

# NHS Constitution 10 Year Review: Draft Consultation Response (V2)

Response Deadline: 25 June 2024, 11:59pm

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## Consultation Introduction

The NHS Constitution sets out the principles, values, rights and pledges underpinning the NHS as a comprehensive health service, free at the point of use for all who need it. It empowers patients, staff and the public to know and exercise their rights in order to help drive improvements in quality, efficiency and responsiveness throughout the NHS. It brings together, in one place, existing rights as set out in various legislation. It does not, in itself, create new rights or replace existing ones.

The Department of Health and Social Care (DHSC) is seeking views on how best to change the NHS Constitution. This consultation is part of the process to complete the 10-year review, as legislated for in the Health Act 2009. There are no proposed changes to the guiding principles of the Constitution. Instead, the proposals include a *“limited set of specific changes to improve the current content, reflect important changes to government policy and to keep both the NHS Constitution and the handbook legally up to date.”* Changes are proposed in relation to the following key areas of the Constitution – of which, it is recommended that The Eyes Have It (TEHI) respond to the topics in **bold**:

- 1. Responding to deterioration**
- 2. Health disparities**
3. Environmental responsibilities
4. Patient responsibilities
- 5. Research**
6. Leadership
7. Sex and gender reassignment
8. Technical changes to reflect the Equality Act 2010
- 9. Unpaid carers**
10. Volunteers
- 11. Health and work**
- 12. Person centred-care**

For any questions on the content of this document, please contact [TEHI@mandfhealth.com](mailto:TEHI@mandfhealth.com).

## 1. Responding to deterioration

**Overview:** Patients and their families, carers and advocates have a critical part to play in their care and can be uniquely placed to identify deterioration in their or their loved ones' condition, including where that indicates a need for an escalation in their treatment or care. We need to facilitate this input more effectively to ensure concerns are listened to and appropriately acted upon, including when there are concerns the local team are not responding to deterioration appropriately. We also need to take a structured approach to obtain information relating to a patient's condition directly from patients and their loved ones at least daily.

**Proposal:** Add the following new pledge for patients and the public under 'Involvement in your healthcare and the NHS':

*"The NHS pledges to provide patients (and their families, carers and advocates) who are in acute or specialist provider sites a structured approach to providing information about their or their loved one's condition at least daily and if they have concerns about physiological deterioration that are not being responded to, access to a rapid review by appropriate clinicians from outside their immediate care team."*

### TEHI Response

This response has been developed by *The Eyes Have It (TEHI)* - a partnership of the Macular Society, Fight for Sight / Vision Foundation, Royal National Institute of Blind People (RNIB), Association of Optometrists, Royal College of Ophthalmologists and Roche Products Ltd. Roche has funded the activities of the partnership.

TEHI agrees with the proposed pledge and believe that alongside the monitoring and rapid review of physiological deterioration, consideration of psychological deterioration is also needed.

For people with eye health conditions, sight loss can have significant mental health and wellbeing impacts on both those affected and their families, and can lead to similar reactions to those associated with bereavement.[1] Research indicates that blind and partially sighted people are more than twice as likely to have experienced difficulties with unhappiness (low mood) or depression compared to the UK average, and three times more likely to experience loneliness and isolation than the general population. [2] [3]

Despite this, only one in five people losing their sight are referred to emotional support services.[4] There is an urgent need for mental health support both at the time of diagnosis and throughout a patient's sight loss journey to ensure people diagnosed with eye health conditions are able to live well with them. At present, however, many

patients report that they do not receive proactive support and the majority state they don't know where to go for support if they need it.[5]

For people with blindness or visual impairment, it is similarly critical that information and support is provided in an accessible format, in line with NHS England's Accessible Information Standard (AIS), the formal review of which is yet to be published. In light of evidence from recent patient surveys indicating only 11% of patients covered by the AIS have equitable access to the NHS, it is vital that the findings from this review are published without delay and plans are put in place to ensure people with blindness and visual impairment have access to information and support.[6] [7]

