Patient Experience of Diagnostics Report

February 2024

Acknowledgments

The Patients Association would like to thank the 1,177 patients who shared their insights and experiences through the online survey that forms the basis of this report. We thank all the organisations that promoted our survey to help us reach a wide range of audiences in our research. Finally, we are grateful to Roche Diagnostics UK for funding the project, its support during it, and for its trust in us to analyse and report on the findings independently.

Contents

Executive summary

> **"Taking a patient-centred approach in diagnostics can involve clear communication, involving patients in decision-making, and addressing their concerns and preferences."**

The overarching message patients have given us on diagnostics is strikingly clear. They view diagnostics as a fundamental part of the NHS and one that should be prioritised over the coming years. The desire for investment in testing capacity and technology was almost universal. Many patients place such importance on diagnostics that they would consider paying for the tests they need if they faced a long wait on the NHS. Some told us they have already done so. Patients should not feel they have no choice but to turn to private healthcare because the services they need are not available through the NHS.

Patients also expressed a clear desire for more information and transparency before, during, and after their tests have taken place. This theme repeated itself time and again in the answers to the questions we posed. Many patients told of the frustrations and consequences that failure to provide it can have.

From the outset, patients feel it should be easier to be referred for the tests they need. Many have found that when they reach the point of the referral, the test they need is not available. They place huge value on understanding why they are being sent for a test, what the different options are, and transparency on what is available in their local area.

The appetite for clear information extends to after the tests have taken place. Understanding how long patients will have to wait for results, and an explanation of what they mean for them and their care, are paramount. Our results show that for many patients, there is unmet clinical need in between, and reinforce the importance of patients being given the information they need to support themselves.

Patients – at least those who are able - are willing to travel to access the tests they need. They also believe that co-locating multiple services in a clinical setting, and expanding the opportunities for them to test themselves, are both part of the solution. They recognise the potential of artificial intelligence to improve diagnostics and largely trust the results it produces. We also saw a willingness to change lifestyles if test results show the risk of developing conditions such as Alzheimer's disease in future, even where no treatment currently exists.

Taken together, this report demonstrates how fundamental diagnostics are to the care patients receive, and the importance of clear communication. We can also see where patients believe the system can be improved. This all points to the need to apply the principles of patient partnership – which our work across the health and care system has shown brings benefits for patients and the services they use – to the system of diagnostics and testing.

It is vital that both politicians and the NHS take heed of these messages if the potential of diagnostics is to be realised. The following recommendations can help make that happen.

Expanding ambitions for community diagnostic hubs: The Government should revisit the rules that permit and govern the operation of community diagnostic hubs. We recommend that the current restrictions, which mean they can only be created on existing NHS estates, are removed to encourage the development of more hubs. The number of tests that hubs offer should be expanded to enable more patients to benefit from their introduction. By 2022 they had only increased testing capacity by 2%, with an ambition for this figure to reach 5% within two years. With demand for tests rising by as much as 7% each year and 1.6 million currently waiting for tests, there is potential for community diagnostic centres to do much more.[1]

Political commitments to expand access to diagnostics: Ahead of the next general election, we urge all political parties to set out their vision for the future of diagnostics. Fundamentally, this should focus on how more patients can access the tests they need, but also include how technological advances will be harnessed to improve the patient experience of diagnostics. As part of wider our call for a review of the NHS Constitution, patient experiences of diagnostics and the pledges the constitution makes to them on this topic should be included in its scope.

Expand opportunities for home testing: While there are limitations on what patients can test for at home, our research showed clear desire to do so where appropriate. The Department of Health and Social Care (DHSC) and NHS England should seek to facilitate self-testing to determine or monitor conditions in future policy directives, where this can be done safely and effectively.

Increased transparency in waiting times: Patients should have clearer understanding of what they can expect while awaiting tests and results. This will require better use of data held by Primary Care Networks, Integrated Care Systems (ICSs) and NHS England. We urge NHS England to initiate a programme of work with local system partners that can help us reach the point where patients have a clear understanding of how long they will wait for a test to take place, and how long it will take for their results to be returned.

Keeping patients informed before, during, and after their tests: We recognise the challenges in meeting different patient expectations across the different layers of the NHS involved from the point of referral to results being delivered and explained.

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[1] The King's Fund, Why do diagnostics matter? Maximising the potential of diagnostics services, October 2022

However, we believe that it should be our ambition to notify patients when they have reached a different stage of the diagnosis journey, and to flag when issues have occurred in the process. This experience should be universal. We urge NHS England and the DHSC to examine the barriers to this objective being met, and how they can be removed. While the NHS App is not a suitable mechanism for everyone, we believe it can serve as the basis to keep many patients informed about their tests and results.

