had enough support from local services or organisations to help you manage your conditions or illnesses?
- Q44. Have you had a conversation with a healthcare professional from your GP practice to discuss what is important to you when managing your conditions or illnesses?
- Q45. Have you agreed a plan with a healthcare professional from your GP practice to manage your conditions or illnesses?
- Q46. How helpful have you found this plan in managing your conditions or illnesses?

The Friends and Family Test – This measures the positive or negative experience for patients across a range of different healthcare settings. Whilst the experience of patients with LTCs will be captured in the data it is not possible to disaggregate the data by type of condition⁵²

CQC National Patient Survey Programme – The CQC uses patient surveys to help it in effectively assessing and regulating services. Surveys usually focus on specific care settings with recent examples being in maternity care, urgent and emergency care and adult inpatient care. As with the Friends and Family Test feedback, patients with LTCs will be included within these findings but it is not possible to disaggregate this

Patient Reported Outcome Measures (PROMs) – Patients undergoing elective inpatient surgery for hip and knee replacement, funded by the NHS in England, are asked to complete questionnaires before and after their operations to assess improvement in health as perceived by the patients themselves. The most recent data found that 84.8% of hip replacement patients and 73.5% of knee replacement patients felt 'much better' after their surgery⁵⁴

^{51 &}lt;a href="https://www.gp-patient.co.uk/analysistool?trend=0&nationaldata=1">https://www.gp-patient.co.uk/analysistool?trend=0&nationaldata=1

⁵² https://www.england.nhs.uk/wp-content/uploads/2025/02/Patient-FFT-Summary-December-24.pdf

⁵³ https://www.cqc.org.uk/publications/surveys

⁵⁴ https://digital.nhs.uk/data-and-information/publications/statistical/patient-reported-outcome-measures-proms/final-2023-24-data

Health Insights Survey – The Health Insights Survey is funded by NHS England and led by the ONS. The survey aims to give patients the opportunity to offer regular feedback about their experiences of the NHS. Questions include asking about the experiences of accessing care including at a patient's GP practice. These include how easy or difficult it is to contact the practice and patient understanding of how their requests are handled⁵⁵

Cancer Patient Experience Survey – The National Cancer Patient Experience Survey asks cancer patients a series of questions about their experience of care including their experience of waiting, whether patients were treated with dignity, patient communication and joint decision making⁵⁶

Integrated Care Experience Survey – Eight areas across the country are piloting a new survey to measure and help improve integrated care for patients. The survey conducted through GP practices asks patients questions about the services they had accessed in the last six months, how they would rate them and their confidence in knowing which health or social care service to contact if they were worried about something, as well as many others⁵⁷

Local surveys and activity

Locally NHS organisations undertake their own local work aimed at engaging with patients and measuring and improving their experience.

CASE STUDY: NEWCASTLE HOSPITALS NHS FOUNDATION TRUST

To support their understanding of patient experience the Trust undertakes a substantial amount of data collection from both inpatient and outpatients. The Trust has just rolled out their inpatient survey to 50% of wards and this is quickly followed up with analysis and feedback to ward teams to inform their improvement work. To undertake this data collection the Trust work with a CQC approved provider partner.⁵⁸

Annie Laverty, Chief Experience Officer at the Trust noted the importance of not only collecting the data and providing insights back to the relevant teams but also acting upon findings to improve services. This action must also be communicated to patients which they do via visual displays on the wards.

The Trust also prioritises the measurement of staff experience noting that this can often flag issues before they begin to impact the experience of patients.⁵⁹

⁵⁵ https://www.ons.gov.uk/surveys/informationforhouseholdsandindividuals/householdandindividualsurveys/healthinsightsurvey

⁵⁶ https://www.ncpes.co.uk/interactive-results/

⁵⁷ https://joinedupcarederbyshire.co.uk/news/jims-blog-understanding-patient-experience-will-help-us-improve-integrated-care/

⁵⁸ https://patientperspective.org/

⁵⁹ Based on researcher interview

CASE STUDY: UCL HOSPITALS FOUNDATION TRUST

The team collect three types of proactive data to help them understand patient experience:

- National survey data while this data is robust, the lag in time before they
 receive results can limit its utility. It can however be used to track performance
 on long standing issues
- Friends and Family Test to which they add additional questions and utilise the results to support a ward accreditation programme
- Soft data Patient Advice and Liaison Services (PALs), complaints, feedback from teams who are tasked with talking to patients, volunteer stories, community groups and local Healthwatch feedback

All of these insights are utilised to identify common challenges across the Trust which can then be addressed through bespoke improvement programmes. A good example of this has been ongoing frustration from patients about the telephone not being answered in a timely manner. This has led to further work to identify the barriers to improvement and then to initiate a transformation programme to improve the experience of patients when telephoning the Trust.⁶⁰

Partnerships and third sector work

Other national patient reported experience measures (PREMs) are being developed across disease areas such as stroke⁶¹, kidney⁶² and diabetes⁶³ – often delivered in partnership between the relevant health charities and NHS.