1. RNIB. Coming to terms with sight loss. Available from: <https://www.rnib.org.uk/your-eyes/navigating-sight-loss/coming-to-terms-with-sight-loss/>
2. RNIB. Eye care support pathway insight report. October 2023. Available from: <https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/reports-and-insight/eye-care-support-pathway-insight-report/>
3. Fight for Sight / Vision Foundation. Outside: Insights into loneliness and isolation for blind and vision impaired people. April 2024. Available from: <https://www.visionfoundation.org.uk/wp-content/uploads/2024/04/Insights-into-loneliness-and-isolation-for-blind-and-vision-impaired-people.pdf>
4. RNIB. Eye care support pathway insight report. October 2023. Available from: <https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/reports-and-insight/eye-care-support-pathway-insight-report/>
5. Trott M et al. Mental health support across the sight loss pathway: a quantitative exploration of eye care patients, optometrists, and ECLOs. 2023. Eye 37, 2554-2558.
6. The Deaf Health Charity: SignHealth. Review of the NHS Accessible Information Standard. Available from: <https://signhealth.org.uk/resources/research/aisreview/>
7. Healthwatch. Our policy position on accessible information. July 2023. Available from: <https://www.healthwatch.co.uk/news/2023-07-10/our-policy-position-accessible-information>

## 8. Health Disparities

**Overview:** There are stark disparities in how long people live and how long people live in good health across England. Poor health outcomes arise from particular combinations of factors and their impact varies geographically: inner city areas have younger populations but higher levels of homelessness and air pollution, and rural and coastal areas typically have an older age demographic, with some coastal areas

and rural areas having high levels of deprivation (as addressed in the Chief Medical Officer's annual report for 2021).

Under the NHS Act 2006, NHS England and ICBs are required, in the exercise of their functions, to have regard to the need to reduce inequalities between persons with respect to their ability to access health services, and outcomes (including outcomes that show the quality of the patient experience). These and other duties on health bodies were strengthened in the Health and Care Act 2022. The Levelling Up White Paper and subsequent Levelling-up and Regeneration Act 2023 established the Levelling Up health mission to narrow the gap in healthy life expectancy by 2030 and increase healthy life expectancy by 5 years by 2035.

**Proposal:** Add the following sentence to the value 'Everyone counts' to provide further detail on how the NHS works to understand the needs of different people and reduce disparities:

*"NHS organisations work with statutory and non-statutory partners, using the best data available, to understand the range of healthcare needs within and between local communities and how to tailor services accordingly and fairly, reducing disparities in access, experience and outcomes for all."*

### **TEHI Response**

TEHI agrees with the proposed change. We emphasise, however, that delivery against this commitment will require appropriate investment in data capture and publication to support NHS organisations (both statutory and non-statutory) to accurately identify health disparities within their local populations and develop strategies to address them. As part of this, there is a need for NHS organisations – including both national and local systems – to review current data collection and identify where further collection is needed to understand service challenges and opportunities for improvement.

With over 2.2 million people across the UK currently living with a condition that causes visual impairment or sight loss, eye health forms a key element of the proposal to understand local healthcare needs and tailor services accordingly.

One way to have access to the "best available data" would be to dedicate further financial resources to maintain the National Ophthalmology Database (NOD) – a national audit coordinated by the Royal College of Ophthalmologists that measures the clinical outcomes for cataracts surgery and age-related macular degeneration (AMD). These national clinical audits are recognised by clinicians, NICE and industry as vital research tools that enable performance benchmarking and patient safety by promoting best practice and eradicating unwarranted variation. As such, it is important that they are safeguarded so they can continue collecting valuable data. There is also an opportunity to expand these resources to include other eye health conditions, which could serve as an example of best practice for other specialties.

To further understand local population eye health needs, TEHI also believes that NHS England should publish detailed statistics on the number of people currently waiting for a follow-up appointment, alongside the routine Referral To Treatment (RTT) publication. While this is an important component in informing local assessments of clinical risk across all specialties, it is especially important in ophthalmology, where the risk of permanent harm from avoidable sight loss is nine times more likely in follow-up patients than in new patients.[8]

People living with sight loss and visual impairment similarly have unique experiences that require tailored advice and support from the health system. Alongside publication of follow-up waiting lists, further data should be published regarding the mental health and wellbeing of people living with eye health conditions to inform local approaches to addressing identified barriers in delivering best practice care.

Finally, addressing health disparities for people with eye health conditions will require action to reduce variation in the number of consultants per person across the country. Based on the latest workforce statistics from NHS England and population data from the Office for National Statistics, there are currently 2.01 consultant ophthalmologists per 100,000 population in the East of England compared to 3.59 in London. The Royal College is therefore calling for a phased increase of 382 ophthalmology training places to ensure there is sufficient consultant capacity to meet future demand across England.

