

# Picker's response to the 'Change NHS' consultation

#### **About Picker**

Picker is an independent health and social care charity based in Oxford, with expertise in understanding, measuring, and improving people's experiences of care. We pioneered the <u>patient experience approach</u>, now widely adopted around the world, and advocate for the delivery of the highest quality person centred care for all, always.

We work with policy makers, providers, professionals, and patients and the public alike to influence, inspire, and empower person centred care. We are commissioned by the Care Quality Commission (CQC) and NHS England (NHSE) to design, deliver and analyse the NHS patient survey programme, the cancer patient experience surveys, and the NHS staff survey. The <a href="NHS">NHS</a> staff survey is the largest workforce survey in the world, receiving over 700,000 responses in 2023.

If you have any questions about this submission, please contact Olli Potter, senior policy officer (oliver.potter@pickereurope.ac.uk).

### The ten-year health plan for England

# 1. What does your organisation want to see included in the ten-year health plan and why?

The need to centre patient experience in the delivery of healthcare has been acknowledged repeatedly in recent decades, including in the NHS plan (2000)¹ and Lord Darzi's 2008 'High quality care for all'² review into the NHS, which cemented 'patient experience' as one of the three cornerstones of quality of care, alongside 'patient safety' and 'effectiveness of care' – a definition enshrined in law in 2012³.

Lord Darzi's recent 'Independent investigation of the NHS in England' further concluded that "the patient voice is not loud enough", while "too many staff are disengaged". Lord Darzi was clear that while the NHS "is in a critical condition", its challenges can be overcome. It is our view that the upcoming ten-year plan offers a tangible opportunity to fully and finally champion patient experience, with the aim of delivering person centred care, for all, for generations to come.

Person centred care is not, however, only about listening and responding to the patient voice. It is crucial to also foreground the workforce's experience. As Bodenheimer and Sinsky (2014) suggest, we should aspire to expand the 'triple aim' – enhancing patient experience, improving population health, and reducing costs – to a 'quadruple aim', that includes improving staff experience<sup>5</sup>.

Picker would like to see a person centred ten-year plan that includes the following:

- Interventions to support 'waiting well'
- Education for self-management, peer support and personalised care



- Clear communication with patients and service users
- A national centre of excellence on patient experience
- Training for staff on person centred care
- Embracing new technologies
- An updated NHS Constitution, with improved visibility among the public and staff
- Improved staff levels.

#### Interventions to support 'waiting well'

With a record 7.57 million cases on NHS elective waiting lists, representing 6.34 million individuals, waiting is now, regrettably, a dominant theme of patients' experience<sup>6</sup>, 7. Long waits are a major factor driving record levels of dissatisfaction with the NHS<sup>8</sup>. While the new government has committed to cutting waiting times and lists, it acknowledges that this will take time<sup>9</sup>.

We would, therefore, like to see the ten-year plan include a strategy for restoring public confidence in the NHS: one that clearly explains how waiting times will be reduced and what patients and service users can expect while they are waiting to access care. Research shows that waiting disempowers patients and increases the use of both urgent and emergency and primary care services. Waiting also has a detrimental impact on people's health, which can lead to deterioration of their health and wellbeing, or the development of secondary conditions.

We know from national surveys (delivered by the Survey Coordination Centre at Picker) that patients report their health getting worse while waiting. More than two in five (43%) of respondents to the most recent adult inpatient survey said their condition got "much worse" or "a bit worse" while they were waiting for care<sup>10</sup>, while 44% of community mental health patients reported their mental health deteriorated while they were waiting between assessment and their first appointment for treatment<sup>11</sup>.

Whilst these figures are already concerning, it is likely that they underestimate the problem. Most patient experience surveys focus on services instead of pathways, which means we only receive feedback once someone has accessed care, not while they are waiting. We would, therefore, also like to see a commitment within the plan to measuring people's experiences of waiting for care, with the results to be used to improve the waiting experience in co-design with patients, service users, their families and carers.