CASE STUDY: STROKE PREMS

The Stroke PREMs was undertaken in 2022/23 through a joint partnership between the Stroke Association and NHS England. A survey was developed in collaboration with stroke survivors with over 6,600 responses received. While the results highlighted a great deal of satisfaction from patients in the care that they had received, it also identified key areas for improvement including the need for better psychological and recovery support services. The findings have been used to inform the work of stroke units and community services, as well as those commissioning services including Integrated Stroke Delivery Networks and ICBs.⁶⁴

Other charities have acted themselves or in a coalition to develop patient experience surveys. However, these are resource intensive exercises, particularly for smaller organisations.

⁶⁰ Based on researcher interview

⁶¹ https://www.stroke.org.uk/prems2022-23 and https://www.stroke.org.uk/prems2022-23/prems-reflections

⁶² https://kidneycareuk.org/get-involved/kidney-patient-reported-experience-measure-prem/

⁶³ https://www.diabetessurvey.co.uk/

⁶⁴ https://www.stroke.org.uk/prems2022-23

CASE STUDY: KIDNEY PREM

Kidney Care UK work in partnership with the UK Kidney Association and the British Association for Paediatric Nephrology to undertake an annual national PREM survey which has been running since 2017. The questions have been developed through a partnership between patients and healthcare professionals. The survey is open to anyone over the age of 16 with chronic kidney disease and aims to:

- Help kidney unit teams understand how patients feel about their experience of care
- Show where improvement can be made from a patient perspective
- Provide a national picture of people's experience of care

This PREM survey receives no funding from the NHS and while participation is open to all hospital trusts, take up is varied.⁶⁵

CASE STUDY: THE NATIONAL DIABETES EXPERIENCE SURVEY

First launched in 2024, the National Diabetes Experience Survey (NDES) is an England-wide survey exploring experiences of care among those living with type 1 or type 2 diabetes, which had been co produced by people living with the condition. ⁶⁶ Up until the launch of NDES, there had not been a national survey of this scale among people living with diabetes.

A random sample of people aged 18 and over, who have been living with type 1 or type 2 diabetes for at least 12 months, were invited to take part in the survey. At the national level, almost 109,000 questionnaires were sent out, with a 39% response rate.

The NDES gathered insights to inform future policy and health service improvements. Headline findings include:

- 78% of people with type 1 diabetes, who have had an annual review, said their overall experience the last time they had one was good;
- 61% of people with type 1 diabetes said that their diabetes is a constant worry;
- 42% of people living with type 2 diabetes shared that managing another longterm conditions makes it more difficult for them to manage their condition⁶⁷

Despite the success of the survey and the effort to develop and launch it, at the point of publication no further funding has been identified by NHS England to repeat it. Without further data collections, it will not be possible to see how service improvements have changed outcomes over a number of years.

⁶⁵ https://kidneycareuk.org/get-involved/kidney-patient-reported-experience-measure-prem/

⁶⁶ https://www.diabetessurvey.co.uk/

⁶⁷ https://diabetessurvey.co.uk/latest-national-results

Other challenges

Alongside a lack of prioritisation of patient experience and a fragmented landscape of data capture, there are a series of other challenges facing efforts to improve patient experience for those with LTCs within the NHS. As part of this research, Future Health held a series of interviews with national and local NHS patient experience experts. A series of challenges emerged from these discussions, set out below.

