

A New Dawn for the NHS

A Manifesto for Putting Personalised Care at the Centre



Executive Summary

The NHS is at a pivotal point. Lord Darzi's recent review, in which he described a health service that is in "serious trouble", is thought by many to represent a reset moment. His report brings to life the pressures of a growing and ageing population, the increasing burden of long-term conditions (LTCs), and a lack of adequate infrastructure and resources, all of which are stretching the system to breaking point. Millions are stuck on waiting lists, running costs are spiralling, and health and care professionals are grappling with unsustainable workloads. Lord Darzi's review highlights public polling that shows a growing dissatisfaction with the health service.

A core strategy to repair the health service already exists - but it is not being implemented at scale. In fact, it is being deprioritised.

Personalised care can play a key role in tackling these challenges

Personalised care is not a buzzword; it's a proven approach that can transform the way care is delivered in the NHS. At its core, personalised care involves working with people to understand their unique needs, preferences and goals, empowering them to take control of their health. It recognises that people have different health goals and seeks to give them more choice and control over how their care is planned and delivered.

It's supported by a wealth of evidence demonstrating its effectiveness, with research showing that people who are more involved in their care decisions are less likely to regret those decisions, report better relationships with clinicians, adhere better to treatment, and generally experience better outcomes.

For these reasons, personalised care has featured at the heart of every major health strategy in recent times, from the 2019 NHS Long Term Plan to the Major Condition's Strategy Consultation in 2023, and the recent independent report by Lord Darzi. Indeed, his report clearly states: "At its heart, the NHS is about people: staff, patients, carers and partners working together to treat sickness and to achieve better health."

At a time when personalised care can play a pivotal role in helping the NHS to tackle many of the biggest challenges it faces, there are signs that it is being deprioritised

Personalised care is being deprioritised – right when it's most needed

At a time when personalised care can play a pivotal role in helping the NHS to tackle many of the biggest challenges it faces, there are signs that it is being deprioritised, with the restructuring of NHSE in 2023 leading to the end of central funding for personalised care and the disbanding of the dedicated team.

This deprioritization is underscored by new research conducted by the authors of this report, the Personalised Care Institute, to understand how widely people feel they are experiencing personalised care and the extent to which healthcare professionals feel they are practising it. The research, involving more than 2,000 adults and over 500 health and care professionals, reveals a worrying picture of the state of personalised care in the NHS, with key findings including:

- **Limited experience of personalised care**, with almost a fifth (17%) of people experiencing none of the 10 key elements of personalised care in their interactions with health and care professionals.
- **Inconsistent delivery across organisations**, with just over half (55%) of health and care professionals believing personalised care is consistently delivered in their organisation.
- **Millions receiving advice or treatments that are unsuitable for their needs and preferences**, with nearly half of people (45%) reporting receiving health advice or treatment that was unsuitable for them. In some cases this has led to additional GP visits, worsening conditions, and unnecessary stress.
- **Almost one in five (19%) of those on waiting lists felt that with more choice and control over their decisions, they might not have ended up on the list at all**, with many reporting not having a clear point of contact or receiving sufficient support while waiting.
- **An estimated 5 million GP appointments could potentially have been avoided through more personalised care, saving the NHS £200 million**, according to indicative data from the survey
- **An estimated 2 million A&E visits, costing £400 million, if the care delivered had been more personalised**, according to indicative data from the survey.
- **Personalised care tools would help people get back into work**, with more than four in ten (43%) of those unemployed due to health reasons stating that receiving support from a healthcare professional to create a Personalised Care Support Plan would help them to return to employment.

A new dawn for the NHS: a chance to put personalised care at the centre

Following the publication of Lord Darzi's review, the new NHS 10-year plan is being developed to 'radically reform' the health service. Personalised care needs to be at the heart of these reforms.

When NHS England announced its desire to embed personalised care right across health and care in 2019, it acknowledged that this would be a fundamental shift to create a new relationship between people, healthcare professionals and the system. That kind of change cannot be achieved overnight but, with the groundwork laid and the lessons learned, there is now a real opportunity to create a truly personalised care-led health system that delivers for people and the country.

“The best change empowers patients to take as much control of their care as possible”

Lord Darzi



It's important to remember that, for health and care professionals, practising personalised care, even at an individual level, is more challenging than it might first appear, requiring, as it does, a wide array of theoretical and practical skills in communication, behaviour and decision-making. Embedding it across whole organisations adds an extra layer of complexity. That's why we strongly believe that those responsible for education in organisations such as NHS Integrated Care Boards, NHS Trusts, NHS Primary Care Training Hubs and private healthcare companies need to play a role, investing in bespoke personalised care training at-scale to give their workforce the skills and practical processes to make daily personalised care a reality. Their legacy will be empowered people taking control of their own care, reducing pressure on services and an inspired workforce.

We also need to invest in the future, and take steps to ensure that the future health and care workforce is ready to make personalised care truly business as usual.