#### Education for self-management, peer support and personalised care

We would like to see these person centred, cost-effective interventions introduced rapidly as part of the plan, in co-production with patients. NHS staff are currently educated on self-management, while patients are not, meaning there is a need for a universal offer from NHSE and the Department of Health and Social Care (DHSC) to support patients to develop coping strategies focused on their quality of life. Education programmes have been found to be effective for patients living with asthma, chronic obstructive pulmonary disorder (COPD) and for those who have experienced a stroke. They could be rolled out to patients living with conditions including diabetes, epilepsy, cancer, and mental health conditions<sup>12</sup>.

Peer support has been mainstreamed in mental health services and should be prioritised for those with long term conditions under the plan via Integrated Care Board (ICB) commissioning. Peer



support has been found to build confidence, allowing patients to feel more in control to make decisions and self manage, while feeling more accepted for their mental health; and experiencing reduced social isolation<sup>13</sup>.

The ten-year plan also offers an opportunity to deliver on overdue personalised care plans (PCPs), which were first promised in *'Our Health, Our Care, Our Say'* in 2006<sup>14</sup>. Unfortunately, progress has been slow, despite re-commitment to PCPs in the 2019 Long Term Plan. Data from the General Practice Patient Survey (GPPS) indicates that only 41.5% of people with a long term condition reported being asked what is important to them when managing their conditions or illnesses and less than 19% had "agreed a plan with a healthcare professional to manage their conditions or illnesses" The GPPS provides one of the few sources of information on PCPs, so it is difficult to measure progress nationally. This is something that should be resolved as part of their wider rollout.

#### Clear communication with patients and service users

Patients and their families value clear communication and information from health services and professionals – it is listed as one of Picker's eight 'Principles of Person Centred Care'<sup>17</sup>. In practice, there are too many gaps and shortcomings in communication with patients. For example, only 72% of patients in the most recent NHS inpatient survey said that they "always" got understandable answers to their questions from doctors or from nurses<sup>18</sup>. Similarly, in 2024 only 58% of mothers said that they were "always" given the information and explanations they needed in hospital after the birth of a child<sup>19</sup>.

The ten-year plan should also include a commitment to clearer, more accessible, and digitised patient information and resources, as well as an expansion of translation services and translated materials. One example of best practice from Picker's 2024 Patient Experience Network National Awards (PENNA) is Birmingham Women's and Children's NHS Foundation Trust's Interpreting and Cultural Insight Department, whose in-house team of translators provide continuity of care, often from ante-natal bookings through to birth. Clinical staff have commented that conversations flow better when they are working with in-house interpreters, who are familiar with medical terminology, benefiting staff and patient experience<sup>20</sup>. Access to clear information and resources is important in ensuring patients feel a sense of ownership over their own health, underpinned by a good understanding of their condition.

A further example of this, as highlighted by the NHS Cancer Programme's Patient and Public Voice (PPV) Forum at Picker's 2024 PENNA, is the provision of a wallet or envelope for patients to put their resources into before leaving the hospital, to protect their dignity as they leave to travel home<sup>21</sup>. These changes should be made in co-design with patients and service users, incorporating small and cost-effective changes that make patients and service users feel heard.

#### A national centre of excellence on patient experience

Research shows that providers and their staff struggle to interpret and interrogate the wealth of patient experience data that they receive, often due to a lack of training and time<sup>22</sup>. This is unsurprising when NHS staff survey data shows only 26% of staff report that they "never" or "rarely" experience unrealistic time pressures<sup>23</sup>.



Healthcare managers have expressed concern that they do not have the staff or expertise within their teams to "produce meaningful conclusions from the data they received"<sup>24</sup>. Patient experience officers are "an emerging professional group" within the health service who, with appropriate training and development, could support the interpretation and use of data<sup>25</sup>.

To ensure that patient and staff experience data is fully utilised to deliver person centred care, NHS organisations must be empowered to understand and act on feedback, which can be achieved through the establishment of a funded national centre of excellence that provides expertise and hands-on support to providers and their staff<sup>26</sup>. This national centre of excellence would be able to coordinate and act as a central source of knowledge and support, while utilising local learnings to ensure it is not a 'one size fits all' approach<sup>27</sup>.