A lack of resource – Both in terms of funding for collecting as well as analysing data and the amount of staff/manager time assigned to patient experience programmes. This is a particular challenge for primary care where most patient contact sits, but where resource is often tighter than in secondary care. The latter is where there are often more experienced and established staff and processes for undertaking patient experience-style work

Evidence – Despite good evidence that improved patient experience improves clinical outcomes, there remains a lack of understanding of 'what good looks like' when collecting and analysing patient experience data to inform improvements⁶⁸

Patient trust and involvement – Building trust with patients is central to successfully understanding and improving patient experience. For those facing health inequalities, for example, there is a need to ensure that effort is taken to collect feedback and that sampling is representative. This will require addressing both cultural and practical barriers to successfully garnering insights from more marginalised communities – including working in different ways to engage communities and using more flexible tools to gather information

Culture change and leadership – Understanding and acting on patient feedback requires a culture shift in how the health system works with patients and the public. This requires a move away from more top-down models of engagement to more open and horizontal co-production strategies. Such approaches require different ways of working and different skills to implement effectively. It must also recognise the challenges presented by people experiencing health inequalities who may be digitally excluded and distrustful of how their responses may both affect their care and be used

Accountability – The importance of patient experience to the health policy agenda has declined in recent years. Even before the announcement of the latest NHS reorganisation in March 2025, there was already a lack of transparency around who is responsible for patient experience locally and regionally following the most recent NHS restructuring. This both limits opportunities for acting on patient feedback and concerns and also hinders co-ordination and collaboration efforts – particularly with the voluntary sector

⁶⁸ https://www.nihr.ac.uk/news/nhs-use-patient-experience-data-growing-imperfect

Integration and systems – The wider challenges of fragmented and disjointed NHS data and related IT systems are a long-standing barrier to improving the coordination of care for patients. In a fragmented system it can be difficult to track the experience of patients across different services and care pathways

Usefulness of data – The majority of patient experience data collected nationally is quantitative rather than qualitative which can limit the depth and usefulness of insights provided to inform service improvements locally. There are also challenges about the depth of the data collected (for example whether it can be broken down demographically to identify specific trends) and the length of time it takes to publish it, which can make meaningful actions relating to it a challenge. The diversity of representation, and the ability to break down data into protected characteristics, must also be considered if patient experience is to make meaningful change for those often experiencing the worst outcomes



Labour's health mission published in May 2023 sets out the need for the health service to transform to better meet the changing needs of patients. It says: The reality is that the NHS is still designed for the world of 1948, where people needed short term treatment for infectious disease or injury. Now, we are looking to the same system to provide more care for people with chronic long-term conditions and it is simply not set up for this.'69

The mission set out three shifts that it feels are needed to 'make the NHS fit for the future.'

Figure 9: Labour's three shifts to deliver an NHS fit for the future



These shifts were re-emphasised in Labour's manifesto at the 2024 election. The manifesto did not mention patient experience specifically, but did emphasise the need to give more power to patients:

"At the heart of every medical decision must be patients and their families. Too many are not treated with the respect they deserve or given the information they need to adequately access services and navigate the system.

"Labour will therefore transform the NHS app, putting patients in control of their own health to better manage their medicine, appointments, and health needs. This will include giving performance information on local services, and notifications of vaccinations and health checks. Patients will be able to see the medical guidelines for the treatment they should get, to hold health services to account and understand what their choices are."

How the three shifts will be delivered will be included within the new ten year health plan published in late Spring/early summer 2025.⁷¹

⁶⁹ https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf

⁷⁰ https://labour.org.uk/change/build-an-nhs-fit-for-the-future/ https://www.gov.uk/government/publications/change-nhs-help-build-a-health-service-fit-for-the-future

⁷¹ https://www.gov.uk/government/publications/change-nhs-help-build-a-health-service-fit-for-the-future

Labour's three shifts and improving the experience of patients with LTCs

Given the large numbers of people with LTCs in England and the continued growth of such conditions in the coming years, the Ten Year Plan presents an opportunity to build a new relationship with these patients and take steps to better understand and improve their experience.

Successfully delivering on the plan's three shifts will help deliver improvements in patient experience for those with LTCs.

Hospital to community – Labour's ambition is to 'shift services out of hospitals and into the community, so that the NHS becomes as much a Neighbourhood Health Service as it is a National Health Service, with healthcare on your doorstep, there for you when you need it.'⁷²

An evidence review from the Health Foundation found that patients expressed greater satisfaction with treatment-at-home regimes than hospital inpatient care. Patients were also generally more satisfied with community-based minor surgery compared with hospital treatment, typically citing ease of access, travel and shorter waiting times.⁷³

Sickness to prevention – Labour argues that a 'relentless government focus on prevention', will see people living healthier and happier lives, higher economic growth and less pressure on the NHS.⁷⁴

For people living with LTCs a greater focus on prevention and earlier intervention will prevent people experiencing complications associated with their condition. For example, in diabetes, structured education programmes have been shown to improve glycaemic control and psychosocial wellbeing, reduce the risk of complications and improve patient quality of life.⁷⁵

