

June 2024

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# People's experiences of diagnosis

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## **Johnson & Johnson**

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

# Acknowledgements

We would like to thank our member organisations and people with lived experience for sharing their insights and inputting on this work, including Age UK, Allergy UK, Alzheimer's Society, Asthma + Lung UK, Compassion in Dying, Crohn's & Colitis, Dementia UK, Diabetes UK, Endometriosis UK, Equally Well UK, Juvenile Arthritis Research, Macular Society, Myaware, National Axial Spondyloarthritis Society, National Rheumatoid Arthritis Society, Pancreatic Cancer, Parkinson's UK, Prostate Cancer UK, Resuscitation Council UK, Rethink Mental Illness, Shine Cancer Support, Stickler Syndrome UK, Stroke Association, The Neurological Alliance, Thomas Pocklington Trust, Thyroid Trust, and others.

## List of Abbreviations

<b>A&amp;E</b>	Accident and emergency
<b>AI</b>	Artificial intelligence
<b>BSL</b>	British Sign Language
<b>CDC</b>	Community Diagnostic Centres
<b>CT</b>	Computed tomography scan
<b>ICB</b>	Integrated care board
<b>ICS</b>	Integrated care system
<b>MRI</b>	Magnetic resonance imaging
<b>VCSE</b>	Voluntary, community and social enterprise

### Examples of Positive Practice

Please note, we have included examples of where things are working well, or positive practice, throughout the report within these turquoise text boxes.

# 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 tests<sup>1</sup> a year, accounting for about 6% of the NHS budget<sup>2</sup> (which is approximately £9.8 billion in 2023/24<sup>3</sup>). 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 patients who get the all the 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

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<sup>1</sup>NHS England (2020) *NHS England and NHS Improvement Board meetings held in common*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2020/10/BM2025Pu-item-5-diagnostics-capacity.pdf>

<sup>2</sup> The King's Fund (2022) *Why do diagnostics matter? Maximising the potential of diagnostics services*. Available at: <https://www.kingsfund.org.uk/insight-and-analysis/reports/why-do-diagnostics-matter>

<sup>3</sup> The Health Foundation (2024) *Health care funding: Three key questions about funding in England*. Available at: <https://www.health.org.uk/publications/long-reads/health-care-funding#:~:text=Planned%20NHS%20England%20DEL%20in,25%20is%20%C2%A3164.9bn>



screening programmes for example. It also provides an opportunity to inform people 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. These people may need a bit of extra support at the beginning, but if the NHS focused more on helping people at this stage of their journey it would not only improve patient experience, it could also 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 providing information, advice and support.

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.

This 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 report, we have outlined nine proposals that we believe 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

# Introduction

*"[I] found this long period very distressing as I was in a lot of pain, plus not knowing what the problem was."*

- Person with lived experience, shared by Age UK

Over the past year, one of the key insights we have heard from our members across conditions, geography and communities, is how difficult it can be to get a diagnosis, as well as the long-term and significant impacts that can have on patients and their journey post-diagnosis.

While this has been a longstanding issue for many people living with symptoms which affect their lives and livelihoods, we heard that access to diagnosis worsened during the pandemic and progress to recover lost ground has been slow. We also are aware, through the work of our members and partners, that significant inequalities in diagnosis exist across groups and geographic areas. Getting diagnosis right for all, with a specific focus on reducing health inequalities, is vital if we are to achieve the aim shifting the NHS to a greater prevention role.

The NHSE Standard Contract 2023/24 states that 99% of people should be waiting less than six weeks from Referral for a diagnostic test.<sup>4</sup> This six-week diagnostic wait was initially introduced as a 'milestone' from March 2008 towards achieving the standard Referral to Treatment (RTT) wait of 18 weeks, but diagnostic waiting times now form part of the NHS Constitution.<sup>5</sup> This gives patients the legal right to treatment within 18 weeks of referral (18 week RTT) and as part of this, pledges that patients should not be required to wait six weeks or more for a diagnostic test.

However, targets have not been met since 2013, before the RTT or A&E pressures. NHSE planning guidance for 2023/24 states that the national objective should be to "increase the percentage of patients that receive a

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<sup>4</sup> NHS (2023) *NHS Standard Contract 2023/24*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2023/04/06-nhs-standard-contract-sf-scs-2324.pdf>

<sup>5</sup> NHS (2024) *NHS Diagnostic Waiting Times and Activity Data*. Available at: [https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2024/05/DWTA-Report-March-2024\\_GL2TC.pdf](https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2024/05/DWTA-Report-March-2024_GL2TC.pdf)

diagnostic test within six weeks in line with the March 2025 ambition of 95%".<sup>6</sup> The most recent statistics show that the proportion of patients waiting six weeks or more has varied between 20.8% (February 2024) and 27.6% (April 2023). The 1% operational standard was last met in November 2013.

### At a glance: **Diagnosis in the NHS**

- The NHS spends about 6% of their budget on diagnostic activity – which is approximately £9.8 billion for 2023/24.
- An estimated 1.5 billion diagnostic tests are carried out every year.
- At the end of March 2024, there were 1,624,600 patients waiting for a key diagnostic test.
- The total number of patients waiting six weeks or more at the end of March 2024 was 354,900. This was 21.8% of the total number of patients waiting at the end of the month.
- At the end of March 2024, the CDC programme was delivering on 160 sites.

One of the key actions the Government has taken to address challenges around diagnosis is the launch of 40 Community Diagnostic Centres (CDCs) across England in 2021.<sup>7</sup> The Government has since pledged to open 160 sites by March 2025.<sup>8</sup> In February 2022, as part of the Elective Recovery Plan, NHSE pledged to increase capacity and offer around 17 million more diagnostic tests

<sup>6</sup> NHS (2023) *2023/24 priorities and operational planning guidance*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2022/12/PRN00021-23-24-priorities-and-operational-planning-guidance-v1.1.pdf>

<sup>7</sup> Merriel, S. W. D., Lee, L., Neal, R. (2021) *Community diagnostic centres: bringing diagnostics closer to home*. Available at: <https://bjgp.org/content/71/713/534#:~:text=In%20October%202021%2C%20NHS%20England,community%20diagnostic%20centres%20in%20England>

<sup>8</sup> Department of Health and Social Care (2023) *Government to deliver 160 community diagnostic centres a year early*. Available at: <https://www.gov.uk/government/news/government-to-deliver-160-community-diagnostic-centres-a-year-early>

over a three-year period. The rollout of further specialist diagnostic centres and a £2.3 billion investment to transform diagnostic services were also announced in a bid to permanently increase diagnostic capacity.

### At a glance: **Community Diagnostic Centres**

- There are currently 155 open CDCs in the UK, with five more set to open before March 2025.
- CDCs have delivered more than 7.5 million diagnostic tests between July 2021 and March 2024.

Despite the investment and ambition to improve diagnosis pathways, very little detailed work has been undertaken to understand people's experience of diagnosis pathways and CDCs. At National Voices, we believe understanding patient experience is fundamental to improving quality of care and addressing inequalities within care.

To better understand people's experiences and identify key priorities to improve patient experience of diagnosis across conditions and communities, we issued a call for insights from across our membership. We hope these insights will help health and care leaders understand the real-life concerns of people using the NHS during a time of immense pressure.

This report explores the challenges in diagnosis, the role of health inequalities in diagnosis, and new innovations. At the end of the report, we have outlined nine proposals which we believe would make a significant difference for people living with health conditions and disability, and in particular people from groups that experience health inequalities.