#### Training for staff on person centred care

In addition to training for staff on understanding and interpreting patient experience data (see 'a national centre of excellence' above), Picker would like to see the ten-year plan commit to training on person centred care, drawing on the eight principles of person centred care, for all NHS staff<sup>28</sup>. This would not only deliver benefits to patients and their experience of care but has the potential improve staff satisfaction with the standard of care provided by their organisation<sup>29</sup>. It could also provide development opportunities for staff, in turn aiding retention and recruitment.

#### **Embracing new technologies**

The government has committed to delivering an NHS fit for the future and we welcome the shift from analogue to digital that forms part of the basis of the ten-year plan. It is essential that the NHS keeps pace with technological developments, for the benefit of patients, staff and the public. It is crucial that the adoption approach is co-designed, including user testing and ongoing evaluation from a patient and staff perspective. Our response to Question 3 outlines our view in full.

#### An updated NHS Constitution, with improved visibility among the public and staff

The NHS Constitution forms the contract between the NHS and the public, but many are unaware of it and its purpose. The former government consulted on changes to the Constitution earlier in 2024. We would like to see an update on progress, either utilising the views submitted by the public and organisations as part of the original consultation exercise, or an interim update to comply with the statutory requirement to update the Constitution every ten years. The government could then commit to a more comprehensive update in 2025/26, to reflect the ten-year plan and the NHS's updated priorities. Either route should result in the updated Constitution being more visible with the public and staff to improve awareness.

#### Improved staff levels

NHSE's Long Term Workforce Plan (LTWP), published in June 2023, is clear that to meet increasing demand, the NHS will need to expand its workforce over the next decades to place the health service on a sustainable footing.

The annual NHS staff survey demonstrates the demands that staff are experiencing, with only 32% of staff responding saying there are enough staff at their organisation to allow them to do their job properly. Additionally, 42% of respondents reported feeling unwell due to work related stress in the



last 12 months. Staff satisfaction with the level of care provided by their organisation has reduced from 71% in 2019 to 65% in 2023 - a difference of 6 percentage points. 29% of survey respondents reported they often think about leaving their organisation, while 16% reported they will leave their organisation as soon as they find another job<sup>30</sup>.

Staff continue to work under significant time and demand pressures, which makes it difficult to offer the care they want to deliver to their patients. This has a negative effect on patient experience, as well as staff recruitment and retention. If staff are to deliver wide ranging reform, they need time to develop new skills, learn to use new tools, and to consider new ways of working to deliver further efficiencies and benefits for patients and their colleagues alike.

### Shift 1: Moving more care from hospitals to communities

# 2. What does your organisation see as the biggest challenges and enablers to moving more care from hospitals to communities?

While we are supportive of this shift, and the two further shifts that will underpin the ten-year plan, it must be acknowledged that these have all been proposed and committed to in the past. It is, therefore, essential that these changes are finally realised - in full - to deliver for patients, staff and the public.

#### **Challenges**

The current funding model, which sees a high proportion of funding flow to acute hospitals, will be a challenge to overcome when moving more care from hospitals to communities. There will also be a need for sustained capital investment to tackle the estates and maintenance backlog, which affects the primary and secondary care estates. The announcement of £1 billion for estate repairs in the Autumn Budget was welcome, but when compared with a maintenance backlog of over £12 billion (of which £6.7 billion is considered 'high' or 'significant risk'), it is clear that further capital investment is required<sup>31</sup>,<sup>32</sup>. Changes to funding flows and capital budgets are both high priorities and must be driven by central government.

A further challenge is the current limited data sharing across care settings, which will need to be improved to ensure this shift is successful<sup>33</sup>. It is promising that consideration of this is already underway, with the government announcing the exploration of Patient Passports and the laying of the Data (Use and Access) Bill before the House of Lords<sup>34</sup>. This is another high priority, which would deliver wider system benefits, that should be delivered centrally, with support from local providers.