To ensure that personalised care is truly embedded in our health and care system, the Personalised Care Institute is calling for three strategic actions to be taken:

- 1. The upcoming NHS 10-year plan should outline a clear strategy for how it will embed personalised care across the health and care system.**
- 2. Ring fenced central funding should be provided to NHS Integrated Care Boards, NHS Trusts and NHS Primary Care Training Hubs to support 'at-scale' training and professional development opportunities across teams, departments and organisations.**
- 3. Personalised care principles should be integrated into all medical and healthcare professional curriculums, so that it is truly business as usual for all future health and care workers.**

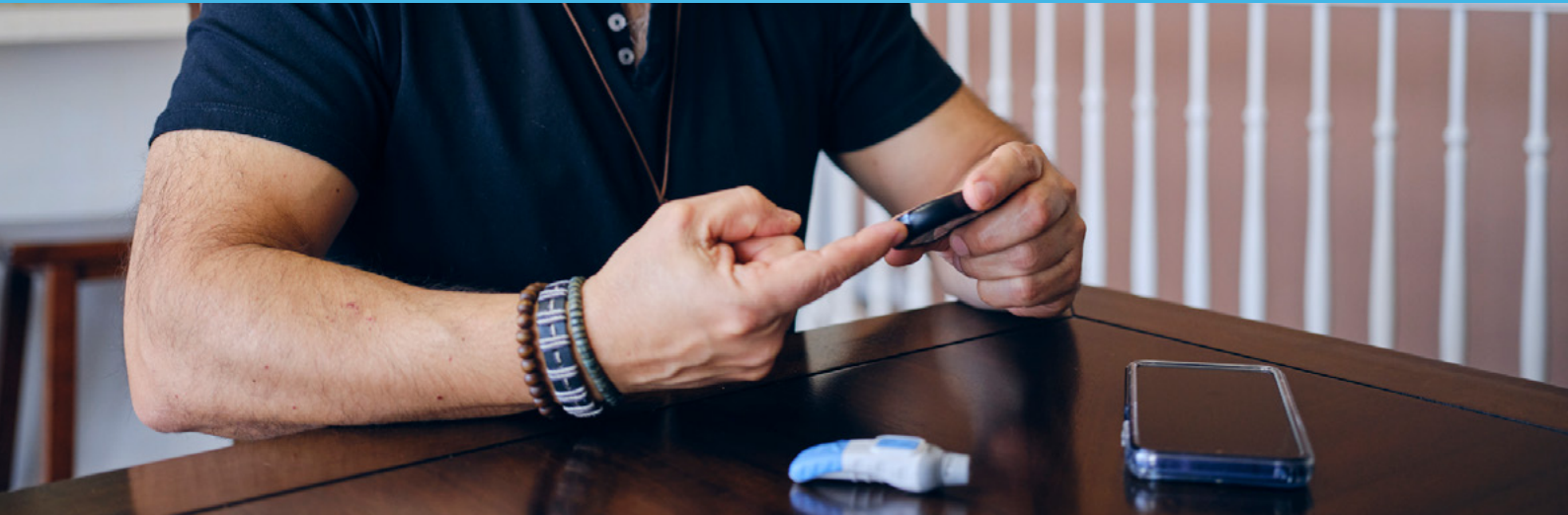
By committing to these actions, the Government, NHS England, health and care organisations and training institutions can ensure that personalised care is truly embedded in the health system.

With Lord Darzi's report making clear that "the best change empowers patients to take as much control of their care as possible", the direction is clear. By investing in personalised care training, NHS organisations can deliver on his vision for a health service where care is truly built around the person. Only by making personalised care 'business as usual', can we create a sustainable health system that delivers for patients.

Section 1

Introduction and background

We are all different, with our own unique goals, preferences, capabilities, circumstances and motivations. When it comes to our health, the best support is the best support for us.



Personalised care is a way of working that tailors health services to the needs, preferences, and goals of individuals. It recognises that people have different health goals and priorities, and it seeks to give people more choice and control over how their care is planned and delivered¹. It's based on prioritising 'what matters' to the individual' rather than 'what's the matter' with them'.

Personalised care approaches, also termed person-centred care, whole-person care or (previously) patient-centred care, are increasingly seen as 'just good care'. It is an ethical principle, a professional standard required by regulators and a clinical legal imperative. Personalised care improves patient experience and outcomes, contributes to improvement in safety, reduces inequalities and ensures that health system money is used wisely.

Personalised care is, in many ways, a necessary approach in the modern health landscape. People are living longer, but with more complex health and care needs² which often require on-going management. Yet people with long-term conditions spend under 1% of their time in contact with health professionals. Today, people also have more access to healthcare information online, and research consistently shows that they want to be more involved in decisions about their care³.

Personalised care is a model that can be used to support people to have the knowledge, skills and confidence to self-manage their long-term health conditions, and to empower people with more complex needs to have greater choice and control over the care they receive⁴."

The NHS Long Term Plan

The NHS Long Term plan, published in 2019, acknowledged that concerns about funding, staffing, increasing inequalities and pressures from a growing and ageing population meant that significant change was needed. It also identified long-term conditions (LTCs) and Multimorbidity – defined as the presence of two or more LTCs – as major contributors to the NHS’s capacity and cost challenges⁵.

