

Our vision for improving patient experience of diagnosis

Foreword

'Diagnosis' is the process of identifying a disease, condition, or injury from its signs and symptoms.

From the patient's perspective this is not always as straightforward as it sounds. It is often a multi-step process beginning with a person experiencing symptoms of ill-health, then either accessing information to try and self-diagnose minor concerns, going to the pharmacist or trying to access their GP. Sometimes they may need a referral for diagnostic tests (such as blood tests, X-rays, MRI, endoscopy and more) and/or specialist secondary care to finally receive a formal diagnosis.

From a system perspective, we know the NHS carries out approximately 1.5 billion diagnostic tests¹ a year, accounting for about 6% of the NHS budget² (which was approximately £9.8 billion in 2023/24³). Making sure we are diagnosing people early and efficiently is therefore essential to the long-term sustainability of the NHS. After all, when people are diagnosed earlier it improves their clinical outcomes and often allows them to live longer and healthier lives.

But the process of diagnosing someone is more than just figuring out what is going on clinically. It is a process that is full of important learning moments for patients and the NHS. For example, for the NHS there is a chance to learn about the specific additional needs of patients or their capacity for self-management.

For those who get the all clear, the process offers a chance to educate people about the signs and symptoms of disease, enabling them to seek appropriate help in the future. This might include increasing the awareness of screening programmes, for example. It also provides an opportunity to inform people about how the NHS works in practice and how best to access care, something which is often a mystery to most people until they become unwell.

For those who are diagnosed with a condition, it can also be the start of a longer healthcare journey. Some people begin intensive treatment plans, and others must learn to live with and manage their newly diagnosed long-term condition/s.

These people may need a bit of extra support at the beginning, but if the NHS focuses more on helping people at this stage of their journey it would not only improve patient experience, but it could significantly increase the numbers of people successfully self-managing their conditions. This wrap-around support could include more regular check-ups for an initial period, access to peer support or enhanced collaboration with charities.

At National Voices, we hear time and time again, from our members that diagnosis is not working in this way at the moment. Not only is the process of getting a diagnosis becoming increasingly challenging, as a result of the intense pressures on primary and secondary care, but the wrap-around support is simply not there. This is having a significant impact on patient care and the journey experienced by many post-diagnosis.

Our **People's Experiences of Diagnosis** report brings together insights from people with lived experience and our members on the entire process of diagnosis – from trying to get an appointment for a diagnostic referral, to undergoing tests, and experiences post-diagnosis. At the end of the report, and in this document, we have outlined nine proposals that make up our members' vision for improving patient experience of diagnosis. We believe implementing these proposals will significantly improve people's experiences of not only diagnosis but health and care more widely.

While people will respond and cope in different ways, being diagnosed with a health condition, whether treatable or not, can be a life-changing time. It is a process filled with anxiety and fear of the unknown. It is therefore imperative that people are well supported and empowered throughout the process and beyond.

Jacob Lant
Chief Executive, National Voices

Johnson & Johnson Innovative Medicine

Johnson & Johnson Innovative Medicine provided a grant towards this project and had no input into the project or this report.

1. NHS England (2020) NHS England and NHS Improvement Board meetings held in common
2. The King's Fund (2022) Why do diagnostics matter? Maximising the potential of diagnostics services.
3. The Health Foundation (2024) Health care funding: Three key questions about funding in England.

Our vision for improving patient experience of diagnosis

What can be done now? Making best use of existing provisions:



01

Adjustments and adaptations to enable access

People facing health inequalities must not have an inferior diagnosis experience. All communication around diagnosis must be accessible and appropriate to the individual, in compliance with the Accessible Information Standard⁴. This means understanding and mitigating the impact of digital exclusion at the level of system, provider and frontline staff⁵. This is particularly important at the point of diagnosis so people understand their individual circumstances and what can be done to address their care needs.

Financial barriers to accessing services must also be addressed, for example with people proactively signposted to sources of support with travel costs, such as the HealthCare Travel Costs scheme⁶.