Introduction

Diagnostics are used to identify and monitor a disease or condition.

Our awareness of diagnostics increased significantly during the COVID 19 pandemic. It has received a new level of attention from policy makers as a result. During the pandemic itself, Professor Sir Mike Richards' review of diagnostics services was published.[2] It is widely acknowledged that diagnostics have a fundamental role to play in the NHS' recovery from the pandemic through reducing waiting times and providing earlier diagnosis.

Increasing diagnostic activity was an important part of NHS England's Elective Care Recovery Plan as a result.[3] In October 2021, the Government announced the creation of 40 new community diagnostic centres to address blockages in accessing tests and to deliver tests closer to home. Restrictions on large new centres, the requirement for them to be built within the NHS estate, and the limited range and volume of tests they carry out, mean that their potential impact is limited. These issues were among those analysed in the recent report into community diagnostic centres by the All-Party Parliamentary Group for Diagnostics.[4]

Patients have legal rights to diagnostics. The NHS Constitution gives patients a right to treatment within 18 weeks of referral, and pledges that they should not have to wait more than six weeks for a diagnostic test.[5] The latest data show that as of November last year, 375,200 patients were waiting for one of 15 key diagnostic tests. That is 23.3% of all patients waiting at the end of the month. The figure has been as high as 31.3% over the last year. More than 1.6 million patients were waiting for tests at the end of November 2023.[6]

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[2] Professor Sir Mike Richards, Report of the Independent Review Diagnostics Services for NHS England, November 2020

[3] NHS England, Delivery plan for tackling the COVID-19 backlog of elective care, February 2022

[4] All-Party Parliamentary Group for Diagnostics, CDCs Unveiled: Challenges and Triumphs, January 2024

[5] The King's Fund, Why do diagnostics matter? Maximising the potential of diagnostics services, October 2022

[6] NHS England, NHS Diagnostic Waiting Times and Activity Data, January 2024

With all this in mind, we wanted to hear from patients about their experience of diagnostics. We explored the challenges and consequences they have faced when things go wrong, as well as their thoughts on how the system could be improved. Our research examined patient understanding of diagnostics, the importance they place on diagnostics, and their attitudes to where and how services should be delivered. We cover how patients believe the benefits of faster diagnoses should be promoted, their willingness to self-test, and thoughts on the future of diagnostics.

The insights they have shared form the basis of this report and enable us to make recommendations on their behalf. A clear message stands out: patients want a clearer understanding and sense of ownership of their tests and results, and of their care overall.

We explore all these issues in the following sections of this report.

Aims and objectives

Our first aim was to develop a comprehensive survey that addressed patient experiences and insights on diagnostics and testing from multiple perspectives. We designed questions to explore the challenges the NHS is facing, the impact they have on patients, the value of diagnostics, barriers to access, and the future of diagnostics.

These results have given us new insights on patient experiences and opinions on diagnostics and testing in the NHS. The results will be used to help increase awareness in the media and wider public engagement on an issue of vital importance, that can sometimes be underrepresented in discourse on the health and care system. Our results will also make an important contribution to policy discussions on diagnostics and testing, both now and in the future.

Methodology

This report is based on the results of an online survey that ran from 24th November 2023 to 2nd January 2024. It was promoted to the Patients Association membership via the weekly newsletter, social media audiences, and through organisations in our stakeholder network. The sample of 1,177 was drawn largely from England, but included people from around the UK. Respondents needed to have received support from the NHS in the last six months to be eligible for the survey. The full questionnaire and demographic information of our sample are given in the appendices of this report.

Understanding of diagnostics

In setting out to learn more about patient experiences and thoughts on diagnostics, we also wanted to test their understanding of what does and doesn't constitute a diagnostic test. We did this in two parts.

During the COVID-19 pandemic, self-testing became a normal part of most of our lives. We wanted to see if this increased exposure to testing had translated to an improved understanding of diagnostics as a whole. The results in our survey were almost evenly split.

Understanding of diagnostics had improved as a result of the pandemic for more than two in five (44%) patients, while almost half (47%) said that it had not. So, while increased exposure to diagnostics has led to a self-perceived uplift in understanding for some patients, there has been far from universal.