The latest data from the Urgent and Emergency Care survey shows that 20% of respondents attended A&E first as they "did not think [their] GP practice would be able to help", while 9% of respondents "did not know where else to go"35. It will be crucial to clearly communicate changes in service design to patients, service users, their families and carers, particularly as recent demand pressures on the NHS have disrupted the access routes patients would normally take. This is a priority and should be co-designed with diverse communities.

Staffing will be another challenge to consider as part of this shift. Data from the most recent Cancer Patient Experience Survey (CPES) shows that 46% of respondents whose GP was



involved in their care while they were having cancer treatment felt they got the right amount of support from the staff at the practice during treatment. Around half (52%) said they "definitely" got enough care and support at home from community and voluntary services during treatment and only 32% said they "definitely" got enough emotional support post-treatment from community and voluntary services<sup>36</sup>. These have all improved in recent years, but there is still room for marked improvement.

Furthermore, it can be particularly difficult to recruit staff to rural and coastal communities. It will, therefore, be important to ensure staff are attracted to and retained in roles at more localised hubs, with opportunities for career development and growth built into planning. This will take time to achieve, but it must be a priority, driven in partnership by the centre and local providers.

Public access - in terms of physical and non-physical barriers to accessing care - will be another challenge to embedding this shift. One example of a physical barrier is the lack of access to reliable, convenient, and affordable public transport outside of major cities. Improving public transport infrastructure will require cost-departmental collaboration and investment. The NHS, however, can prioritise locating community health services in convenient, well-connected locations. Non-physical barriers to accessing care include jobs that lack flexibility or caring commitments, which both mean that standard opening hours are inconvenient. It is within the health service's gift to overcome this barrier, in partnership with patients, carers and staff, by offering increased flexibility around appointment times, opening hours, communication preferences, and whether certain care interactions are delivered face-to-face or over the phone/virtually. Addressing physical and non-physical barriers to accessing care must play a central role in future planning if health inequalities are to be tackled and reduced.

#### **Enablers**

The enablers of this shift are largely centred on engagement – either with patients and service users, or with Integrated Care Systems (ICSs) and their Boards (ICBs), particularly their local government partners.

It is critical that this shift involves patients and the public in decision-making and service design, with diverse voices representing the needs of patients, families and carers. On an ongoing basis, it will be important to utilise patient experience metrics collected via CQC and NHSE national survey programmes, as these will aid monitoring and evaluation of changes.

Strong multi-body relationships at a local level will also be key to embedding this shift successfully. Formalised ICSs are relatively new in the NHS, having been placed on a statutory footing in 2022. It was reassuring to recently hear the role of ICBs and NHSE clarified by the NHS Chief Executive, with NHSE undertaking "planning, assurance and support" and ICBs focusing on "strategic commissioning", prevention and the neighbourhood health model<sup>37</sup>. While the NHS is experiencing well documented pressures, these pressures are arguably more profound in local authorities – key partners in ICSs – where funding reductions were severe in the 2010s<sup>38</sup>.

## Shift 2: Analogue to digital

3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?



The Health and Social Care Committee's report into digital transformation in the NHS notes that previous attempts to drive transformation have been "frustrated by a number of factors" Picker recognises these frustrations but remains supportive of this shift. We foresee the following challenges and enablers to making better use of technology in health and care.

#### **Challenges**

While funding is currently a challenge, it can be an enabler to digital transformation in the health service. For this to be the case, funding must, however, be adequate and long-term to provide stability for longer-term transformation projects. In recent years, however, transformation budgets have been raided to pay for day-to-day spending, which has a direct impact on longer-term transformation. This is apparent in concerns from NHS staff and patients about the use of outdated technology, which has an impact on efficiency, as well as on patient and staff experience. A simple but clear example comes from the most recent Under 16 Cancer Experience Survey, which found that only 36% of parents or carers felt that the hospital Wi-Fi "always" met the needs of them and their child<sup>40</sup>. Building strong digital foundations and long-term funding are both high priorities to be driven by central government with local support related to implementation.