8. Royal College of Ophthalmologists. Scale of ophthalmology follow-up backlogs and need for better data collection highlighted by thinktank. October 2023. Available from: <https://www.rcophth.ac.uk/news-views/scale-of-ophthalmology-follow-up-backlogs-and-need-for-better-data-collection-highlighted-by-thinktank/>

## 9. Research

**Overview:** Under the NHS Act 2006, the Secretary of State, NHS England and ICBs have duties to facilitate or otherwise promote research on matters relevant to the health service, and to facilitate the use of evidence obtained from research.

In partnership with the NHS, the National Institute for Health and Care Research (NIHR) has recently launched the [Be Part of Research](#) service to help support the discharge of these duties. Members of the public can sign up to the service and get in touch with researchers to discuss eligibility for participation in particular research studies. NHS England has also integrated the Be Part of Research service into the NHS App.

To better support our aim to embed research in the NHS, we propose strengthening the existing pledge (“to inform you of research studies in which you may be eligible to participate”).

**Proposal:** Add an additional sentence to the pledge:

*“Health research and the offer to be part of research should be integrated into health and care across the NHS.”*

## **TEHI Response**

TEHI supports the proposed addition. In eye health, integrated research into health and care across the NHS is vital not only in supporting improvements in our understanding of the causes, diagnostics and treatments for disease, but also in ensuring the UK remains an attractive proposition for the next generation of discovery and clinical researchers. The opportunity to be involved in research is similarly important for patients, particularly those that are currently living with untreatable conditions, as well as trainees, 54% of which recently reported that they want to be more involved in research activity in the NHS.[9]

Despite the significant potential benefits that increased investment into eye health research could generate, there is currently a significant gap in funding compared to other prevalent conditions such as dementia. At present, just £9.60 per year is invested in eye research for each person with sight loss, which is around one tenth of the funding available for dementia research (£97 per person, per year). [10]

Integration of health research across the NHS will also require dedicated infrastructures that support access to data, collaboration between researchers and enable patient participation.

9. Royal College of Ophthalmologists. Census Report. March 2023. Available from: <https://www.rcophth.ac.uk/wp-content/uploads/2023/03/2022-Ophthalmology-census-Facing-workforce-shortages-and-backlogs-in-the-aftermath-of-COVID-19.pdf>

10. Fight for Sight. Time to Focus. Available from: <https://www.fightforsight.org.uk/media/3302/time-to-focus-report.pdf>

## **10. Unpaid carers**

The government is committed to supporting the health and wellbeing of unpaid carers and supporting people who are carers to balance employment with their caring responsibilities, where they wish to do so. The proposed amendments update the NHS Constitution to reflect changes introduced in the Health and Care Act 2022.

Section 10 of the Health and Care Act 2022 imposed a duty for NHS England to involve unpaid carers in the planning of commissioning arrangements and, in certain circumstances, the development and consideration of proposals by NHS England to change commissioning arrangements and decisions of NHS England relating to the operation of commissioning arrangements.

The Health and Care Act 2022 also includes provisions in respect of:

- the promotion of the involvement of unpaid carers in decisions by ICBs relating to the prevention or diagnosis or care and treatment of patients
- the involvement of unpaid carers in commissioning arrangements by ICBs
- where a patient is likely to have needs for care and support following discharge from hospital, the involvement of unpaid carers in discharge plans

Within ‘Patients and the public: your rights and the NHS pledges to you’, we propose referencing unpaid carers explicitly. The aim is also to reinforce the principle that the NHS has specific responsibilities towards unpaid carers as part of recent legislation and to capture duties and entitlements that have been introduced in the last 10 years relevant to unpaid carers and young carers.

**Proposal:** add an additional pledge to ‘Involvement in your healthcare and the NHS’:

*“We pledge to recognise and value your caring responsibilities.”*

*“The NHS pledges to provide you the opportunity to give feedback, make suggestions and raise concerns about the care we provide for the person you care for. We pledge to respect your expertise, listen and to involve you in decisions (with the consent of the patient).”*

*“You have the right to be involved (with patient consent) at the earliest available opportunity when plans are being made to discharge the person you care for from hospital.”*

### **TEHI response (grouped)**

TEHI supports the proposal to recognise and incorporate carers in the decisions made about the person they care for, with appropriate patient consent. This should be facilitated in a way that recognises where carers themselves may require information in an accessible format, in line with NHS England’s Accessible Information Standard.

Family and friends can play a role in providing emotional and practical support to people living with visual impairment and sight loss, both at the time of diagnosis and throughout their sight loss journey. It is therefore vital that informal carers are appropriately recognised as a key component of a patient’s support team to ensure they receive the information, advice and support they need to care for their loved one.