# Challenges in diagnosis

## The burden of patient advocacy

### Delays seeking help due to lack of awareness / stigma

Members told us that people often wait before seeking help with symptoms. This can be due to a lack of awareness of signs and symptoms of illness, stigma around certain symptoms or conditions, and lack of awareness around how to approach health services and/or where to go for diagnosis. These issues can be compounded for people from minoritised communities, people living in deprived communities and on low incomes, and people facing communication challenges.

For example:

- Alzheimer's Society told us that people who experience symptoms of dementia are often reluctant to come forward for help due to the stigma of the disease.
- Asthma + Lung UK told us that 36.1% of people diagnosed with COPD waited more than a year before seeking help with symptoms.<sup>9</sup> When asked about barriers to getting a COPD diagnosis 34% said that they did not know the symptoms.
- The Macular Society told us that professionals don't regularly share information about signs and symptoms with members of the public.
- Crohn and Colitis UK told us that people delay seeking help because they don't expect to be taken seriously, and often attempt self-treatment for their symptoms due to a combination of time pressures, fear of diagnosis and embarrassment.

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<sup>9</sup> Asthma + Lung UK (2022) *COPD in the UK*. Available at: <https://www.asthmaandlung.org.uk/sites/default/files/2023-03/delayed-diagnosis-unequal-care.pdf>

## Raising public awareness of signs and symptoms

Several members told us about effective work to raise awareness among members of the public about signs and symptoms of different conditions. These initiatives were often led by patient organisations, sometimes with NHS support.

For example, Alzheimer's Society told us that the Dementia Symptom Checklist it developed, endorsed by the Royal College of GPs, provides a foundation for people with dementia and their carers to speak about symptoms with a GP or health professional.

## People not being taken seriously

Many members told us that the people they worked with had their symptoms dismissed or not taken seriously by frontline professionals. In many cases people were told their physical symptoms had psychological causes. It can also be recognised that people not being taken seriously is often a symptom of wider cultural issues in the NHS which need to be addressed.

For example:

- Juvenile Arthritis Research told us of one eight-year-old child who waited five years for a diagnosis meaning over half their life was lived in pain and not knowing what was wrong. This was because their symptoms were repeatedly dismissed as being down to injury.
- The National Axial Spondyloarthritis Society told us people's symptoms were often dismissed as psychological rather than physical, and patients wanted to be believed and respected for their own knowledge of their body.
- Pulmonary Fibrosis UK shared this quotation - *"It took years for diagnosis because health professionals kept saying it was something else, even suggesting it might be psychosomatic."*
- Endometriosis UK highlighted the need for GPs and gynaecologists to take a more empathetic stance and to believe patients and take them

seriously. The charity shared the story of Natalie who has continuously not had her pain believed: *"I was diagnosed with stage 4 endometriosis three years ago. Diagnosis has been incredibly difficult, with GPs not believing my pain, or telling me it's "all in my head". I've had pains in my chest which could be indicative of thoracic endometriosis yet I am constantly told "I've got anxiety" or "It might be a panic attack". I know my own body, and I am a personal trainer, yet am constantly undermined and dismissed by healthcare practitioners."*

## Listening to the VCSE sector

Allergy UK told us that the work of patient organisations has led to improved access to information around allergies and allergic conditions among health professionals which in turn is increasing diagnosis with more diagnostic testing being undertaken in primary care.

## Poor administration

Members reported that individuals were impacted by administrative problems – including lost referrals, missing appointment notifications and poor information sharing. This meant that people who were seeking diagnosis were having to do a lot of administrative work to secure their diagnosis. This was more challenging for those who were digitally excluded, time-pressured, have learning disabilities or sensory impairments, or did not have good spoken and written English.

Specific communication challenges experienced by particular groups, as identified through work we did as part of our [Accessible and Inclusive Communication within Primary Care](#) report, would also need to be addressed in diagnostic pathways<sup>10</sup>:

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<sup>10</sup> National Voices (2023) *Accessible and inclusive communication within primary care: What matters to people with diverse communication needs*. Available at: <https://www.nationalvoices.org.uk/publication/accessible-and-inclusive-communication-within-primary-care-what/>

- **For D/deaf people:** Failure to meet communication needs – for example, failure to provide access to BSL interpretation for people reliant on BSL and assumptions that written communication is a substitute for interpretation (for many BSL users English is a second language). As another example, failure to support lip reading for people reliant on lip reading – by not communicating face-to-face, or using masks / communicating from behind barriers.
- **For people who do not speak English fluently:** Failure to provide access to language interpretation; often leading to reliance on family members to interpret, which in turn can lead to reluctance to disclose personal information vital to patient care. Failure to ensure effective interpreting, or in some cases matching people with a translator who speaks the wrong dialect. Often interpreters will interpret English jargon using the equivalent jargon, which in many cases doesn't help. Furthermore, for Roma people, often interpreters have their own negative views about communities, and this impacts the quality of the service.
- **For people experiencing homelessness and those who live nomadically:** Refusal to register or provide services to people without a fixed address / proof of address / identification, or communicating primarily by post to people with no fixed address. This is often also the case for people who live in precarious housing who can't procure proof of address or have landlords who do not allow use of the address.
- **For people with low or no literacy:** Failure to provide verbal explanations for written information or to support with form filling.
- **For digitally excluded people or people who prefer not to use digital services:** Lack of access to information and systems which are offered online e.g. text message, especially where links are included; and lack of choice around online versus telephone or in-person appointments; online only appointment systems. For some, failure to use technology in a way that includes carers where appropriate.
- **For people who have experienced educational inequalities:** Failure to explain information in a way that is understandable e.g., using formal language, or medical jargon.

## Stress and worry while waiting

Many members explained that long periods of waiting took a significant psychological toll, and that people usually faced these waits without any support from health professionals – indeed they often faced additional stress during these periods due to having to chase up appointments and request updates.

For example, Age UK shared a quotation from an older person who said *"I had to wait five months to see anyone for an eventual diagnosis of Meniere's Disease – four months waiting to get an audiology appt, followed by consultant appointment one month later to get diagnosis. Found this long period very distressing as I was in a lot of pain, plus not knowing what the problem was."*

For example:

- Diabetes UK's research with people with Type 2 diabetes found that people who recall being reassured by their healthcare professional and presented with a clear plan of action at diagnosis tend to have lower diabetes distress and better self-management 1 to 5 years later.<sup>11</sup>
- Research shared by the National Axial Spondyloarthritis Society found that patients wanted to experience a purposeful, consistent pathway of care underpinned by effective administration and communication, and for professionals to help them know what they could do to help themselves at home – *"help me make a plan"*.
- In an Age UK survey, 37% of those asked said shorter waiting times for diagnosis would change confidence in accessing NHS services.<sup>12</sup>

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<sup>11</sup> Diabetes UK (2024) *Chapter 3: Diabetes Distress*. Available at:

<https://www.diabetes.org.uk/for-professionals/improving-care/good-practice/psychological-care/emotional-health-professionals-guide/chapter-3-diabetes-distress>

<sup>12</sup> Age UK (2024) *We have to take it one day at a time*. Available at:

[https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health-wellbeing/we-have-to-take-it-one-day-at-a-time/age-uk\\_we-have-to-take-it-one-day-at-a-time.pdf](https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health-wellbeing/we-have-to-take-it-one-day-at-a-time/age-uk_we-have-to-take-it-one-day-at-a-time.pdf)

- Thomas Pocklington Trust shared a checklist of people's wants around diagnosis with sight loss (much of which could be generalised across all conditions). They found that people wanted to:
  - o Receive a sensitive diagnosis.
  - o Understand the next steps and how their condition will be treated and managed, what treatments are available, and that in some cases treatment may not be available.
  - o Know about research and any clinical trials which may be relevant to them.
  - o Be offered specific eye care information.
  - o Understand their eye condition and implications.
  - o Be able to participate in their chosen treatment options and understand if there is no available treatment for their condition.
  - o Be able to communicate their eye condition and how it affects their life to others.
  - o Know about genetic testing, if appropriate, and how to access testing.
  - o Be provided with information about Charles Bonnet syndrome, and other conditions linked to eye care needs and sight loss, and how it might affect them.
  - o Speak with an Eye Care Liaison Officer (ECLO) or be able to access support in person/remotely.
  - o Understand that the ophthalmic nursing team can provide
  - o information and support as part of their care.
  - o Know where to go and be able to access practical and emotional support and information.
  - o Know what local support is available.
  - o Know about low vision services, the Certificate of Vision Impairment (CVI) process and what other eye care services they may need to access in the future.