Further challenges are tackling the 'digital divide', with health inequalities front of mind, and attracting staff with IT expertise to the NHS. It is essential that the public are not excluded from accessing the information they require, in the format they prefer, in a drive to increase digitisation. There is a wider challenge as part of this for cross-departmental work on poverty reduction and digital exclusion. There is also a need to attract and retain highly skilled staff in digital and technology roles in the NHS. This is currently a challenge for the public sector more broadly, but specifically in the NHS where recruiting and retaining staff with the right digital skills can be challenging due to the constraints of Agenda for Change terms and conditions, which means the base salaries for these roles are not competitive<sup>41</sup>. It is disappointing that the digital workforce plan due to be published after the LTWP has not yet be published, and this should be rectified.

#### **Enablers**

Centralised support and guidance from the centre is key to the success of this shift to ensure interoperability and to avoid disparities across geographies: clear standards should be adopted and maintained. Simultaneously, there should be local input within the planning and design processes to allow for variation as required at a local level.

Digitised resources on self-care and peer support, as well as digitised personalised care plans, will make access easier for most patients, and with the right data sharing agreements, will make joined-up care a reality. A choice for patients to access resources offline should remain, if this is their preference, but in our view personalised care plans should be digitised by default to ensure their security, accessibility, and portability within the system.

The government has already suggested it would like to see an increased role for the NHS App, which is welcome. Allowing patients to do more, will increase the number of active users, making it the 'first point of access' to the health service. While the NHS App currently has a strong user base with over 30 million downloads<sup>42</sup>, a recent study found that registration rates vary across demographics, with higher usage seen in less deprived, less ethnically diverse and younger populations<sup>43</sup>. Extending the functionality of the NHS App is likely to improve its adoption and use,



whilst simultaneously empowering active users to manage their care, appointments, and personal health records more effectively.

To make a success of the shift from analogue to digital it will be crucial to engage diverse groups of patients and service users, their families, and carers in decision-making and design processes. Acceptance of new technologies, among both staff and service users, requires engagement as part of the adoption and implementation process, as well as at the design phase. It will also be critical to engage the public on data sharing and security, to provide reassurance due to the sensitive nature of healthcare data, widely publicised examples of breaches of data security both domestically and internationally, and due to misinformation about data governance and the marketing of private data. Sharing of health data has the potential for profound, transformative benefits for individuals, providers, and the research community – but it will be stymied if the public are not persuaded that it is safe, secure, and serves their best interests first and foremost.

Finally, it will be essential to upskill staff to ensure they are trained and supported to use new tools and technologies. This requires protected time. Training staff in new tools not only provides them with the confidence they need to adopt new tools but also aids recruitment and retention. Picker would also advocate for all staff to be trained in the basics of understanding data.

### Shift 3: Sickness to prevention

# 4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

We are supportive of this shift from sickness to prevention, with a focus on earlier diagnosis and tackling the causes of ill health. If implemented effectively, this will have significant impact on wellbeing and quality of life. To succeed, it is important that the plan recognises the wider determinants of health and supports people to live healthier lives.

#### Challenges

Data sharing across care settings and providers will be a key challenge in driving this shift forward, particularly as successful interventions on prevention will need to be cross-departmental at a government level and cross-system at a local level.

In this context, it is concerning that Public Health England was disbanded to become the UK Health Security Agency, which has a remit for "infection diseases and environmental hazards" instead of wider public health prevention<sup>44</sup>. Additionally, public health grants distributed to local authorities have been cut in real terms in recent years, presenting challenges when addressing public health concerns. Research by the Health Foundation estimates the largest cuts have been to sexual health services, public health advice, and drug and alcohol services for young people<sup>45</sup>.

It was welcome to see public health measures in the most recent Autumn Budget, including an increase to the Soft Drinks Industry Levy, a review of current sugar thresholds and the exemption for milk-based drinks, alongside a new vaping products duty and the renewal of the tobacco duty escalator<sup>46</sup>. It is positive that the Tobacco and Vapes Bill has also been reintroduced to parliament by the new government.