As a key component of its transformative approach, this ten-year plan identified personalised care as a central strategy to address these issues. The plan acknowledged that embedding personalised care would require a “fundamental shift in how we work alongside patients and individuals to deliver more person-centred care” and that there would be a need to train staff to have the conversations which help patients make the decisions that are right for them⁶.

A continued strategic priority

Since then, almost every key health strategy has continued to reinforce the importance of personalised care. From the NHS Long Term Workforce Plan 2023, which stated that “personalised care core skills and knowledge must be embedded across the wider NHS workforce to improve population health”⁷ to the Major Condition’s Strategy Consultation 2023, which asserted that we should be “shaping services and support around the lives of people, giving them more choice and control.”⁸

Lord Darzi’s new reset for the NHS - with personalised care again at the centre

The NHS is facing significant challenges. In fact, the new Government’s official position is that the NHS is broken⁹ and the independent report¹⁰ that it commissioned from Lord Darzi described a health service that is in “serious trouble”, highlighting a myriad of problems related to performance, trust and engagement. Once again, personalised care features prominently as a core strategy to repairing the health service.

As the report states: “At its heart, the NHS is about people: staff, patients, carers and partners working together to treat sickness and to achieve better health.”

However, the report concludes that, often, patients and healthcare professionals are not working together and, unfortunately, right now, people are “less empowered to make choices about their care.”¹¹

Darzi references people not feeling listened to, people (particularly disabled people, people with long-term conditions and women) experiencing communication issues with the NHS, and integrated care often not being delivered for people with long-term conditions due to

personalised care and support plans only being in place for about 60% of people with long-term conditions and only 40% of people with dementia. Lord Darzi describes personalised care and support plans as “one of most important tools to coordinate and manage care.”¹²

With a waiting list that now stands at 7.57 million cases - comprising approximately 6.33 million individual people waiting for treatment¹³ - the system is under unprecedented strain. The Darzi report states that people frequently say that good communication is key to their experience of the NHS, yet, in the context of the waiting lists, 45% have received none or not enough information while waiting and 82% have received no help at all with pain relief, physiotherapy or mental health support while waiting. Personalised care would mean equipping people to manage their condition while they wait.

The costs associated with running the NHS continue to spiral, with The Health Foundation recently projecting that improvement would require a 4-5% funding growth over the next five years just to recover from the pandemic and increase activity¹⁴.

At the same time, health and care professionals are under unsustainable pressure, with workforce shortages persisting across the NHS and research from the University of Bath suggesting that half are showing signs of burnout¹⁵ and a recent survey by the Royal College of General Practitioners revealing that over three-quarters of GPs (76%) worry that patient safety is being compromised by their excessive workloads¹⁶. Lord Darzi’s report describes the more than a million-strong NHS workforce as “profoundly passionate and motivated to raise the quality of care for patients,” but suggests that they sometimes experience feelings of being disengaged. He says: “Their talents must be harnessed to make positive change. The best change empowers patients to take as much control of their care as possible.”

Ultimately, care is being impacted across the system, with polling suggesting that, unfortunately, the public is increasingly dissatisfied with the health service, with research by The Health Foundation showing that only 28% of people think the NHS is providing a good service nationally¹⁷.

Personalised care has proven to be effective

Evidence supporting the effectiveness of personalised care is compelling. The NHS Long Term Plan cites research that found that people with LTCs who are more able to manage their health condition have 18% fewer GP contacts and 38% fewer emergency conditions¹⁸.

A study from The Health Foundation suggests that if people who currently feel least able to manage their conditions were supported to manage them as well as those who feel most able, it could prevent 436,000 emergency admissions and 690,000 A&E attendances annually¹⁹. This is important from a financial perspective as well as a care perspective. According to the Nuffield Trust, 70% of the money we spend on health and social care is spent on supporting people with LTCs²⁰.

Furthermore, studies have consistently shown that people who are more involved in their care decisions are less likely to regret those decisions, report better relationships with clinicians, adhere better to treatment, and generally experience better outcomes²¹.

The Personalised Care Institute, the organisation that authors this report, was established by NHS England in 2020 and made accountable for setting the standards for evidence-based training in personalised care in England. As a result of its world leading programme, tens of thousands of the NHS workforce have been trained in personalised care approaches and there are countless successful examples of personalised care being delivered effectively regionally. Of the health and care professionals that have undertaken Personalised Care Institute training, 87% strongly agreed that the training would have a positive impact on their day-to-day practice.

However, training can only benefit those who complete it.

Personalised care being deprioritised - right when it's most needed



Despite the evidence of its clear benefits and the great enthusiasm for personalised care across Royal Colleges, professional member organisations and patient groups, in recent months there have been worrying signs that it is being deprioritised within the NHS.

The recent restructuring of NHS England²² led to the end of central funding for personalised care in 2023 and the disbanding of NHS England's dedicated personalised care team. It appears that many roles that had been focused on embedding personalised care within the regions have been removed from Integrated Care Boards too.

When the NHS Long Term Plan was published, the stated goal for personalised care was that it should become 'business as usual' throughout the NHS. Yet, while a milestone of 10 million personalised care interventions²³ was recently celebrated, the fact that primary care alone currently delivers 1.4 million appointments every day²⁴ shows that there is still a long way to go until it can be considered business as usual.