- o Know how to access psychological support e.g., counselling services.

We are concerned that growing elective waiting lists for both treatment and diagnosis are increasingly leaving people without support while waiting, with a resultant worsening not only in physical but also in mental health conditions, including the new onset of the latter. Linked to this is rising concerns about the lack of social support while waiting.

One person, interviewed as part of our [Patient Noun Adjective: understanding the experience of waiting for care report](#), had been suffering from Crohn's since June 2018. Following an MRI in August 2019 she then met her surgeon in October<sup>13</sup>. She was told that an operation would be her only option and that no other treatment would help at this stage. She was also told that the longer she would have to wait the worse her condition would get. At the time of the interview (approximately one year on), she had no date set. She said: *"I have waited years for a diagnosis. When I met the surgeon, he said it's urgent. I can't get hold of them. I have phoned everyone, there's a helpline run by nurses, but they say there's nothing they can do. I have been trying to keep busy, distract myself, but I am in terrible pain, I can't eat, I haven't slept, my muscles ache. They don't know what it's like to be me."*

Another participant shared: *"My daughter has been crippled by nine months of waiting for a diagnosis... (involving an A&E visit, emergency admissions and various consultations with specialists across different departments). She has lost over two stone ... and feels her life has come to an end. What we don't understand is the lengthy times between seeing anyone. It appears that you have to wait up to two months between moving on to another consultant's department. She has to wait 8-10 weeks to get a CT scan results and two months to see a pain management team."*

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<sup>13</sup> National Voices (2020) *Patient Noun Adjective: understanding the experience of waiting for care*. Available at: <https://www.nationalvoices.org.uk/publication/patient-noun-adjective-understanding-experience-waiting-care/>

## Unsympathetic treatment by professionals making diagnoses

Members explained that even once people had reached the point of diagnosis the challenges continued. Several members told us that people found that when told their diagnosis staff were unsympathetic and failed to take account of the impact of the news.

For example:

- Research by The Neurological Alliance<sup>14</sup> found that 31% of people said their diagnosis was not handled sensitively. They shared a quotation from one person who said: *"I had a three-minute appointment with a neurologist in a corridor and he told me I have [Functional Neurological Disorder] with no testing apart from an MRI scan. I asked him to explain the condition and he told me to Google it."*
- The Alzheimer's Society told us that people living with dementia reported a lack of empathy and sensitivity from GPs in speaking about diagnosis. In one example, a person living with dementia said that they were handed pills in the waiting room and told to "stop panicking," after which no follow up was provided, and they were left to understand the diagnosis and its effects on their own.
- Diabetes UK told us that people diagnosed with Type 2 diabetes often feel overwhelmed and ashamed when they are diagnosed. It shared a quotation: *"I don't feel like the way that I've been treated since my diagnosis has not been very warm, I guess. Like, they've not really acknowledged my feelings and emotions."*
- Diabetes UK shared that studies have found that rather than keeping diagnosis conversations short (which professionals often think is preferable to avoid overwhelm) patients want more information to facilitate self-management and feel empowered to take control of their condition<sup>15</sup>.

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<sup>14</sup> The Neurological Alliance (2022) *Together for the 1 in 6: UK Findings from My Neuro Survey*. Available at: <https://www.neural.org.uk/wp-content/uploads/2022/05/Together-for-the-1-in-6-UK-Findings-from-My-Neuro-Survey-v6.pdf>

<sup>15</sup> Pikkemaat, M., Boström, K. B., Strandberg, E. L., (2019) *"I have got diabetes!" - interviews of patients newly diagnosed with type 2 diabetes*. Available at: [https://www.researchgate.net/publication/333364979\\_I\\_have\\_got\\_diabetes\\_-\\_interviews\\_of\\_patients\\_newly\\_diagnosed\\_with\\_type\\_2\\_diabetes](https://www.researchgate.net/publication/333364979_I_have_got_diabetes_-_interviews_of_patients_newly_diagnosed_with_type_2_diabetes)



- Parkinson's UK told us that people's responses to receiving a diagnosis were often compounded by the way in which they were told. These experiences included a lack of eye contact from consultants, and being treated as a 'novelty' as they were much younger than the average age for diagnosis.
- Thomas Pocklington Trust shared quotations from people who had experienced sight loss. One person said: *"The specialist looked at me and said 'You'll go blind in four years', and then just walked out. I was stunned. I turned to my wife and said, 'Did he just say what I think he said?'"* Another said: *"I was told in no uncertain terms by the doctors, quite callously I thought... 'The sights gone in that eye. Cells have been damaged beyond repair, that's gone, forget that.' That's what was actually said to me."*
- Pulmonary Fibrosis UK told us that some people were not informed of their diagnosis and found out subsequently, by looking at their records in the NHS App or when asked to participate in a clinical trial. They shared a quotation from one person who said: *"They left a message on my phone, it was an almighty shock. Left me in a dreadful state, I fell apart. I didn't get any support at all, appalling."*

## Enabling support around diagnosis

Several members mentioned that it made a difference when people were able to bring someone with them to support them at the point of diagnosis. For example, in the NHS National Cancer Patient Experience Survey 2022, 76% of patients said they had been given the option of having a family member, carer or friend with them when they were first told they had cancer.

Action for Pulmonary Fibrosis told us that their research had found people wanted to receive their diagnosis face-to-face from a healthcare professional trained in breaking bad news sensitively, along with a nurse or other healthcare professional to ask about the diagnosis and digest what is usually a terrible shock. People also wanted a written plan of what will happen next.

## Staffing gaps in knowledge and capacity

### Access to specialist professionals at point of diagnosis

Some members told us about examples of specialist services improving the experience of patients at the point of diagnosis. For example, Pulmonary Fibrosis UK told us that where people had access to a specialist nurse at the time of diagnosis, they had been given plenty of information and support. Nurses and other healthcare professionals such as specialist pharmacists are often able to spend more time with them than the consultants explaining the disease process and their individual needs.

### A postcode lottery in diagnosis

Several members highlighted significant geographic variations in access to diagnostic services and they wanted to see improved planning, funding, and commissioning at the local level to address these geographical disparities. It is recognised that to underpin improved commissioning, ICBs need to have relevant diagnosis data available comparable to ICB level to understand how they fare against similar geographies.

For example:

- Alzheimer's Society research (Alzheimer's Society (2023) *Raising the Barriers: An action plan to tackle regional variations in dementia diagnosis in England*) revealed significant geographical variation in access to services.<sup>16</sup> As of January 2024, the latest data from NHS England shows a 21-percentage point variation in diagnoses rates between South Yorkshire at 74.7%, England's highest performing Integrated Care Board (ICB), and Herefordshire and Worcestershire at 53.7%, England's worst performing ICB<sup>17</sup>.