Finally, reasonable adjustments to the diagnosis environment must be made so people with disabilities or other impairments can fairly access diagnostic tests. Under the Equality Act 2010, all organisations are required to promote equality for disabled people in every aspect of their work, including access to buildings and services⁷. In addition, public sector bodies are also required to take proactive steps to ensure that disabled people have full access to buildings and service, under the Public Sector Equality Duty⁸.



02

Provide better support while waiting

Perhaps unsurprisingly, the priority for many of our members is to reduce the overall time taken to secure diagnoses, primarily by bringing down waiting times for appointments (for GPs, to see specialists and for testing).

However, within the context of current system pressures, we must at the very least better support people waiting for a diagnosis:

- Help from multidisciplinary teams in primary care to alleviate symptoms where appropriate.
- Access to primary care psychological support, for example talking therapy, group programmes for peer support and psychoeducation on coping strategies.
- Clear communication in accessible formats regarding how long the wait will be and points of contact for further information if required.

We also urge NHS England to advise Integrated Care Systems on how to better understand what is happening to people whilst they are waiting for a diagnosis (e.g., how their condition is progressing, their support needs) so they can understand and address the health inequality impacts.

4. [Accessible Information Standard](#)

5. [See for example here](#)

6. [NHS \(2023\) Healthcare Travel Costs Scheme \(HTCS\)](#)

7. [The Building Regulations 2010: Equality Act clarification](#)

8. [Legalities of providing disabled access](#)



03

Listen to the patient

Many members have highlighted the need for a shift in culture among healthcare professionals towards listening to, and believing, the patient. We have heard too often that this is not happening and leading to delayed diagnosis, often of many years. This also results in the NHS delivering extra appointments over this delayed time period which could have been avoided, thus reducing system efficiency and increasing the workload for an already under pressure workforce. By listening to patients, we can not only increase productivity, but also improve people's experiences of care.

Addressing this is an absolute priority in helping to reduce health inequalities. This will involve addressing stigma experienced by specific demographic groups (e.g., related to age, ethnicity and gender) and the presence of other conditions (e.g., obesity). There is a role for Integrated Care Systems to work in collaboration with VCSE (Voluntary, Community and Social Enterprise) organisations and people with lived experience to co-design training, continue to develop awareness and provide inclusive approaches to working with local populations.

Offer wrap around support for newly diagnosed patients:



04

Better communication around diagnosis

Improving the way that professionals communicate diagnoses is a key priority for many members, who highlighted the need for compassion and skilled communication when people receive a diagnosis. People absorb information in different ways. For example, one person may prefer to have a single longer appointment while another might prefer to have multiple shorter appointments to help them better understand and adjust. Adequate time and space to ask questions during the diagnosis appointment and afterwards, once people have had time to take in the diagnosis, should be a minimum offer. People must be given an option of whether they want to receive the news face-to-face, online or via phone call and be allowed to take someone with them to the appointment.

Continuity of care is also an important factor in helping people feel heard and understood throughout the diagnosis process. For some this may be seeing the same clinician for an initial diagnosis or treatment, while others may prefer seeing the same clinician for the majority of their treatment and care over a longer period of time.



05

Make sure people have a plan

Creating a shared agenda during a diagnosis conversation is important, as often healthcare professionals want to focus on preventing adverse health outcomes, while patients are initially more concerned with changes to their daily life such as being able to drive or relying on others for help. Listening to patients' ideas, concerns, and expectations of their condition is a necessary first step in building confidence in their ability to cope.

Most members emphasised that giving people a clear plan of the road ahead of them – both through their journey toward diagnosis and beyond – was a really important way of reducing the person's stress and enabling people to cope with their conditions better. This may not always be appropriate during the diagnosis meeting (e.g people may need time to process the news of a diagnosis) but can be supported via follow up with community navigators, support workers/advisors from condition-specific VCSE organisations, and post-diagnostic healthcare appointments.



06

Provide access to support groups

Many members highlighted that action was needed to ensure that those diagnosed with a condition are routinely referred and signposted to specialist organisations including peer support groups and patient organisations. Compassion in Dying highlighted that peer navigator services could deliver tangible benefits for people with a new diagnosis of a serious illness and could help address multiple issues to do with their health and wellbeing through innovative, person-centred and community-based methods.