We also presented patients with a series of tests and asked which they considered to be part of diagnostics. Blood test was the most popular choice, with more than four in five (86%)of respondents identifying this as a diagnostic test. The results for the remaining options were more clustered. Nasal swab, biopsy, colonoscopy, mammogram and cervical screening were all selected by between just over half to around two thirds (54% to 64%) of respondents. Only a blood glucose meter, at 46%, was selected by less than half of those who took our survey. Less than one in 20 (4%) thought that none of these options were diagnostic tests.

It is possible that what patients consider to be a diagnostic test is led in part by what they have experienced in their own care, or in the care of someone close to them. On that basis, given that all of us are likely to have had a blood test at some point in our lives, it is unsurprising that the majority of respondents identified them as a diagnostic test.

The responses to other options show that more widely there are varying perceptions about what does and doesn't constitute a diagnostic test. This also reflects our mixed findings on whether patient understanding of diagnostics improved as a result of pandemic.

The importance patients place on diagnostics

> **"There needs to be more investment so diagnostic procedures can be improved and results speed up."**

While there were mixed levels of understanding of what constitutes a diagnostic test, the importance patients place on diagnostics is nearly universal. More than nine in ten (93%) patients wanted testing capacity to be invested in over the coming years so that patients can receive tests and diagnosis more quickly.

> **"More health funding. It's pointless to promote it if we're not investing in the capacity to actually test more people faster. That's the core of it across so many specialisms."**

Similarly, investing in diagnostics and new technology was again a priority for more than nine in ten (91%). The rationale behind patients holding this view was also clear: almost nine in ten (86%) felt that testing and diagnosing conditions more quickly would help reduce the NHS backlog.

> **"Delays mean more deterioration and will cost the NHS more as patients are sicker. Investing in diagnostics is expensive in the short term but cost effective in the long term."**

Patient priorities for improvements in diagnostics

> **"There needs to be one consistent approach, adopted by all GPs/clinics, so that patients are informed of the result, no matter what."**

We wanted to know where patients saw potential for the improvements in the diagnostics system. To give context for this, we wanted to know how effectively patients thought the system of being referred for tests and getting results works currently. There was a mixed picture in the open responses we received. This was also reflected by the 44% of patients that told us that the system works well.

> **"My recent experience has been very positive in almost every respect. The only one where I feel more information would be useful would be having a realistic timeline for results."**

> **"The current system works OK, but could be so much better to catch diseases earlier and make treatment more effective and less burden on the NHS."**

Nevertheless, the scale of enthusiasm we saw for potential improvements suggests that even those who think the system works well could see positive changes that can be made.

> **"Treating me holistically instead of like a number of spare parts."**

> **"I'd like an outline of the diagnostic process as a whole, not just individual tests, so I know what to expect next."**

Nine in ten (90%) stated that it should be more straightforward for patients to get tests, through changes such as making it easier for clinicians to refer them. The open responses we received shows that this extends to being given a wider understanding of how tests fit together as part of wider patient care.

> **“Not having to battle to get necessary tests.”**

> **“Clarity of when results are due back and where to view or collect them from.”**

> **“Realistic and improved waiting times. If you are told urgent then 7 months is not acceptable.”**

Throughout this area of the survey there was a clear desire for better information, and a sense of control. Almost three quarters (73%) wanted a better understanding of why they are being sent for a test and what it will involve. In turn, more than four in five (82%) wanted more discussion about the different types of tests they could be referred for.

> **“Being given options on the types of tests that you could have.”**

> **“Clear communication in layman's terms.”**

> **“To be kept informed while waiting for answers.”**

The preference for transparent information was even stronger after the test had taken place. Almost nine in ten (88%) patients wanted a realistic timeline for their test results to come through and a similar percentage (87%) called for a better explanation of what those results mean for them and their treatment.

> **“Clear information around diagnostics and follow up treatments - no point having one without the other.”**

> **“Being given any timescale for the results.”**

More than two thirds (68%) wanted more clinical support while they waited for their test. Although this was the least popular response in this section of the survey, it shows that large numbers of patients felt they had an unmet clinical need while they await the results of their tests. This demonstrates the importance of patients being given the information they need to care for themselves – a theme that comes up repeatedly in the Patients Association’s work.

> **“No follow up appointments or support groups offered.”**

In our open responses patients also expressed a clear desire for information to be made available to them earlier, with lay explanations where necessary. Many failed to understand why existing means of providing them with that information – such as the NHS App - could not be utilised.