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<sup>16</sup> Alzheimer's UK (2023) *Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England*. Available at:

<https://www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf>

<sup>17</sup> NHS England (2024) *Primary Care Dementia Data*. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data>

- Dementia UK also highlighted that dementia diagnosis rates vary between local authorities in England from 88.9% to 49.3%. Factors such as rurality and deprivation can affect dementia diagnosis rates, but the vast majority of variation is not explained by either factor<sup>18</sup>.
- Myaware (supporting people affected by myasthenia, a group of rare neuromuscular conditions), told us that patients who do not live near a specialist neurologist will undoubtedly experience a longer time to diagnosis.

## Lack of awareness among GPs

Several members – particularly those working with people with rarer conditions – told us that lack of awareness of their condition among GPs was a major barrier to diagnosis, leading to unhelpful referrals and missed symptoms. For example, the National Axial Spondyloarthritis Society told us that most GPs have not heard of the condition, while Endometriosis UK told us that people were often wrongly referred by GPs, often to someone other than a gynaecologist.

Compounding this lack of knowledge is a perceived lack of specialist diagnostic staff, Allergy UK told us that a lack of allergy specialists and a lack of funding to train more had meant that referral waiting times were now typically between 6 months and 2 years. Short staffing, alongside NHS staff strikes witnessed through 2023 into 2024 have caused delays before and after diagnosis too. Age UK shared a quotation from an older person: *"Had surgery then radiotherapy for breast cancer, long wait from diagnosis (January) to operation (May) due to short staffed, plus strikes"*.

The impact of the public perceptions surrounding strikes should also be recognised in relation to diagnosis. In 2023, Healthwatch found that 15% of people surveyed in their research were told that their care was postponed due to

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<sup>18</sup> The Independent (2023) *Hundreds of thousands of dementia sufferers still undiagnosed as targets missed for third year running*. Available at: <https://www.independent.co.uk/news/uk/home-news/dementia-diagnosis-rates-nhs-undiagnosed-b2444416.html>

strikes<sup>19</sup>. However, a further 24% believed that 'strike action was the reason for the cancellation – even though NHS services had not told them this'<sup>20</sup>.

In September 2022, NHS England asked the Academy of Medical Royal Colleges to review how to reduce unnecessary work on the interface between general practice and NHS trusts. Its report was published alongside NHS England's primary care recovery plan in May 2023<sup>21</sup>. Part of this plan is to develop clear points of contact between general practice and secondary care teams to allow them to communicate rapidly on issues such as advice and guidance or referrals. As GPs are by training generalists, this plan could improve the advice GPs can secure on conditions they are less familiar with, but it does not address the concerns around lack of specialist diagnosis staff. It should also be recognised that whilst advice and guidance helps in reducing waiting times, it may also cause some patients to feel excluded from discussions surrounding their health and care.

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<sup>19</sup> Healthwatch (2023) *Delays to NHS care: Understanding the impact*. Available at: <https://www.healthwatch.co.uk/report/2023-07-27/delays-nhs-care-understanding-impact>

<sup>20</sup> The Kings Fund (2024) *Counting the cost of NHS strikes*. Available at: [https://www.kingsfund.org.uk/insight-and-analysis/blogs/counting-cost-nhs-strikes#:~:text=The%20impact%20on%20public%20perceptions,-An%20even%20more&text=For%20example%2C%20in%20Healthwatch's%20research,this'%20\(Figure%203\).](https://www.kingsfund.org.uk/insight-and-analysis/blogs/counting-cost-nhs-strikes#:~:text=The%20impact%20on%20public%20perceptions,-An%20even%20more&text=For%20example%2C%20in%20Healthwatch's%20research,this'%20(Figure%203).)

<sup>21</sup> NHS England (2023) *Delivery plan for recovering access to primary care*. Available at: <https://www.england.nhs.uk/long-read/delivery-plan-for-recovering-access-to-primary-care-2/#cutting-bureaucracy>

## Access to specialist diagnostic services

Some members told us about examples of specialist services improving the diagnosis pathway.

Bristol Dementia Wellbeing service provides support to people with dementia during and after the diagnosis process, delivering a high diagnosis rate of 71.4% as of December 2023. The service is delivered by the Bristol Dementia Partnership (an Alzheimer's Society and Devon Partnership NHS Trust collaboration) and brings together partners across Bristol to create personalised wellbeing plans for service users.

Every GP Practice in Bristol has a named Dementia Practitioner and Dementia Navigator. The Dementia Practitioners support people with memory problems and possible dementia by providing Specialist Memory Service to aid early diagnosis. The Dementia Navigator supports people with a dementia diagnosis and their carers by working in a person-centric way to maintain the independence of people with dementia. The Navigators also signpost people to agencies and provide practical and emotional support and guidance. In this way, services to support people with dementia are made available as early as possible and remain present for as long as needed.

## Multiple conditions and misdiagnosis

Several members highlighted the additional challenges faced by people with multiple conditions in getting diagnoses. In some cases, aspects of their conditions may mask other symptoms, in other cases living with a long-term condition created practical barriers to accessing diagnostic services.

Diagnostic pathways tend to be organised around individual conditions, rather than being aligned to the needs of people who may have multiple diagnoses. Similarly, disabled people can face barriers to diagnosis – as noted in the discussion on inequalities.

Several members also told us that people have often been misdiagnosed initially, sometimes linked to the rarity of the condition, leading to delays in getting the right diagnosis and treatment.

For example:

- Rethink Mental Illness told us they had qualitative insights which established a significant theme surrounding people in inpatient settings not receiving a definite diagnosis, especially where people are being considered for a diagnosis of personality disorder.
- Crohn's & Colitis UK told us that nearly a third (29%) of people diagnosed with Crohn's or Colitis had either been previously diagnosed with irritable bowel syndrome or been prescribed antispasmodic drugs prior to their diagnosis. The average time between having a diagnosis of irritable bowel syndrome (IBS) and the diagnosis of inflammatory bowel disease (IBD) was 5.5 years.<sup>22</sup>
- Blood Cancer UK told us that blood cancers were often misdiagnosed initially. Some symptoms of blood cancer include breathlessness, a fever, and tiredness, which may be misdiagnosed as flu or similar<sup>23</sup>.
- Pulmonary Fibrosis UK told us people are often diagnosed with asthma, COPD and other conditions before getting a correct diagnosis, meaning diagnosis often takes many years.
- Research by Incisive Health showed that the average person with a rare disease receives three misdiagnoses and speaks to five doctors before receiving their correct diagnosis and that diagnosis of a rare disease takes an average of over four years<sup>24</sup>.
- Juvenile Arthritis Research highlighted that co-morbidities can make it harder to diagnose Juvenile Idiopathic Arthritis (JIA) and doctors need to listen to patients better and trust parent's gut instincts. It said this can be particularly important where JIA goes along with Down Syndrome which may impact the patient's ability to articulate their symptoms.

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<sup>22</sup> Crohn's & Colitis (2024) *Back our call for early diagnosis*. Available at: [https://crohnsandcolitis.org.uk/media/xykeyq00/crohns-colitis-uk-early-diagnosis-policy-paper\\_final.pdf](https://crohnsandcolitis.org.uk/media/xykeyq00/crohns-colitis-uk-early-diagnosis-policy-paper_final.pdf)

<sup>23</sup> Blood Cancer UK (2021) *Fears blood cancer cases are being missed, as more than half of Brits can't name symptoms*. Available at: <https://bloodcancer.org.uk/news/fears-blood-cancer-cases-are-being-missed-as-more-than-half-of-brits-cant-name-symptoms/>

<sup>24</sup> Specialised Healthcare Alliance (2023) *Navigating the labyrinth: reducing delays to a rare disease diagnosis*. Available at: <https://shca.info/wp-content/uploads/2023/06/Navigating-the-labyrinth-SHCA-report.pdf>

Many members described very long periods of trying to get a diagnosis – several members reported taking 10 or more years on average to get a diagnosis – during which patients experienced complex routes to diagnosis, often linked to multimorbidity or misdiagnosis. These often involved multiple referrals to different professionals, all of which came with delays and saw patients having to chase appointments and push for referrals.