Recently, numerous patient experience surveys demonstrate that, across services, people often do not feel that they are experiencing personalised care.

For example, the latest 2024 GP Patient Survey by NHS England²⁵ found that over a fifth (21.9%) of people were not confident in managing issues related to their condition. More than half (52.1%) reported that they had not had a conversation with their healthcare professional about what is important to them when managing their condition or illness.

Similar gaps are evident across a range of conditions and care pathways too, with people frequently reporting that they are not adequately informed or involved in their treatment choices. For example, the 2023 NHS National Cancer Patient Survey found that over a fifth (20.4%) of cancer patients felt they were not as involved in decisions about their treatment options as they would have liked²⁶. Additionally, The Stroke Association and NHS England found that 24% of stroke patients disagreed or strongly disagreed that they were involved in planning their therapy and care while on the acute stroke unit, and 21% felt similarly about their involvement in planning their care in the community²⁷. In its 2023 Community Mental Health survey, The Care and Quality Commission also found that 28% of respondents did not feel in control of their care²⁸. In maternity, 18% of women were not offered a choice of about where to have their baby and 19% said they did not receive enough information to help them decide where to have their baby²⁹.

Now, more than ever, it's vital that personalised care is prioritised, not deprioritised, if the NHS is to navigate its current challenges and emerge as a robust, efficient, and person-centric health service for the future.

Section 2

Our research

As we move towards what could potentially be a new dawn for the NHS, the Personalised Care Institute, as the world-leading educational institute on personalised care, wanted to get a full picture of personalised care practice in this country.

This included understanding the extent to which patients feel they are experiencing personalised care, the extent to which healthcare professionals feel they are practising it and, among healthcare professionals who have been trained in personalised care, the extent to which they believe that it is embedded within their organisations.



Methodology

We worked with Censuswide to survey 2,262 adults across the UK to understand their experiences of receiving personalised care and how it has impacted their health. The survey population was weighted by gender, age, ethnicity, region, socioeconomic status and employment status, to ensure that it was nationally representative. Within the sample, we also identified the following priority demographics:

- Those people who have visited a healthcare professional in the last two years (822 people)
- Those people who have a long-term health condition (623 people)
- Those people who have multiple health conditions (499 people)
- Those people who are on an NHS waiting list (276)

In addition, we also conducted a survey of 558 health and care professionals, including GPs, nurses, doctors, pharmacists, physiotherapists and occupational therapists across England.

Our findings are below.

Limited experience of personalised care among patients

Our patient survey outlined ten key elements that define a personalised care appointment, including active listening, shared decision-making, and tailored advice based on individual circumstances (see appendix for the full list). Nearly one in five patients (17%) stated that none of these 10 elements were evident in their interactions with healthcare professionals over the last two years and only 2% reported experiencing all of these elements.

Only 26% felt that their healthcare professional helped them to make the right decision based on their personal preferences.

Among those patients who have had a conversation with a healthcare professional over the last two years, only 26% felt that their healthcare professional helped them to make the right decision based on their personal preferences. Additionally, only a third (34%) said that their healthcare professional had checked to ensure they understood the advice provided and felt confident to follow it - while just a quarter (25%) believed that their personal circumstances were considered when advice was given.

Among those who had had surgery, only 22% were given information about other options and 39% said they didn't feel as involved in the decision as they would have liked.

Inconsistent delivery of personalised care across health organisations

Health professionals who have been trained in personalised care (i.e. they have completed training with the Personalised Care Institute) also highlighted significant gaps in the delivery of personalised care across the organisations they work in. While the vast majority felt that their conversations with people incorporated the ten elements of a personalised care appointment (as outlined in the appendix), many believed that personalised care was not consistently practised across their organisation.

For example, although 92% (512) reported that they 'avoid any medical jargon and ensure the person finds it easy to understand the advice', only 55% (305) believed this was common practice throughout their organisation. Similarly, 90% said they 'avoid just treating the condition, instead seeing a whole person with their own skills and strengths', yet just over half (54%) felt that this approach was routinely practised across their organisation.

Even more concerning, 9% believed that none of the ten key elements that define a personalised care appointment were typically happening in their organisation. These findings suggest that personalised care has not been embedded and that there are significant variations in practice between organisations and among healthcare professionals. This is perhaps not surprising, considering that almost a fifth (18%) of healthcare professionals felt that personalised care has become less of a priority in their organisation over the last 12 months, and a quarter (25%) reported a reduction in personalised care training and education during the same period.

Furthermore, the research findings revealed a significant mismatch in the perceived importance of personalised care between healthcare professionals who have undergone personalised care training and their organisations. Nearly a third (31%) of healthcare professionals feel that their employer perceives personalised care as 'nice to have but not central to good care', yet only 4% feel the same way themselves. It is a similar story when it comes to perceptions around personalised care being a 'tick box exercise' or 'just another thing to do', with 29% of healthcare professionals reporting that they believe that this is how it is perceived within their organisation.

Nearly half (45%) of people reported that they had received health advice or treatment recommendations that were unsuitable for them in the last two years.