Analogue to digital – Labour believes that 'the explosion of innovation in health technology is where we have the opportunity to create a step change in people's health. The incredible advances of today would have been unimaginable 30 years ago and could enable the NHS to deliver truly personalised medicine, improve efficiency and back office functions, reduce administrative burdens on staff, and speed up care.'⁷⁶

⁷² https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf

⁷³ https://www.health.org.uk/sites/default/files/GettingOutOfHospital_summary.pdf

⁷⁴ https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf

⁷⁵ https://www.england.nhs.uk/ourwork/prevention/secondary-prevention/diabetes-high-impact-interventions/

⁷⁶ https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf

Advances in technology present opportunities to better support people with LTCs to self-manage the condition as well as improving rates of health literacy. Evidence has highlighted that the use of mobile health applications has improved self-management behaviours and outcomes in chronic conditions.⁷⁷ Telehealthcare – the remote monitoring of patients – has also demonstrated positive effects on self-care and adherence to treatment plans.⁷⁸

Realising the opportunity: a four-point action plan for change

The lack of prioritisation of both patients with LTCs within NHS priorities, coupled with fragmented and outdated data collection systems, and set alongside the other challenges laid out in the previous chapter means that understanding whether these three shifts are working for this significant group of patients is not currently possible.

The following sets out a four point action plan for remedying this and putting together a new architecture for capturing and improving the experience of patients with LTCs aligned to the three shifts.

1. Review and refresh national patient experience data already collected

As laid out earlier, an enormous amount of data is already being collected relating to patient experience within the NHS, including for those with LTCs.

However, it is often siloed, slow to be published and hard to action. Resource is currently being expended across a number of different surveys that is duplicative and could highly likely be effectively rationalised.

As part of the Ten Year Plan the Government should commit to a rapid audit of existing patient experience surveys and measures. The audit should be used as a foundation for a clear approach for tracking and acting on the experience of patients with LTCs that more closely aligns to the three shifts in the Ten Year Plan, and to develop ways to bring together insights from the different surveys to create an overview of LTC experience data. The audit should be undertaken by a new patient experience directorate established in the Department of Health and Social Care.⁷⁹

2. Recognise the importance of patient experience for those with LTCs in delivering the three shifts in the Ten Year Plan

The Ten Year Plan should recognise the importance of improving patient experience for those with LTCs as a core part of work to track progress on the three shifts. Positively the working groups for the Ten Year Plan included vision working groups based around four patient centred 'I' statements, based on National Voices' previous development of these:

⁷⁷ https://www.nature.com/articles/s41533-021-00248-6

⁷⁸ https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-016-1717-7

⁷⁹ https://s42139.pcdn.co/wp-content/uploads/Covering-the-fall-out-Abolition-of-NHS-England-and-ICB-running-cost-cuts.pdf

- I can stay healthy and manage my health in a way that works for me
- I can access the high-quality and effective care I need, when and where I need it
- · My care is integrated around my needs and wishes, and I am listened to
- I am treated in a fair and inclusive way, irrespective of who I am⁸⁰

Introducing an overarching national metric assessing how well supported people are to manage their LTC would help provide an assessment of whether the plan and its three shifts are working for patients.

This could be supplemented with specific supporting metrics for each shift as set out in Figure 9.

Figure 9: Designing a set of metrics to capture the experience of patients with LTCs aligned to the Ten Year Plan shifts

Overarching metric: I feel supported to manage my condition	
Hospital to community	A measure focused on access to community services for people with LTCs. This could include capturing unnecessary hospitalisations and provide a sense of whether the enhanced community offer is working
Sickness to prevention	A measure focused on patients with LTCs developing other conditions/ experiencing complications. This would be a good way to watch performance on secondary prevention
Analogue to digital	A measure focused on whether digital services and support are effective helping people with LTCs in managing their condition(s). The aim being to keep improving both the proportion of people who say their condition(s) is/are well managed and the proportion using digital services and support

For the Government this new architecture will support tracking patient experience of care and provide regional and local data that can be used to address variation. In prioritising the improvement of patient experience measures, the Government should over time see a flow through into improvements in overall patient satisfaction rates (captured through the British Social Attitudes Survey) with the NHS.⁸¹

⁸⁰ https://www.gov.uk/government/publications/working-group-tasks-10-year-health-plan/tasking-statements-for-the-10-year-health-plan-working-groups

⁸¹ https://www.kingsfund.org.uk/insight-and-analysis/reports/public-satisfaction-nhs-social-care-2023

3. Support action on patient experience locally that embeds co-production with patients and improves accountability

Greater national prioritisation of patient experience for those with LTCs needs to be balanced with the importance of locally-led approaches to patient engagement in service priorities, the design of services and in ongoing efforts to improve care.