For example, research by the National Axial Spondyloarthritis Society found that, among those diagnosed with the condition, the period of life prior to, and when seeking, a diagnosis was often long and drawn out. They went through various stages on their route to diagnosis, but progress through these was not always linear and the route through did not feel logical, predictable or even tangible, except in hindsight. This meant that diagnosis could take a number of years.


Many members told us that people were increasingly feeling forced to pay to see different professionals in order to reduce delays in their diagnosis. This, inevitably, meant that people on lower incomes were waiting longer.

### Multidisciplinary working

Some members reported that multidisciplinary working between health professionals could support diagnosis of people with complex or rare conditions. Myaware (Myasthenia) told us it works well when multidisciplinary teams are involved in diagnosis and care.

### Challenges in getting an appointment (especially face to face)

Members told us that getting an appointment with a GP was a major barrier to diagnosis. People faced a range of challenges in getting an appointment including having to telephone at particular times or use unfamiliar online systems. Several members told us that the people they worked with were reluctant to discuss symptoms over the phone or online and that people often delayed going to the doctor as they were unable to see someone face to face. NHSE's Primary Care Recovery Plan led to this shift to online requests to see a primary care team. It was created to reduce the rush for 8am appointments, which does not prioritise based on clinical need, and pushes to free up



telephone lines for those who cannot manage online access. We have heard concerns from members that some receptionists are not using their discretion when making GP appointments over the phone, incorrectly applying a blanket policy to ask everyone to book online regardless of ability, or extenuating circumstances. People who struggle with online booking tend to be facing greater health inequalities or have one or more protected characteristic.

For example:

- An older person who spoke to Age UK said - *"It is impossible to get a doctors appointment, it seems you have to go online and it feels to me a form of self-diagnosis."*
- Another older person who spoke to Age UK said - *"Seeking a diagnosis of my arthritis. I was able to be referred for an x-ray. I had to push quite hard for a face-to-face GP appointment but did eventually see my GP."*
- Cancer Research UK told us that concerns about remote consultations were a barrier to diagnosis

## Diagnosis and beyond

### Impacts of delayed diagnosis

Members shared a range of insights into the negative impacts of delayed diagnosis. These included reducing the period in which people can get to grips with their symptoms and treatments and conditions progressing past the point at which treatment can be effective. Not only is this a heart-breaking loss for the individual but compounds NHS costs of treatment as often people need specialist support or treatment for longer periods of their life as a result.

For example:

- Most dementia medication is only effective in the early stages of the disease.
- Where allergy diagnosis for babies is delayed, the period in which reintroduction is possible can be missed.



- People experiencing stroke need access to a brain scan within an hour of arrival in hospital otherwise access to time-sensitive treatments can be impossible, increasing the risk of long-term disability.
- Late diagnosis significantly reduces the survivability of cancers like pancreatic cancer.

## Lack of information at point of diagnosis

Members told us that many people came away from appointments at which they were diagnosed without enough information to understand or manage their condition. Many members reported that healthcare professionals sharing diagnoses rarely made referrals to specialist charities or other sources of support.

For example:

- Allergy UK told us that many people diagnosed with allergies were not given information about the severity of their disease.
- Alzheimer’s Society told us that less than 2% of people living with dementia get the advanced diagnostic tests needed to get an accurate subtype diagnosis<sup>25</sup>. This would make it more difficult to access appropriate medication that may become available.
- Compassion in Dying told us that people diagnosed with terminal illnesses often came away lacking confidence around their diagnosis and the support available.<sup>26</sup>
- A survey by Asthma + Lung UK found that 63.4% of people said they did not feel fully prepared to manage their condition after diagnosis.<sup>27</sup>

<sup>25</sup> Alzheimer’s Society (2024) *UK comes a step closer to blood tests for diagnosing dementia*. Available at: <https://www.alzheimers.org.uk/news/2024-04-04/uk-comes-step-closer-blood-tests-diagnosing-dementia#:~:text=At%20the%20moment%20only%20,at%20Alzheimer's%20Research%20UK%2C%20said>

<sup>26</sup> Compassion in Dying (2023) *Peer support, power and personalisation*. Available at: <https://compassionindying.org.uk/resource/peer-support-power-personalisation/>

<sup>27</sup> Asthma + Lung UK (2022) *COPD in the UK*. Available at: <https://www.asthmaandlung.org.uk/sites/default/files/2023-03/delayed-diagnosis-unequal-care.pdf>

- Blood Cancer UK told us that people with blood cancers were less likely to fully understand their conditions after diagnosis than people with other cancers.
- Diabetes UK told us that people diagnosed with Type 2 diabetes often had to seek out additional information from friends or other source after their diagnosis to understand their condition.
- A study by Endometriosis UK of diagnosis in Scotland found 75% of patients did not receive any written information on diagnosis. Of those that did, only a minority of patients were satisfied with the information they were provided with (17%,) whereas over half (56%) were either 'very dissatisfied' or 'dissatisfied'<sup>28</sup>.
- Research shared by the Macular Society found that while healthcare professionals reported that they usually shared information at the point of diagnosis, patients do not recall receiving this information.
- Pulmonary Fibrosis UK told us that where written information was provided to patients, it was difficult to understand due to complex terminology and abbreviations.
- Endometriosis UK shared a quotation: *"After I was diagnosed with endometriosis, no information was provided. I was told to just go on the [contraception] pill with no further information about other treatments."*
- Parkinson's UK reported a range of worrying experiences including:
  - Being given a prescription for medication without any explanation or discussion about what it was, what it would do and any side effects
  - Leaving the appointment without an understanding of whether they had Parkinson's or not.

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<sup>28</sup> Endometriosis UK (2024) *"Dismissed, ignored and belittled" The long road to endometriosis diagnosis in the UK*. Available at: <https://www.endometriosis-uk.org/sites/default/files/2024-03/Endometriosis%20UK%20diagnosis%20survey%202023%20report%20March.pdf>

## Need for a clear plan

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 their stress and enabling people to cope with their conditions better.

For example:

- Diabetes UK research with people with Type 2 diabetes found that people who recall being reassured by their healthcare professional and presented with a clear plan of action at diagnosis tend to have lower diabetes distress and better self-management one to five years later.
- Research shared by the National Axial Spondyloarthritis Society found that patients wanted to experience a purposeful, consistent pathway of care underpinned by effective administration and communication, and for professionals to help them know what they could do to help themselves at home – *"help me make a plan"*.
- Thomas Pocklington Trust shared a checklist of people's wants around diagnosis with sight loss, much of which could be generalised across all conditions. They found that people wanted to:
  - Receive a sensitive diagnosis, with specific information on care, condition and implications, and how to explain it to other people in their lives
  - Be able to participate in their chosen treatment options, or understand if none are available, including knowing about clinical trials and research
  - Know about genetic testing, if appropriate, and how to access testing
  - Know where to go and be able to access practical and emotional support and information, such as via a nursing team, primary care team support, psychological services, social care etc.

## Lack of support following diagnosis

While this report is focused on diagnosis itself, one of the most commonly reported concerns by members was the failure to provide people who had been newly diagnosed with a condition with ongoing support in managing their condition and coping with the physical, psychological and practical impacts of diagnosis. National Voices recognises more work must be done in this important area especially around the additional impact of health inequalities and multiple health conditions.


### Supportive professionals

Members told us that professionals working in a supportive way “on the patient’s side” could make a huge difference in diagnosis.