> **“ We need GPs to send results rather than patients having to ask. Ban the phrase ‘if you don't hear from us, assume all is OK’.”**

> **“Test results from any NHS source to be shown online in the same app.”**

> **“Patients should be copied in for all letters and test results.”**

Attitudes to travel and location of services

> **“Patients often have a lot of travelling and waiting. Community hub hospitals for tests, health condition maintenance etc, would be fab.”**

Several of the questions we asked concerned patients attitudes towards travel and where they wanted to be able to access tests. What emerged was an overarching desire to be able to access tests in a shorter timeframe, whether close to home or further afield.

> **“I would like to be given the option to undertake medical support through a third party such as a private clinician, or be able to travel to another area for support.”**

> **“I have had no problem getting tests. I have travelled within our area for tests recently. Yesterday I had a blood taken in my local hospital for a test required by another hospital where I travelled to for treatment last year.”**

Almost four in five (78%) patients felt that testing facilities should be provided closer to patients’ homes to make tests easier to access. Equally, the same percentage (78%) also said that they would be willing to travel outside their area if it meant that they were able to access diagnostic testing or screening faster. Only 15% said that they would not be willing to travel.

> **“If there could be more triage of diagnostics on a local basis this could make life better. Local health centres and pharmacies, local community hospitals would be my choice for frontline diagnostics.”**

Several patients pointed out that mobility or logistical issues would mean that some patients would not be able to exercise that option even if it was made available to them.

> **“I am waiting for a local test. I have been offered one outside my area but due to my disabilities I cannot travel. This discriminates against me by making me wait longer for a test.”**

> **“I can travel wherever to get a test, but others can't.”**

Promoting the benefits of faster diagnosis

> **“More awareness of the tests that are available, and their accuracy, would be very useful”**

We wanted to glean patient insights on how to promote the benefits of faster diagnosis. A majority were in favour of all the options we presented. More than half (51%) wanted more information about the latest advances in diagnostic testing and almost three in five (57%) supported public awareness campaigns on the importance of testing.

> **"Early diagnosis is imperative in many cases, so raising public awareness should be a priority. Everyone knows about cancer … but heart failure, diabetes? They kill more and block more beds."**

However, there was more enthusiasm for the options that put more information in the hands of patients either regarding their own care, or the wider availability of care in their area.

Nearly two-thirds (63%) wanted more information on the diagnostics tests available in their area and almost three quarters (70%) wanted to be given a clearer understanding of how to access tests. Some patients highlighted that services are sometimes not available as advertised.

> **"More explanation of tests available and wider availability of tests. It's preventative health care so could help reduce pressure on the NHS."**

> **"I feel that the advertised NHS services and tests are not readily available, or are more of a struggle to get access too than they should be."**

Only 1% of the patients we spoke to felt that the benefits of faster diagnosis should not be promoted at all.

Speeding up diagnosis in practice

We asked patients what measures would help speed up diagnosis and reduce pressures on the NHS. Responses were mixed. The only option that was selected by fewer than half of the patients was introducing testing for common conditions such as flu (29%). This suggests patients see limited value in testing for conditions that in most cases are unlikely to do significant harm to patients.

There was more enthusiasm for screening programs in the wider population, with more than half (52%) selecting that option. A similar number (55%) were in favour of making testing facilities available in the community in locations such as shopping centres.

> **"More effort should be spent on developing tests that detect early stage disease and on promoting it to make people at risk seek out these tests."**

The most popular option respondents were presented with was being able to access more medical services in one place (69%). This suggests that many patients see the potential for the co-location of multiple services to improve care and believe that diagnostics should be part of the suite of options included as part of that offer.

> **“Simple planning, organisation and communication could avoid a lot of issues. Community services need to improve to ease the burden on hospitals.”**

> **“More local access for blood tests and having the option to have as many appointments at the same place as possible on the same day.”**

Enthusiasm for home testing

> **“Doing diagnostics at home yourself would be good, so long as people were shown how to carry this out, or it was made as simple as the covid test.”**

More than three in five (61%) patients believed that expanding opportunities to test at home could help speed up diagnosis. This enthusiasm was even stronger in other parts of our survey, perhaps building on our collective experience of testing at home during the pandemic.

> **“Self-testing should be made available for patients to reduce pressures on the NHS.”**

We wanted to know whether patients would be happy to test themselves either at home or in a clinical setting such as a GP surgery or a pharmacy. The results were clear. More than three quarters (77%) said that they would be happy to test themselves at home, far more than the 44% who said that they would be happy to self-test in a clinical setting. Only 4% said they would not be willing to self-test in either environment.