Informal care for people with sight loss is also estimated to cost the UK economy up to £9.4 billion every year.[11] In addition to the vital role of informal carers being recognised, Government and policymakers should also provide them with necessary financial and respite support, as has been recommended by Fight for Sight / Vision Foundation. [10]

11. McDaid and Park (2020) Appendix 4 to the Time to Focus report. Cost of vision loss calculator. London School of Economics.

## 11. Health and Work

**Overview:** Work is an important determinant of health, both directly and indirectly on the individual, their families and communities. Fifteen million of the working age population have a long-term health condition and although 10 million of those are in employment, many with long-term conditions are economically inactive.

The government has an ambitious package of support to help people with health conditions and disabled people to start, stay and succeed in work. In the Spring Budget 2023 and the Autumn Statement 2023, we announced new investment to improve access to joined-up work and health support.

The only reference to employment in the current NHS Constitution is with regard to NHS employees' rights and this does not reflect the NHS's key role in supporting people to work.

**Proposal:** Add the following wording:

*"We support people to remain in, and return to, work, reflecting the good impact that work can have on a person's health and wellbeing."*

### **TEHI Response**

TEHI supports the proposal to include reference to the importance of supporting people to remain in, and return to, work.

Eye health conditions alone are estimated to cost the UK economy £27.9 billion in 2024, a notable proportion of which is due to the impact of lost productivity.[11] This is in large part due to lost employment, with research indicating that only 27% of blind and partially sighted people are in work, compared to 51% of disabled people and 75% of the general population. [12]

To deliver on the proposed ambition set out in the consultation, we believe that local systems should commission Eye Care Liaison Officers (ECLOs) as a core element of ophthalmology services. ECLOs are non-clinical staff that can play a central role in helping patients to navigate complex pathways - e.g. signposting to additional support such as mental health and wellbeing, social services, employment and specialist support charities and local support groups – all of which can provide people living with sight loss conditions with the support they need to remain in or return to employment after their diagnosis.

Despite patients emphasising the importance of ECLOs, they are not routinely funded or commissioned in all areas of the country.

12. RNIB. Employment facts and stats. 202. Available from: [https://media.rnib.org.uk/documents/Employment\\_facts\\_and\\_stats\\_2020\\_-\\_External\\_version.docx#:~:text=There%20is%20a%20significant%20employment,and%20partially%20sighted%20%5B7%5D](https://media.rnib.org.uk/documents/Employment_facts_and_stats_2020_-_External_version.docx#:~:text=There%20is%20a%20significant%20employment,and%20partially%20sighted%20%5B7%5D).



## Person-centred care

**Overview:** With 1 in 4 adults living with at least 2 health conditions, for many people care is rarely about a single visit to a single service. To effectively support people to manage the complexity of multiple health conditions, there is an increased need for co-ordinated clinical support across primary, community and secondary care. A critical aspect of this is greater join-up between mental and physical health services. Experiences of healthcare and support should feel person-centred, co-ordinated and tailored to the needs and preferences of the individual, their carers and family. This expectation is also set out in CQC's fundamental standards, which includes a standard on person-centred care.

**Proposal:** Amend the existing pledge in 'Access to health services' from:

*“make the transition as smooth as possible when you are referred between services, and to put you, your family and carers at the centre of decisions that affect you or them.”*

to

*“support a co-ordinated approach to your care and make the transition as smooth as possible between services, including physical and mental health services, particularly if you have a number of health conditions, and to put you, your family and carers at the centre of decisions that affect you or them.”*

### **TEHI response:**

TEHI supports the proposal to better reflect the need for coordinated care and seamless transition between healthcare services and believe this should include explicit reference to the transition between primary and secondary care.

This is particularly important to reflect for people with eye health conditions, where there is added complexity in the patient pathway due to the involvement of providers across high-street optometry and secondary care specialist settings. At present, the lack of IT connectivity and interoperability between these settings presents particular challenges for patients during their transition between services; barriers to sharing data such as images and patient information are one such example.

To ensure the NHS delivers on the ambition to support coordinate approaches to care and smooth transitions between services, improvements are needed in connectivity and electronic referral systems. This should include working with commissioners, clinicians and industry to deploy a single, consistent mechanism for image and information sharing, to facilitate timely, secure and effective communication between different parts of the system.

TEHI similarly emphasise that a key element of ensuring a smooth transition between services for people with eye health conditions is the provision of information, advice and support in an accessible format.