Millions of people receiving unsuitable advice

The inevitable consequence of people receiving advice or treatments without being involved in the decision about their care is that, sometimes, that advice or treatment will be 'unsuitable' because the recommendation did not take into account their personal preferences, capabilities, circumstances or motivations.

Nearly half (45%) of people reported that they had received health advice or treatment recommendations that were unsuitable for them in the last two years. The most common reasons for the unsuitability of the advice included not being physically able to follow the advice (11%), not being warned about potential side effects (11%), not understanding the benefits (10%), and affordability (7%). For people with multiple health conditions, these challenges were even more pronounced, with 64% having received unsuitable health advice or treatment - indicating that those with more complex needs are less likely to receive appropriate, personalised care.

Healthcare professionals who had undergone personalised care training also recognised this issue. More than a quarter (29%) felt that changes that have occurred in personalised care in their organisation meant patients are now more likely to receive advice unsuited to their personal preferences, capabilities, circumstances and motivations.

Almost a third (32%) said their condition worsened due to this avoidable unsuitable advice, increasing to 40% for those with long-term conditions and nearly half (45%) for those with multiple conditions.

The implications of receiving unsuitable advice are significant. Nearly a quarter (24%) of patients who experienced this felt unable to follow the given advice, 22% reported a lack of motivation to adhere to the recommendations, and almost one in five (19%) felt they were being 'set up to fail' by their healthcare professional - something that we know healthcare professionals desperately want to avoid. Furthermore, more than four in ten (41%) patients said they didn't believe that their healthcare professional was interested in their view, and 35% felt they were viewed merely as a condition rather than a 'whole person'.

More than 6 in 10 people who were given unsuitable health advice believe it could have been avoided, if they had received personalised care.

Consequences of a lack of personalised care

The consequences of not involving people in decisions about their care extend far beyond patient dissatisfaction.

Three in ten (30%) people who received unsuitable advice reported that it resulted in an additional GP visit that could have been avoided if personalised care principles had been followed – with this figure rising to 40% for people with long-term conditions. Almost a third (32%) said their condition worsened due to this avoidable unsuitable advice, increasing to 40% for those with long-term conditions and nearly half (45%) for those with multiple conditions. More than a quarter (26%) stopped following the avoidable unsuitable advice or treatment early - with the figure rising to 31% among those with long-term conditions and 40% for those with multiple conditions.

Health professionals who have been trained in personalised care echoed these concerns. Almost three in ten (29%) stated that, due to changes in the way personalised care is delivered in their organisation, they believe patients will feel less in control over decisions about their care in the future, while 27% expect patients will be less able to self-manage their conditions. If correct, this is likely to lead to an increased number of repeat appointments and poor outcomes, putting further strain on an already stressed NHS. This is a point not lost on healthcare professionals, with 38% anticipating extra pressures on capacity and services due to negative changes in the level of personalised care delivered in their organisation.

These findings underscore a critical point: when care is not personalised, it can lead to repeated, unnecessary interactions with healthcare services, such as GP visits, A&E admissions, and calls to NHS 111. 20% of patients reported that they needed at least one admission to A&E that could have been avoided, with this percentage rising to 22% for people with a long-term condition and 21% for those with multiple conditions. On average, patients requiring additional GP appointments due to unsuitable advice needed approximately four (3.88) extra visits over two years, while those needing additional A&E appointments required around three (3.04) extra admissions.

An estimated 5 million GP appointments could potentially have been avoided through more personalised care, saving the NHS £200 million, according to indicative data from the survey

Based on the UK adult population of 47.21 million³⁰ and 3.29% of our nationally representative sample stating that they required at least one additional GP appointment that could have been avoided if personalised care had been practised (i.e. their personal preferences, capabilities, circumstances and/or motivations had been taken into account), that would be an estimated 1.5m people who had avoidable appointments in the last 24 months. This equates to roughly 6m appointments when we consider that the average was 3.88 additional GP appointments, among those who we required at least one.³¹ The Kings Fund estimates that the average cost of a face-to-face GP consultation is £56³². Even if we just consider the 64.6% of appointments that are carried out face-to-face³³, that would be an estimated saving of £222 million³⁴ if those appointments had been avoided via the earlier implementation of personalised care. The numbers are similar for A&E admissions, with the survey results being equivalent to an estimated 2.88m visits to A&E³⁵ which, at a cost of £137 per time³⁶, is equal to around £400m. These numbers can be considered indicative at best, but they give a sense of the scale of impact that could be achieved if personalised care really were delivered at-scale, in the way that both the NHS Long-Term Plan in 2019 and the new report by Lord Darzi suggest that it should be.

Workplace implications

The impact of poor health management due to lack of personalised care extends beyond healthcare settings into the workplace. 9% of respondents stated they were currently unemployed due to health issues, while 14% reported said they had taken some time off work



in the past year for health reasons. Among those who took time off due to their health, the average number of days taken was equivalent to a full month (30 days).