What needs to happen in the longer term?



07

Collect better data to understand the drivers of diagnostic health inequalities, and act on it rapidly

Our members identified wide-ranging concerns faced by people experiencing health inequalities, for example regarding access to services, communication, bias and discrimination. National data collection (for example via NHS England and the Office for Health Improvement and Disparities (OHID), must be better at collecting data on these issues, use it to develop an understanding of the true depth and breadth of concerns, and act to rapidly mitigate against these inequalities. We know that where this has occurred, for example OHID's data analysis on disparities in dementia diagnosis rates, targeted avenues for improvement can be identified.⁹

Several members highlighted the need to make it easier for people in all parts of the country to access diagnostic services so we can end the postcode lottery for accessing a diagnosis. For example, Cancer Research UK highlighted the potential of using mobile diagnostic services to bring services closer to people, and to support people to be able to discuss concerns with a wider range of health professionals with whom they may come into contact.



08

Upskill, coordinate and ultimately increase the workforce

Improving GP awareness, particularly of rarer conditions, was another common priority for members. To support this, we need to see rapid implementation of NHS England's Primary Care Recovery Plan to develop clear points of contact between general practice and secondary care teams to allow effective and timely sharing of advice and guidance between them. Such communication must be inclusive of the person seeking a diagnosis and others involved in their care to enable shared decision making.

9. Alzheimer's Society (2023) *Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England*



New innovations must have health equity embedded from the start

Innovations such as Community Diagnostic Centres, and the more disruptive move into AI, must recognise the potential impact on health inequalities at their inception and have a clear plan to address them. Equality Impact Assessments alone are not enough to mitigate risks. We recommend meaningful engagement with the VCSE sector and people with lived experience to properly explore the acceptability and impact of these new services.

We, the undersigned, believe that these proposals would make a significant difference to people living with mental and physical health conditions and disability. Underpinning these reforms, it will be critical to ensure diagnostic services are adequately funded and that the health and care workforce is supported to expand in response to the level of need for diagnostic services.

Jacob Lant

Jacob Lant, Chief Executive



Addison's Disease Self Help Group



Age UK



Allergy UK



ARMA
(Arthritis and Musculoskeletal Alliance)



Arthritis Action



Aspergillosis Trust



Asthma + Lung UK



Behcet's UK



Behind the Smile



Borderline Support UK CIC



Bowel Cancer UK



British Geriatrics Society



British Heart Foundation



Cardiomyopathy UK



Your end of life. Your way.

Compassion in Dying



Dementia UK



Diabetes UK



Ectodermal Dysplasia Society



Endometriosis UK



Epilepsy Action



Esme's Umbrella



Forgotten Lives UK



Furness Mental Health Trust (FMHT)



GAIN (Guillain-Barré and Associated Inflammatory Neuropathies)



Juvenile Arthritis Research



Long Covid SOS



LUPUS UK



Macmillan Cancer Support



Macular Society



Motor Neurone Disease Association



MS Society



Myaware



Myeloma UK



National Axial Spondyloarthritis Society



National Rheumatoid Arthritis Society (NRAS)



Northern Cancer Voices



OUTpatients



Pancreatic Cancer UK



Parkinson's UK



PatientsCann UK



PCD Support UK



Pregnancy Sickness Support



Pseudomyxoma Survivor



Rethink Mental Illness



Scleroderma & Raynaud's UK (SRUK)



SignHealth



Stickler Syndrome UK



The Hepatitis C Trust



THALIDOMIDE SOCIETY

The Thalidomide Society



The Thyroid Trust



Thomas Pocklington Trust

Thomas Pocklington Trust



Thyroid UK



Time To Talk Mental Health UK



Incorporating all types of urinary diversion

Urostomy Association



VCSE Nutriri



Versus Arthritis



Yorkshire Cancer Community



SimPal
Keeping you connected

Your SimPal

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

We make what matters to people matter in health and care.

Do get in touch:

 info@nationalvoices.org.uk

 www.nationalvoices.org.uk

 [@NVTweeting](https://twitter.com/NVTweeting)

June 2024