For example, Parkinson’s UK shared an example of a patient whose consultant had worked hard to support them to take a positive approach to their illness, and in that paved the way for acceptance to begin at diagnosis. The person’s consultant had told her she had Parkinson’s, and then immediately said ‘That’s the worst thing I’m going to tell you today. It all gets better from here. There’s lots we can do.’ As the person explained, “Within 10 minutes he had me on a positive way of thinking.”

Our members gave us several insights into the direction this work could take with a clear focus on how to stop people being left feeling they are alone in their diagnosis. For example:

- Allergy UK told us that people were rarely offered ongoing support following diagnosis, and this was particularly the case for those diagnosed through patch testing.
- Alzheimer’s Society and Dementia UK told us that people were often discharged from memory clinics following diagnosis without a clear plan of ongoing support. People were therefore left to cope alone with fragmented post diagnostic support and poor signposting to formal support channels.
- Diabetes UK told us that there is usually a gap after diagnosis with Type 2 Diabetes of around six months when people aren’t receiving



any care or support where people are left to cope alone. One person quoted said: *"I feel like I've been let down by the NHS since my diabetes diagnosis. I've just kind of been left to it."*

- Diabetes UK told us that options for after care were often provided online, leaving them inaccessible to some. One person said: *"Everything's online and it's impossible to access it. I don't have good internet access or really know how to use it."*
- Thomas Pocklington Trust shared a quotation from a person affected by sight loss: *"I didn't get told anything that was available, any support, when I was diagnosed. It's only because I had a friend who worked for one of the local charities for the blind that I found out anything at all."*

# Inequalities in diagnosis

Members highlighted a range of data that demonstrated additional disadvantages faced by some groups in accessing diagnostic services and the inequalities in their diagnosis experience.

## Ethnicity

Members across a wide range of conditions highlighted the significant disparities in rates, and experiences, of diagnosis among people from minority ethnic communities.

Several members highlighted the significant barriers to diagnosis caused by failure to provide appropriate communication support, as well as feeling not listened to by healthcare professionals.

Members wanted to see improved access to interpretation services and communication support, such as translated materials. They also recognised the need to address other practical barriers, such as providing more culturally appropriate services and the need to address bias and discrimination, especially by working through trusted community organisations to break down such barriers.

For example:

- Blood Cancer UK told us about that people from ethnic minority communities report facing higher barriers and longer delays to diagnosis – they are four times more likely to experience delays in referral for a blood cancer diagnosis and 45% of blood cancer respondents from ethnic minority communities visit their GP three or more times before referral for testing.<sup>29</sup>
- Compassion in Dying shared findings from their report, *Advance Care Planning with people from South Asian Communities*, which found that obtaining information and understanding new diagnoses was

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<sup>29</sup> Blood Cancer UK (2024) *Because people are less likely to be diagnosed quickly*. Available at: <https://bloodcancer.org.uk/about-us/current-projects-and-campaigns/raising-the-profile-of-blood-cancer/because-people-are-less-likely-to-be-diagnosed-quickly/>

challenging for people from South Asian Communities<sup>30</sup>. Some felt it was impossible to see a doctor, access translators or get information in their own language. Many people said they had no faith that the healthcare system would meet their needs after a diagnosis.

- Dementia UK told us that Black people and those of South Asian heritage have increased risk of developing dementia but are less likely to receive a timely diagnosis and are more likely to die younger and sooner after diagnosis compared to white people with dementia<sup>31 32</sup>. The latter group are also more likely to face barriers including late or missed diagnosis, reduced access to treatments, and inappropriate or inadequate support coupled with problems caused by language barriers<sup>33</sup>.
- Endometriosis UK shared a quotation from a woman of colour who said: *"Even now I have had my diagnosis, I still feel I am fighting to be heard for my pain to be taken seriously. A lot of women of colour who I know, who have gone to A&E with endometriosis symptoms, or even diagnosed endometriosis, they have been told to have CBT therapy instead. It seems that we constantly have to justify our pain and fight for a diagnosis and support."*
- Juvenile Arthritis Research told us that people from minority ethnic communities were less likely to be listened to or taken seriously.
- Yorkshire Cancer Community told us there was anecdotal evidence that GPs don't take the concerns of South Asian women seriously, leading women to be more worried about going to the GP.
- Cancer Research UK told us people from an ethnic minority background are more likely to be diagnosed at a later stage than white people. They

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<sup>30</sup> Compassion in Dying (2023) *Advance Care Planning with people from South Asian Communities*. Available at: <https://compassionindying.org.uk/resource/advance-care-planning-south-asian-communities/>

<sup>31</sup> UCL (2018) *Likelihood of dementia higher among black ethnic groups*. Available at: <https://www.ucl.ac.uk/news/2018/aug/likelihood-dementia-higher-among-black-ethnic-groups>

<sup>32</sup> UCL (2022) *Dementia rates over 20% higher among black adults than UK average*. Available at: <https://www.ucl.ac.uk/news/2022/sep/dementia-rates-over-20-higher-among-black-adults-uk-average>

<sup>33</sup> Race Equality Foundation (2022) *New toolkit launched to improve dementia care for South Asian people*. Available at: <https://raceequalityfoundation.org.uk/press-release/new-toolkit-launched-to-improve-dementia-care-for-south-asian-people/>

also found that white people are more likely than those from an ethnic minority background to identify lumps or blood in poo as symptoms of cancer.

- Crohn's & Colitis UK told us that consultations and endoscopies can be very difficult experiences for patients, especially when they do not speak English. People who are non-English speaking are also less likely to get the information they need to manage their care.
- Alzheimer's Society told us that language barriers experienced by patients posed a hindrance to receiving a proper diagnosis<sup>34</sup>.

## Age

Several members reported disparities based on age, with youth often being aligned with misdiagnosis or dismissal of symptoms

For example:

- Research for the National Axial Spondyloarthritis (an inflammatory arthritis where the main symptom is back pain) Society found that some participants believed that, because they were young, they were not taken seriously by the GP who would often resort to stereotypical or stigmatising explanations. Young women felt they were more likely to be judged if they became upset during appointments and that this could exacerbate a tendency to offer a mental health rather than physical diagnosis.
- Endometriosis UK shared quotations from young people:
  - *"My age was held against me. I was 14 when my symptoms started, and I was told I would grow out of them. It was only when I had trouble conceiving that endometriosis was investigated".*
  - *"I was 14 was when I started seeing the doctors about my period pain, and was told that some women or some girls have more*

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<sup>34</sup> Alzheimer's Society UK (2023) *Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland*. Available at: <https://www.alzheimers.org.uk/about-us/policy-and-influencing/improving-access-timely-accurate-diagnosis-dementia-england-wales-northern-ireland>



*painful periods than others, and that's it. The thing is, at a vulnerable age when you're 14 you don't question a doctor, or you don't question what you're told ... I didn't have the confidence to go back to the doctor and ask any questions, nor did I even want to be put in that situation. It's just like you've been told so many times, why am I going to waste my time waiting at the doctors to then be told this is normal.'*

- Diabetes UK told us that Type 2 Diabetes diagnosis given at a younger age has been linked with a higher level of emotional distress. Younger patients were also more likely to be dissatisfied with their care if the healthcare professional did not present and discuss suitable treatment options at diagnosis.
- Dementia UK told us that young onset dementia was often misdiagnosed as other conditions.
- Blood Cancer UK shared research showing that older people had more knowledge of signs and symptoms of blood cancer<sup>35</sup>.

## Gender

Several members highlighted difference in the experience of diagnosis related to gender with relation to how they coped with a diagnosis, as well as knowledge of health conditions.