A Personalised Care and Support Plan is an essential tool for integrating a person's experience of all the services they access, so they have one joined up plan that covers all of their health and care needs - Lord Darzi's report calls them one of the most important tools in integrated care. The Personalised Care Institute offers free training to health and care professionals on how to create one³⁷. Of those who are unemployed due to their health, more than four in ten (43%) believed that receiving support from a healthcare professional to create a Personalised Care Support Plan to help manage their condition at work would help them to return to employment. Similarly, with the same support, almost two-fifths (37%) of those who have taken time off work due to health reasons felt that most or all of these days could have been avoided.

Lack of personalised care adding to NHS waiting list and surgery stresses

Shared decision-making is a central part of personalised care. It ensures that anyone receiving care is fully supported and informed to understand the options, decisions, and care available to them. Yet the survey revealed significant gaps in this element of personalised care at every stage of the care pathway, across primary care and secondary care.

Of those who are unemployed due to their health, more than four in ten (43%) believed that receiving support from a healthcare professional to create a Personalised Care Support Plan to help manage their condition at work would help them to return to employment.

Patients on NHS waiting lists are particularly affected by the lack of personalised care. Nearly one in five (19%) felt they might not have ended up on a waiting list if they had been given more choice and control over earlier medical decisions. Additionally, over a third (34%) reported having no clear point of contact within the NHS while waiting, and 30% said they did not receive enough support to manage their pain.

The survey also highlighted an absence of personalised care in those people who were recommended surgery to treat their condition. Of these individuals, only half (50%) reported

being asked if they fully understood the procedure, while even fewer (48%) felt fully informed about the potential risks or side effects associated with their surgery.

A similar trend was observed among those who had been recommended medication; only a third (32%) felt fully informed about the risks and side effects of their medication. Additionally, only three in ten (34%) said they were as involved as they would have liked to be in the decision to take medication, suggesting many were dissatisfied with their level of involvement in the decision-making process.

Health professionals also highlighted inconsistencies in the application of shared decision-making: while 84% stated that they ensure patients fully understand all options and the associated risks and benefits in their practice, only 65% believe this happens consistently within their organisation. This inconsistency underscores the need for more robust, standardised approaches to personalised care and patient engagement across the NHS.

Section 3

What needs to change

Unlocking the potential of personalised care

Lord Darzi's report makes clear that the NHS is about people and healthcare professionals working together to treat sickness and improve health, and that the best change we can deliver is for patients to be empowered to take as much control of their care as possible. As Darzi argues, "listening to patients about what's important to them would help the NHS deliver tangible improvements to people's experience of the NHS"³⁸.

The evidence shows that personalised care leads to better health and care outcomes, people want it, and health and care professionals believe it is essential for creating a sustainable health and care system. But, as we have seen, personalised care is far from 'business as usual'. Instead, it is inconsistently delivered throughout the system, often leading to poor outcomes and experiences for patients and wasted NHS resources.

If we are to truly fix the 'broken NHS' and meet the needs of an ageing population that is increasingly living with long-term conditions and multimorbidity, personalised care must be made a priority and invested in. Only then can it be used to its full potential as a vital mechanism for tackling the most urgent challenges facing the NHS, harnessing the talents of its staff to empower patients to take greater control of their care.

Taking Action

To ensure that personalised care is truly embedded in our health and care system, we are calling for three strategic actions to be taken.

1. The upcoming NHS 10-year plan should outline a clear strategy for how it will embed personalised care across the health and care system.

Following the publication of Lord Darzi's important review, referenced throughout this report, the new NHS 10-year plan is being developed to 'radically reform' the health service³⁹. We are calling for the spirit of Lord Darzi's recommendations to be followed and for personalised care to be at the heart of these reforms, with a commitment to a clear strategy on how the Government and NHS England will embed personalised care throughout the health and care system to empower people to have more choice and control.

When NHS England announced its desire to embed personalised care right across health and care in 2019, it acknowledged that this would be a fundamental shift to create a new relationship between people, healthcare professionals and the system. That kind of change cannot be achieved overnight. 50,000 healthcare professionals trained in personalised care and 10 million personalised care appointments delivered are significant achievements - but with a health and care workforce of three million people and 1.4 million daily appointments every day in primary care, they simply aren't enough. Lord Darzi's report makes clear that more needs to be done.

Now is the time to truly embed personalised care at-scale. The groundwork has been laid, the lessons have been learned and there is now a real opportunity to create a truly personalised care-led health system that delivers for people, increases capacity and reduces costs

Just as people need to be at the centre of their care, personalised care needs to remain at the centre of the NHS's plans for the future.

2. Ring fenced central funding should be provided to NHS Integrated Care Boards, NHS Trusts and NHS Primary Care Training Hubs to support 'at-scale' training and professional development opportunities across teams, departments and organisations.

For health and care professionals, practising personalised care, even at an individual level, is more challenging than it might first appear, requiring, as it does, a wide array of theoretical and practical skills in communication, behaviour and decision-making.

Embedding it across organisations adds greater complexity as it requires structural, cultural and attitudinal change and the responsibility for achieving this does not just sit with healthcare professionals and patients, but also with those who manage, lead and commission services⁴⁰, as well as, in our view, those responsible for education in organisations such as NHS Integrated Care Boards, NHS Trusts and NHS Primary Care Training Hubs and private healthcare companies.