> **“Getting help in the first place is the biggest problem with the NHS. I think it's a great idea to open up access to testing and, as we did with COVID, to make self-testing more available.”**

Patient confidence in testing themselves without supervision may drive these numbers. A belief that in a clinical setting, clinicians should carry out the tests, could also be a factor. The open responses suggest that some patients are enthusiastic about self-testing because they feel it will open the door to the wider services they need.

Attitudes towards artificial intelligence

> **“Embracing innovative technologies can streamline the diagnostic process, making it faster, more accurate, and less invasive.”**

The attitudes patients displayed towards artificial intelligence in our survey were enthusiastic in the main, with some potential caveats. Near three in five (57%) felt the use of new technology such as artificial intelligence could speed up diagnostics and reduce pressures on the NHS.

> **“Use artificial intelligence (AI) to develop an intelligent diagnostic system to improve the speed and accuracy of diagnosis, thereby reducing pressure on the NHS.”**

Advances in technology mean that artificial intelligence can be used to detect conditions more quickly and can provide faster test results. We wanted to know to what extent patients trust results generated using artificial intelligence. Nearly three quarters (73%) said that they were very likely or quite likely to trust the results, demonstrating both a faith in its potential and confidence in the results it provides.

> **“If artificial intelligence can take the strain off temporarily, then perhaps that's okay, but long term I'd prefer investment to go into the hard-working staff.”**

The fact that 44% said they were ‘quite likely’ to trust the results suggests that some patients may still have some lingering doubts over the technology. However, only 16% were quite unlikely or unlikely to trust the results, pointing to limited outright opposition to its use.

Testing without known treatments

In some cases, our ability to test for conditions has overtaken our ability to treat them. For example, tests exist for diseases such as Alzheimer’s disease that are able to predict the probability of someone developing them, but they are not widely used because effective treatments are not yet available.

We wanted to understand patient attitudes towards tests of this type. Nearly three quarters (72%) said they would be likely to take such a test if it was made available to them. If these tests revealed that they were likely to develop Alzheimer’s, nearly nine in ten (89%) said that they would make lifestyle changes that might delay the onset of symptoms.

So, if tests show that a patient is likely to develop a condition for which there is currently no treatment, we can be confident that the majority of patients would take their health into their own hands and make lifestyle changes in an attempt to prevent it from developing.

The consequences of delays in accessing tests and getting results

> **“I am so tired of being misdiagnosed and having to research and analyse my results myself until I can prove to GP I have a condition and get referred for treatment.”**

Difficulties in accessing tests or results can have very serious consequences for patients, both for their short-term health and long-term recovery. Only 11% of patients said they have never had any issues getting either a test or their results, or faced no consequences if they did.

> **“My husband died through the GP not offering any tests and a misdiagnosis saying he had arthritis when it was kidney cancer. The hospital doctor was amazed at how it was missed.”**

The wait made more than three in five (61%) patients nervous, perhaps in anticipation of the potential consequences they might face as a result of delays. Our results also show serious consequences for the health and wider lives of many patients. More than a third (36%) said their physical health suffered during the wait, while mental health declined for 34%.

> **“The problem is predominantly the wait for diagnostic procedures, and then the wait to see a consultant, and for treatment. In my daughter’s case it took 18 months to diagnose the break in her upper spine and it was too late for surgical repair. So at 55 she is in permanent pain.”**

> **“I suffer from severe mental health issues already, I was - and continue to be - in a state of terror. I cannot focus, and I am in danger of losing my job and partner. I have asked the NHS for help but have basically been told that’s the way it is, you have to wait.”**

Outside of the direct impacts on their health, around a third (35%) reported that difficulty accessing tests or results made it hard to focus on things like work and family. Nearly one in five (17%) said their long-term recovery was set back significantly. Across the countries, that is millions of patients facing these difficulties. These impacts were strikingly illustrated in the personal stories that patients shared with us.

> **“I lost a young family member because they had to wait a whole year before their GP referred them for an endoscopy. It took for him to pass out in the GP clinic for them to get the endoscopy done and by then it was too late. He passed away age 30 from stomach cancer. The outcome might not have been different but it could have saved him a year of pain and suffering.”**

Why patients delay or don’t seek tests

> **“I have several uncommon conditions. My GP refuses to recognise them. Some I had to pay to have diagnosed and my GP still refuses to recognise them.”**

We wanted to understand the reasons why patients don’t seek tests, or delay getting one, when they display symptoms. Only one in five patients (20%) said they had never been in this position.