For example:

- Diabetes UK highlighted that in their research on diagnosis of Type 2 diabetes women were more likely to turn inward and experience feelings of shame and self-loathing after diagnosis. For some, a complex mixture of shame, judgement and anxiety are all apparent.

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<sup>35</sup> Boswell, L., Harris, J., Ip, A. et al. (2023) *Assessing awareness of blood cancer symptoms and barriers to symptomatic presentation: measure development and results from a population survey in the UK*. Available at: <https://doi.org/10.1186/s12885-023-11149-x>

## Learning disabilities

Some members highlighted that people with learning disabilities could be particularly disadvantaged in diagnosis, especially due to diagnostic overshadowing (when symptoms of physical ill health are wrongly ascribed to someone's mental health<sup>36</sup>) making some healthcare professionals dismissive of new symptoms.

- Juvenile Arthritis Research highlighted that people with learning disabilities could face particular barriers to getting a diagnosis.
- Dementia UK told us that it is difficult to diagnose those with learning difficulties with dementia due to 'diagnostic overshadowing', stigma, and memory clinics not accepting referrals<sup>37</sup>.
- Health and Wellbeing Alliance members also shared challenges around diagnostic overshadowing which meant that for people with learning disabilities and autistic people, assumptions are sometimes made that it is their disability which is affecting their mental health and wellbeing, rather than an additional organic condition.

## Barriers for carers

Carers UK highlighted the significant additional barriers to diagnosis faced by carers. It said it can be difficult for carers to seek help with their own health conditions due to lack of time, with carers feeling they don't have time to prioritise themselves and get help for medical conditions. It is also difficult for carers to make appointments in the first place, with for example some GP surgeries operating a first-come-first-served system that is not helpful for carers who spend the first part of the day washing and dressing the person they care for. However, it was recognised that the Primary Care Recovery Plan, with its focused on removing the 8am rush for appointments, may address the latter concern. Providing more adjustments to diagnosis pathways to facilitate carers was seen as a priority.

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<sup>36</sup> RCN Magazine (2018) *All you see isn't all there is*. Available at: <https://www.rcn.org.uk/magazines/Bulletin/2018/May/Overshadowing>

<sup>37</sup> Javaid, A., Nakata, V., Dasari, M., (2019) *Diagnostic overshadowing in learning disability: think beyond the disability*. Available at: <https://wchh.onlinelibrary.wiley.com/doi/10.1002/pnp.531>

The most recent survey State of Caring 2023 found that:

- 44% of carers said they had put off health treatment because of their caring role<sup>38</sup>.
- 42% of carers said they needed more support from the NHS or healthcare professionals.

Carer quotes included:

*"I have put off seeking medical advice regarding personal medical issues. I worry about needing treatment and not being able to carry out my caring duties."*

*"I can't seem able to get the time to make GP appointments or anything like that for me without having to cancel them at short notice due to having to suddenly travel to assist my daughter so I simply no longer try."*

*"I am unable to sit for hours in the morning on the phone and then wait for a call back. Then drop everything to go to an appointment. GP will not make reasonable adjustments for carers."*

## Income inequality

Several members highlighted significant inequalities in the experience and rates of diagnosis based on socioeconomic status. Members highlighted the links between low income and living in poorly served communities, and also the cost of accessing diagnostic services.

Several members also highlighted the growing inequality resulting from growing waiting lists, which has created a gap between those who can pay for private diagnoses and those who cannot.

For example:

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<sup>38</sup> Carers UK (2023) State of Caring survey. Available at: <https://www.carersuk.org/policy-and-research/state-of-caring-survey/>

- Prostate Cancer UK told us that men from socioeconomically deprived areas were more likely to be diagnosed too late for a cure.
- The National Axial Spondyloarthritis Society told us that groups that were most likely to have had negative experiences on their journeys with axial spondyloarthritis (an inflammatory arthritis where the main symptom is back pain) were those on lower incomes, as well as women, younger people, and people with more recent diagnoses.
- Juvenile Arthritis Research highlighted the cost of getting to appointments as a significant issue.
- Cancer Research UK highlighted that people from more deprived populations in England are more likely to be diagnosed with advanced cancers<sup>39</sup>.
- Thomas Pocklington Trust shared the story of Mrs D, 88 from Liverpool, who attends Aintree Eye hospital for her various eye conditions. She has had to attend on occasion to have new symptoms diagnosed. The round trip in a private hire taxi is in excess of £50. It is not feasible to use public transport for this journey and Mrs D has not been offered any support with the costs or any physical support. She could have taken advantage of the free Northwest Ambulance Transport service but was never told about this. Not only is this service free, but Mrs D would have the support of a trained person to guide her to the vehicle and then take her into the hospital to the actual clinic. This also reduces stress and anxiety. To remedy this, the appointment service should be able to identify those patients who need financial and practical support and offer solutions. This also has the advantage of reducing 'Did Not Attend' (DNAs).

## Lack of reasonable adjustments

Members highlighted examples of failures to make adjustments to diagnostic services for people with disabilities.

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<sup>39</sup> Cancer Research UK (2023) Health inequalities: Improving early cancer diagnosis for everyone. Available at: <https://news.cancerresearchuk.org/2023/11/23/health-inequalities-early-cancer-diagnosis/>

For example:

- Thomas Pocklington Trust told us about the challenges people with sight loss experience when accessing Bowel Cancer Screening because the current home testing kit for bowel cancer is not suitable for those with low vision and/or dexterity problems (Arthritis, Dupuytren's etc).
- In February 2023 our member, 'Sex With a Difference' (SWAD) launched a two-year disability access campaign, *Better Access for Better Access*<sup>40</sup>. The campaign goal is to have at least one hoisting system and a set of leg supports on an examination couch, in every sexual health clinic and GP surgery in the UK, by the end of 2024, to enable people with disabilities to access smear tests, prostate cancer tests and other diagnosis tests. SWAD told us some people have had prostate cancer tests whilst kneeling on the floor of a GP surgery, as they were unable to get onto the couch. Another person was three years late in having a smear test as an accessible couch was not available to them.

## Digital exclusion

Several members highlighted the additional challenges faced by people who are digitally excluded when accessing diagnostic services, often linked to inequalities such as age, capability and poverty. These challenges included difficulties booking appointments, reduced access to appointments which may be offered remotely, and less access to information following diagnosis.

For example:

- Cancer Research UK shared research which showed that some people don't have access to the technology needed for remote consultations<sup>41</sup>.

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<sup>40</sup> SWAD (2023) Better Access for Better Access Campaign. Available at:

<https://www.swaddorset.org/better-access-for-better-access-campaign/>

<sup>41</sup> Cancer Research UK (2023) Health inequalities: Improving early cancer diagnosis for everyone. Available at: <https://news.cancerresearchuk.org/2023/11/23/health-inequalities-early-cancer-diagnosis/>

- Research by BT Group found that at least 10% of households in the UK do not have a broadband connection<sup>42</sup>.
  - The largest cohort of these digitally excluded individuals are older people, with 90% of those without a broadband connect being over 55 years old.
  - 6% of households in the UK are finding it difficult to afford a broadband connection.
- As part of a previous report on remote consultations, '[The Dr Will Zoom You Now](#)', we heard from people with lived experience. One participant shared that it would be useful for patients to be able to upskill in order to be able to make the most of digital service provision: *"I would suggest training be made available to the patients to enable them to use whatever equipment they have. This could be undertaken by technically savvy volunteers."*<sup>43</sup>
- In some situations, even though someone might have access to digital technology, they may not be able to navigate the NHS App or other online services in order to find out more about accessing diagnostic services or even their appointment details. One person, as part of the '[Unlocking the digital front door](#)' project, said: *"I could not complete an online form, I couldn't do it, I wouldn't know how to access the app in the first place or how to put an app on an iPad, I wouldn't know where to start. I seem to get in a muddle but if I had to do something out the ordinary i.e. access and fill in an online form, I wouldn't be able to do it."*<sup>44</sup>