The policy approach adopted should mirror the Core20PLUS5 programme to tackling health inequalities where national priorities are mixed with locally identified issues (see figure 10 below).

Figure 10: Core20PLUS5 model for reducing healthcare inequalities



Under this approach, the centre can set a small number of priorities, provide oversight of progress on the national measures, along with guidance and best practice for ICBs based on what has worked well in improving patient experience in other geographical areas. Alongside the small set of national measures relating to the three shifts on patient experience, ICBs in partnership with their local populations should develop other measures locally to track their progress.

As part of their responsibilities, ICBs should have a named board officer responsible for patient experience. ICBs working with others in their area such as primary care networks, Trusts and the voluntary sector should publish plans on how they intend to improve patient experience for those with LTCs and report back on progress on this regularly across both national and locally selected measures.

In undertaking such activities ICBs should set out how they are ensuring representation from all communities within their area as part of efforts to address health inequalities. Resource released from the patient experience survey audit

(see above) should be redeployed to local systems to engage patients and the public on their experiences and priorities. This patient feedback should then be used to inform local service design and to make service improvements. Such an approach can help build on the wider positive public engagement exercise undertaken on the Ten Year Plan.⁸²

CASE STUDY: NHS NOTTINGHAM AND NOTTINGHAMSHIRE ICB

At ICB level the place teams have focused on building strong connections and understanding of those community groups which are often less heard from in terms of patient experience. This has involved the development of innovative engagement strategies where healthcare staff go out into the community to provide care. One example is the creation of the 'dominos and blood pressure' outreach programme in the Afro-Caribbean community where blood pressure checks took place alongside a game of dominos. The programme has helped build trust between the community and healthcare staff, enabling more preventative work to take place.

CASE STUDY: SOLENT NHS TRUST

The talking therapies service were struggling to effectively engage the local Asian community. Sarah Balchin, Director, Community Engagement and Experience, Solent NHS Trust was asked to devise a programme to improve engagement with the service. This initially focused on a series of 1:1 interviews with service users - both with those who had left the service and those who never took up the service when offered. 108 interviews were undertaken and a key theme from them was the tension between cultural stigma within intergenerational households and engagement on the phone with mental health services. This research insight resulted in changes being made to the talking therapies booking system and appointment times which are now more sensitive to these cultural challenges when engaging people from this community. It has also led to a training programme for healthcare professionals in this field around the topic of mental health and stigma in their local community. As a result of the programme the Trust have seen a decrease in crisis presentations from this part of the community.

4. Utilise new methods of collection and analysis on patient experience:

The transformation of digital services in the coming years presents new opportunities to capture and act on the experience of patients with LTCs. Examples include:

 Digitising surveys and feedback and providing more real time and actionable data and information for services to respond to

⁸² https://www.england.nhs.uk/long-term-plan/

More easily integrating patient feedback mechanisms across care pathways.
 For patients with LTCs who are often in contact with multiple, different services a more integrated and co-ordinated approach to feedback and service improvement would be needed to ensure people feel able to offer feedback across the services they engage with

- Using new patient tools such as the NHS App to engage with patients on their experiences of care
- The use of AI and other data technologies can help more quickly process patient feedback and information. It also has the potential to support analysis of free text responses and identify trends

Any such moves will need to be coupled with the continuing use of other non-digital channels aimed at supporting engagement with groups who may not have easy access to digital tools and devices. Al software will also need to be carefully deployed so that it is relevant for analysing and assessing the feedback across the UK's diverse population.

CONCLUSION

A combination of financial pressures, the pandemic, and challenges with accessing care, have seen the importance of patient experience for people with LTCs decline over recent years.

A new Ten Year Plan offers real prospects to focus on keeping people healthier for longer through improved prevention, delivering care closer to home and by unlocking the power of digital technologies. It also presents an opportunity for a new and invigorated approach to the patient experience agenda.

The public is clear that it wants better information, shared decision making and more co-ordinated action that meets their care needs.

This paper sets out how the experience of patients with LTCs aligns to the three shifts in the Ten Year Plan and how by measuring it and acting on it the Government's reform agenda can be successfully delivered. It will also give the Government a meaningful way to understand how patient satisfaction is being addressed with the view of improving such a vital, political measure.

The Ten Year Plan will ultimately only be a success if it works for patients, and this needs to include the millions with LTCs who have for too long been a forgotten majority.