However, this integration can be achieved when training is provided at-scale across teams and organisations. We have seen it.

While in the last few years, the majority of personalised care training has been accessed by health and care professional individuals with a natural interest in it - creating thousands of advocates in the process - the greatest gains for patients and organisations have been when it has been delivered to broader teams and organisations.

This kind of approach can help to shift cultures and create shared understanding of personalised care, which is so important when it comes to offering patients joined up integrated care. For it to become a reality though, NHS Integrated Care Boards, NHS Trusts and NHS Primary Care Training Hubs will need ring fenced funding and private companies will need to invest.

3. Personalised care principles should be integrated into all medical and healthcare professional curriculums, so that it is truly business as usual for all future health and care workers..

One of the most important steps to embedding personalised care across our health and care system will be to ensure that it is also embedded into all medical and healthcare curriculums.

Our survey found that only half of health and care professionals learned about personalised care during their training to become a healthcare professional, while previous research by organisations such as the Patient Association suggests that key facets of personalised care such as discussing options and preferences are often either not included in training or are only mentioned briefly⁴¹.

For a majority of healthcare professionals, daily practice is all about interacting with patients and our role is to support them to make the right decision for them based on their individual preferences, capabilities, knowledge and motivations. It is vital that the next generation of health and care professionals is ready for that.

The Personalised Care Institute created what we believe was the world's first curriculum in personalised care education⁴². We would be delighted to work with organisations, institutes, and universities to provide support to update and adapt existing medical and health and care professionals curricula to ensure that personalised care is embedded in a way that will best prepare the health and care professionals of tomorrow to put it at the very centre of their daily practice.

Support for these actions

All three of these calls are backed by surveyed health and care professionals, with 85% backing the inclusion of a personalised care delivery strategy in the upcoming NHS 10-year plan, 66% backing ring-fenced at-scale training opportunities, and 90% supporting the embedding of personalised care principles in all medical and healthcare professional training.

Making personalised care ‘business as usual’

By committing to these three actions, the Government, NHS England, health and care organisations and training institutions can ensure that personalised care is truly embedded in the health system.

With Lord Darzi’s report making clear that “the best change empowers patients to take as much control of their care as possible”, the direction is clear. By investing in personalised care training, NHS organisations can deliver on his vision for a health service where care is truly built around the person, achieving improved outcomes, experiences and efficiencies as a result. Only by making personalised care ‘business as usual,’ can we create a sustainable health system that delivers for patients.

The difference personalised care makes

Noah, Luke and Katie

When Luke and Katie, from Leeds, noticed that their baby, Noah, was growing more and more sick, they spent weeks going back and forth with healthcare professionals trying to get him help. Not taking a holistic view of Noah’s symptoms and not listening to the concerns of the worried parents who were watching their child deteriorate over a period of several weeks at home, despite concerns being raised at lots of appointments with numerous healthcare professionals, left these new parents on the brink of despair. When they finally were offered a urine test, which led to a diagnosis, everything changed. This is their story.



"In 2018, we began to notice that our 11-month-old son, Noah, was not quite himself. He was always tired, drinking lots of water, urinating frequently and looking gaunt. He also had a chesty cough. We knew he was poorly, but we did not know exactly what was wrong.

"We spent six weeks going back and forth to see various healthcare professionals, in different settings, sometimes twice a week, trying to get him help.

"There was a big focus on his cough initially and he was given antibiotics, but it didn't improve. We let the various healthcare professionals know that we were worried, but it didn't feel like our concerns about other factors such as him drinking lots of water and losing weight were being heard.

"His individual symptoms, like drinking lots, were put down to the warm weather and there wasn't really a holistic focus on what was happening with him and not much opportunity for us to discuss what we were seeing at home or the concerns that we had. We knew that something wasn't right - call it a parent's intuition - but it never felt like things were properly explored in the various consultations.

Fortunately, Noah is now thriving and managing his condition well, and that's due to the brilliant personalised care that we are now receiving

"The possibility that it was something more serious was never raised with us and we were repeatedly told he didn't seem that ill. We started to feel like maybe we were being neurotic, just keeping contacting them and saying the same things, but we knew something was wrong. He just wasn't getting better.

"Due to all the urinating, Noah developed a terrible nappy rash, which we feared was scarlet fever. We took him to hospital, where a urine test was taken, with no explanation as to why that was needed or what it meant for Noah. We were then told to use nappy cream; that they'd be in touch about the results of the test and sent home.

"Over the next three days, Noah deteriorated rapidly, and we took him to A&E, where a further urine test and then blood tests were ordered, with the results coming back very quickly this time. Within minutes, he was on an insulin drip and Noah was diagnosed with type one diabetes. Once the diagnosis happened, everything changed, and the care we have received since then has been first class. We feel fortunate that the diagnosis happened when it did, as we firmly believe that if it had been even a day or two later, things could have been worse, as his organs were shutting down.

"We have since learned about personalised care which is about people having choice and control over their or their family's care, based on what matters to them. We feel that if

personalised care had been more present in our conversations with healthcare professionals in that diagnosis phase, things could have been different.