#### **Enablers**

It is our view that there are several enablers for this third shift, yet as with the challenges, these require unified collaboration across government departments – particularly across education, work and local communities. ICSs will again play a central role in the success of shift three. As the Hewitt review, published in 2023, recommended, there is a need for collaboration on promoting health. Hewitt noted a shift in resources is required and suggested that "the share of total NHS budgets at ICS level going towards prevention should be increased by at least 1% over the next 5 years" 47.

While all three shifts are interlinked and interdependent, success in shifts one and two will be fundamental to achieving success with the move from sickness to prevention, which should lead to increased local diagnostics, expanded home testing, and a truly digital NHS.

It will be key to involve diverse groups of patients and service users in decision-making and design, while personalised care plans, peer support, and education for self-management can support people with existing conditions to live well, preventing the onset of co-morbidities, particularly mental health issues. As part of this, it will be essential to signpost the public to the most appropriate and reliable support channels and educational resources, avoiding misinformation in the digital realm.

More broadly, a whole government approach to prevention will need to consider legislative changes to further tackle smoking and vaping, obesity, and the harms of drugs and alcohol. These should be delivered in tandem with public health initiatives that support the public in making informed choices related to their health and wellbeing. One example of success that could be used as a model would be the NHS Diabetes Prevention Programme (DPP)<sup>48</sup>.

While Picker advocates for a person centred approach to care, empowering patients instead of taking a paternalistic approach to health and care, it is essential that efforts to move from sickness to prevention adequately recognise the social determinants of health<sup>49</sup>. This will require cross-government collaboration, funding and accountability to ensure that issues like poor quality housing, poverty, and insecure work are tackled as a root cause of ill health.

As part of a wider cross-government approach, there should be a wider roll out of social prescribing within the NHS, particularly for those who are waiting to access care. Additionally, communities need to be able to access fairly-priced and well-maintained exercise facilities. Active travel should be promoted alongside a recognition of the barriers that prevent active travel, including limited infrastructure and concerns about safety.

# Ideas for change

5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in.



In order of priority, Picker would advocate for the following policies to be implemented:

#### 1. 'Waiting well' strategy for patients on waiting lists

This policy would be cost effective and could be introduced rapidly, with provision for tried-and-tested interventions including self-management, peer support and personalised care plans. This should include a focus on clear communication with patients while they are waiting to keep them informed on progress, as this can remove anxiety and empower patients and service users. Peer support offers and personalised care plans should be digitised, and patients' experiences of waiting should be measured as part of newly commissioned national survey. We would consider these interventions as 'quick to do'.

#### 2. National centre of excellence for patient experience

Commissioning of a funded national centre of excellence to support providers and their staff understand patient experience data and how to utilise this for improvement. A national centre of excellence would be able to coordinate and act as a central source of knowledge and support, while utilising local learnings to ensure it is not a 'one size fits all' approach<sup>50</sup>. We would consider this intervention as 'in the middle'.

#### 3. Investment in digital infrastructure and training for staff

We would consider this intervention as both 'in the middle' and 'long term' as funding for this would need to start sooner, but it will take longer than five years and requires sustained funding for stability. It will be important to involve staff in the design phase, as well as the implementation phase. Additionally, comprehensive staff training will be required, which needs dedicated protected time. In the longer term, AI tools will continue to play an ever-increasing role in society and the healthcare system, but it is crucial to first build strong foundations to 'get the basics right'. This will ensure staff can do their jobs efficiently and effectively and assist patients in accessing the information and tools they need, both in the short term and into the future.

#### 4. Public education on the benefits of data sharing and importance of data security

Data will continue to play an ever-increasing role in the health service of the future, and it is critical to making it more efficient, effective, and person centred. It is essential that efforts to bring the public along are prioritised as soon as possible to offer reassurance and to tackle misinformation. This intervention should be tailored and co-designed with diverse communities to ensure a wide cross-section of views are considered. We would consider this intervention 'quick to do' and would advocate for such a campaign to be delivered under NHS branding and/or supported by a trusted third-sector organisation.



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