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<sup>42</sup> BT Group (2023) *Written evidence to the House of Lords Communications and Digital Select Committee inquiry 'Digital exclusion and the cost of living*. Available at: <https://committees.parliament.uk/writtenevidence/118868/pdf/>

<sup>43</sup> National Voices (2020) *The Doctor Will Zoom You Now*. Available at: [https://s42139.pcdn.co/wp-content/uploads/the\\_dr\\_will\\_zoom\\_you\\_now\\_-\\_insights\\_report\\_min.pdf](https://s42139.pcdn.co/wp-content/uploads/the_dr_will_zoom_you_now_-_insights_report_min.pdf)

<sup>44</sup> National Voices (2021) *Unlocking the digital front door*. Available at: [https://s42139.pcdn.co/wp-content/uploads/unlocking\\_the\\_digital\\_front\\_door\\_-\\_keys\\_to\\_inclusive\\_healthcare\\_report.pdf](https://s42139.pcdn.co/wp-content/uploads/unlocking_the_digital_front_door_-_keys_to_inclusive_healthcare_report.pdf)

# New innovations in diagnosis

## Roll-out of Community Diagnostic Centres

Members had very limited insight to offer on the roll out of Community Diagnostic Centres. The majority of members told us that they did not expect the people with whom they worked to benefit from Community Diagnostic Centres as they did not offer services relevant to the diagnosis of the conditions on which they worked, and / or did not include the specialist staff needed to support diagnosis.

For example, Allergy UK told us allergy is not benefitting from the roll out of Community Diagnostic Centres because you need the expertise from a health care professional experienced in allergy to interpret the patient result alongside the patient medical history.

Some members also had concerns about the lack of access to specialists within the settings where tests were undertaken. Thomas Pocklington Trust told us they are concerned that the increasing use of diagnostic hubs, where there are only technicians on hand, may result in patients being left with questions about their condition that would in the past have been answered by doctors following the diagnostic tests at the same appointment.

The APPG for Diagnostics report, *CDCs Unveiled: Challenges & Triumphs. An Inquiry into Community Diagnostic Centres*, explains that progress on rolling out CDCs is slow and that while more are now being located outside of hospital settings, there are still concerns about securing access for the most deprived communities<sup>45</sup>. The report also highlights a need for the scans and tests available in each site to be tailored to the health needs of the local population, alongside concerns around workforce.

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<sup>45</sup> All-Party Parliamentary Group for Diagnostics (2024) *CDCs Unveiled: Challenges & Triumphs An Inquiry into Community Diagnostic Centres*. Available at: <https://www.rcr.ac.uk/media/kiknoh1o/cdcs-unveiled-challenges-and-triumphs.pdf>

## The role of AI in diagnostics

Members had relatively limited insight to share around the use of AI in diagnostics. The key message emphasised by most members was that the development and use of AI needs to align with people's priorities, rather than being led by the tech industry and/or the drive for cost savings. Members also highlighted the need to address bias inherent in current AI and algorithms and for robust protections around people's data.

For example, we are conscious of historical concerns around the unequal roll out of technology, most recently highlighted through the COVID-19 pandemic. It was found that pulse oximetry meters often result in inaccurate readings in Black people<sup>46</sup> and this may be one reason why Black people fared worse with Covid than white people as health professionals were basing treatment decisions on inaccurate readings.

We also aware of concerns that AI wasn't picking up breast cancer effectively amongst black women because of physiological differences in breasts compared to white women<sup>47</sup>.

Any AI development must reduce rather than widen existing health inequalities and make the lives of clinicians and patients easier. It is also important to gain and maintain public trust by only using people's data in a way they've consented to and be transparent in how it is making decisions.

Members additionally highlighted the following points:

- The Stroke Association emphasised that AI-powered imaging software is already a reality in stroke care, with just over 90% of stroke units are using AI-powered imaging software with image sharing capability that can support clinicians to make fast and efficient decisions.<sup>48</sup> The remaining


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<sup>46</sup>Fawzy, A., Wu, T. D., Wang, K., et al. (2022) *Racial and Ethnic Discrepancy in Pulse Oximetry and Delayed Identification of Treatment Eligibility Among Patients With COVID-19*. Available at: <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2792653#:~:text=A%20recent%20investigation%20also%20reported,patients%20who%20were%20about%20to>

<sup>47</sup> Gastounioli, A., Eriksson, M., Cohen, E. A., Mankowski, W., Pantalone, L., Ehsan, S., McCarthy, A. M., Kontos, D., Hall, P., & Conant, E. F. (2022) *External Validation of a Mammography-Derived AI-Based Risk Model in a U.S. Breast Cancer Screening Cohort of White and Black Women*. Available at: <https://doi.org/10.3390/cancers14194803>

<sup>48</sup> Stroke Association (2022) *Saving Brains*. Available at: [https://www.stroke.org.uk/sites/default/files/integrated\\_campaigns/thrombectomy\\_campaign/saving\\_brains\\_thrombectomy\\_report\\_july\\_2022\\_final.pdf](https://www.stroke.org.uk/sites/default/files/integrated_campaigns/thrombectomy_campaign/saving_brains_thrombectomy_report_july_2022_final.pdf)





stroke units have approved plans to adopt this by the end of 2024. The Stroke Association want to see rapid adoption of these and other new technologies to improve diagnosis and treatment of stroke.

- Cancer Research UK highlighted the potential role of AI in using increasingly large datasets around health to enable better understanding of health and disease, and to support health systems to operate most efficiently. They highlight the potential to develop data-driven solutions for healthcare, for example for cancer, AI holds promise to improve the development and delivery of care right across the pathway.
- Cancer Research UK also highlighted that AI can be expected to improve the health system in several ways over the next five-to-ten years including by: reducing administrative burdens on clinicians by automating simple tasks; supporting risk prediction; flagging patients who may be eligible for trials; and in the longer term by potentially identifying new patterns to support diagnosis.

# Our vision for improving patient experience of diagnosis

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

## 1. 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 Standard<sup>49</sup>. This means understanding and mitigating the impact of digital exclusion at the level of system, provider and frontline staff<sup>50</sup>. 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 scheme<sup>51</sup>.

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 services<sup>52</sup>. 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 Duty<sup>53</sup>.

## 2. Provide better support while waiting

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<sup>49</sup> NHS England (2017) *Accessible Information Standard*. Available at:

<https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/>

<sup>50</sup> See for example <https://www.learningdisabilityengland.org.uk/top-tips-to-help-with-digital-inclusion/> and [VCSE Health and Wellbeing Alliance - Good Things Foundation](#)

<sup>51</sup> NHS (2023) *Healthcare Travel Costs Scheme (HTCS)*. Available at: <https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>

<sup>52</sup> <https://www.gov.uk/government/publications/the-building-regulations-2010-equality-act-clarification>

<sup>53</sup> Croneri (2024) *Legalities of providing disabled access*. Available at:

<https://app.croneri.co.uk/questions-and-answers/legalities-providing-disabled-access>

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.

This should include:

- 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.

### 3. 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:

### 4. 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.

### 5. 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.

## 6. 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?

### 7. Collect better data to understand the driver 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.<sup>54</sup>

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.

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<sup>54</sup> Alzheimer's Society (2023) *Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England*. Available at: <https://www.alzheimers.org.uk/sites/default/files/2023-10/Raising%20the%20Barriers.pdf>

## 8. 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. 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 we recommend meaningful engagement with the VCSE sector and people with lived experience to properly explore the acceptability and impact of these new services.

# National Voices

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

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