“We would also have really benefited from having conversations that recognised how we, as his parents, were really concerned about our son and that invited us to share our observations of what we were seeing in the 24 hours-a-day that we were spending with Noah at home, to try to explore alternative explanations for Noah’s symptoms. This would have given us a much greater sense of control and understanding and, again, we think could have helped to discover his condition sooner.

“If, instead of just being passed around the system, we had received joined up care that meant the staff we saw were all aware of our individual consultation history and notes, it may have meant they could have recognised they were going down the wrong track, and something new was needed to help us. We may have got to a diagnosis much quicker.

“When a test did finally happen, we would have benefited from knowing why this was needed and what it could mean for us as a family. We were already scared parents, being rushed from place to place, and not knowing why the tests were being done only made that worse. No one seemed to think we ought to have the test or what was going on explained to us.

“Fortunately, Noah is now thriving and managing his condition well, and that’s due to the brilliant personalised care that we are now receiving. Both Noah and we, as his parents, have been given choice and control over how his condition is managed in a number of really important ways.

“We were given comprehensive, tailored advice on managing Noah’s diabetes, including how to administer insulin. Eventually, Noah was able to get a closed-loop insulin pump, a fantastic piece of technology that has reduced the need for injections and significantly improved his quality of life. Through the hospital’s peer support programme, he’s also met other children with type 1 diabetes, so he knows he’s not alone.

“As his parents, we’ve been empowered to make care decisions based on what’s best for Noah. For example, he has personalised insulin targets tailored to his weight and daily routine, and we’ve been given the ability to adjust those levels if we notice any trends in his blood sugar.

But it could have been a very different story. We think that it is so important that the system changes so that all people can benefit from personalised care, meaning they feel fully involved and in control over decisions. We know sadly, what can go wrong when they aren’t. “

Vera Foreman

Vera Foreman, 67, from Thorington, East Suffolk, was diagnosed with breast cancer in 2020, followed by bowel and ovarian cancer. Here, she shares how personalised care, provided by the Cancer Care Navigator team at NHS East Suffolk and North Essex NHS Foundation Trust, helped her cope with cancer.



"I was first diagnosed with breast cancer in 2020, which was initially treated with a new pilot drug. However, the cancer returned, this time in my bowel, and then again in my ovaries. These subsequent diagnoses really hit me, and I realised I needed more support than I was currently receiving.

"When you're living with cancer, it's not just a physical condition that you have to deal with, but something that affects every part of your life. And it impacts each person differently. The Cancer Care Navigator team understood this, and visiting them was the best thing I ever did.

They offered me tailored support that addressed my individual needs.

"They offered me tailored support that addressed my individual needs. I was able to take a comprehensive course that empowered me to manage my own wellbeing, cope with stress and side effects, and connect with people who truly understood what I was going through. They also provided help with practical matters like accessing benefits and other important non-medical support for those who needed it.

"Having this kind of personalised care was incredible. It helped me manage my wellbeing and made what can be quite a lonely experience much more bearable. This support, combined with my chemotherapy treatment, ensured that both my medical and non-medical needs were addressed and, consequently, things are looking positive for me now.

“Giving people this kind of personalised care is so important. When you’re going through cancer or any other long-term health condition, it affects not just your body, but also your work, family, and every aspect of your life.

“That’s why you need support that is tailored to address your whole needs, not just the medical condition itself. When you receive that level of care, it can drastically improve your experience. It certainly did for me.

“But unfortunately, not everyone has the same experience. This level of personalised care isn’t consistently experienced across the country, though it should be. That’s why I believe more NHS organisations should invest in training their staff to provide this kind of life-changing personalised care, to help everyone achieve the best possible health outcomes.”

About the Personalised Care Institute

The Personalised Care Institute (PCI) is the independent, not-for-profit, home of personalised care education.

Originally established by NHS England in 2020, the PCI has helped train more than 50,000 health and care professionals to develop the skills needed to empower people to have more choice and control over their care.

It works in partnership with an extensive network of royal colleges, healthcare professional bodies and patient representative groups to champion the principles of personalised care in order to build a sustainable and patient-centred healthcare system.

The PCI is the creator of the official curriculum for personalised care and provides bespoke consultancy and training for health and care organisations on delivering personalised care.

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You can also contact or follow the Personalised Care Institute through the following social media channels: [X \(formerly Twitter\)](#), [LinkedIn](#), [Facebook](#) and [YouTube](#).

Appendix

Item 1.10 key elements of a personalised care appointment, based on the official Personalised Care Curriculum - developed by the Personalised Care Institute.

They checked to ensure that I understood the advice and felt confident to follow it
I understood the different options, and the risks, benefits and consequences of each of them
I felt really listened to because of their words and body language
They helped me to make the right decision for me, based on my personal preferences
They avoided any medical jargon and ensured I found it easy to understand the advice
They took the time to understand my personal circumstances e.g. work, family, religion or financial situation and tailored their advice to suit
They acknowledged and praised the positive steps I had already taken
They reassured me that my experience was normal and that others said similar
They didn't just treat the condition or symptom, they saw me as a 'whole person' with my own skills, strengths and needs'
They didn't assume they had all the knowledge they needed, they asked about my experiences

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