For some patients, consideration of the wider pressures on the NHS was a factor; 29% didn’t want to waste NHS time and resources. Lack of time was a factor for others, with one in five (20%) saying they didn’t have time to visit their GP. Nearly one in ten (9%) didn’t believe the test they needed was available on the NHS, while 13% said their GP was unwilling to refer them for one. Fear played a role for a minority of patients. More than one in ten (13%) stated they didn't seek a test because they were worried about what the results might say. Previous research has demonstrated that many patients seek to avoid information about their health, even when displaying symptoms.[7]

> **"NHS GPs will not send me for a specific test even though I have a familial link."**
>
> **"I didn't know there was a test I could have."**

The most striking finding here was that one third of patients (33%) tried to get a test but found there were no appointments to get a test nearby. Our findings here reflect national data on the large numbers of patients unable to access the tests they need to identify the cause of their health issues, before any waiting lists for the treatment they need begin.

> **"Scared of having the procedure again after a very bad experience.'**
>
> **"I was afraid they would just blame my weight as usual."**

Attitudes to private treatment

> **"In the end, I was forced to obtain private treatment and surgery."**

Our survey explored attitudes to paying for tests privately. We asked patients whether they would be willing to pay to get a test done privately if they faced a long wait, or the test they needed was not available.

> **"I had a wait but I also appreciated how stretched the NHS is. However, if it had been a serious test (this was about seeing an audiologist) I would have paid privately (no, I'm not rich!)."**
>
> **"The diagnostics wait on the NHS is too long. Four out of five times I have had to go private."**

Three in five (60%) patients said that they would be likely to pay to have a test done privately under these circumstances, compared to 30% who said they would be unlikely to. As with other findings in our research, the fact that so many patients would be willing to pay to have the test they need done once again shows the importance they place on getting results and diagnosis in good time.

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[7] 2020health and AbbVie, The Fear of Finding Out, Identifying psychological barriers to diagnosis in the UK, January 2017

> **"The NHS refused to refer me for testing due to my age as it 'it wouldn't be accepted'. I got this test privately which showed I had cysts in my breasts - it's unfair that I had to go elsewhere to be taken seriously."**

While private treatment is ultimately a matter of patient choice, this should not be one that patients feel forced to make because the services they need are unavailable on the NHS.

Conclusions

Taking the results of our research together, the findings patients have given us and the stories they have shared demonstrate the critical role that diagnostics play in patient care. While there is an understandable tendency to focus on the quality of care delivered, or the struggles patients face in accessing it, diagnostics can be an overlooked entry point to the treatment people need.

Without timely access to diagnostics, many patients can't begin the journey to the support they need. Undiagnosed and untreated conditions or illnesses are likely to become worse over time. This brings more harm to patients themselves and leads to costlier interventions for the NHS further down the line. It is in the interest of patients and the health and care system to deliver a diagnostics system that works as efficiently as possible. This has been recognised by both policymakers and the patients who took part in our research.

Patients' insights into how that can be delivered are clear. There is an overwhelming consensus that investment in diagnostic capacity and in the technology that underpins it should be a priority. The clearest finding on how diagnostics should be delivered was on the co-location of multiple clinical services in one place. This was borne out in both the statistics and patient testimony we received. There is some momentum behind this already, but new impetus will be needed to deliver it at scale.

Patients also want a diagnostics system that includes them in the process and is honest with them about what that journey will look like. This means being kept in the loop about what their results say, how long it will take for them to receive the results, and the options available to them at each stage. They are willing to take control of that process when they are offered the chance and are able to, whether this is testing at home or travelling to access the services they need. All these themes link back to the principle of patient partnership, which the Patients Association advocates across the health and care system, and which too often is marked by its absence.

Our research also gives shocking examples of the human cost when things go wrong. We heard many stories of the suffering that problems in the diagnostic system can cause patients. Even where these do not come with tragic consequences, the negative impact on their lives is widespread. Physical and mental issues stemming from delays, as well as problems in wider life, are commonplace. Difficulties in accessing tests and results can also set back patient recovery in the long-term.

These are the issues we should look to rectify and avoid as we seek to improve the system of diagnostics and testing. We hope our recommendations can be part of making that happen.

Recommendations

Expanding ambitions for community diagnostic hubs: The Government should revisit the rules that permit and govern the operation of community diagnostic hubs. We recommend that the current restrictions which mean they can only be created on existing NHS estates are removed to encourage the development of more hubs. The number of tests that they offer should be expanded to enable more patients to benefit from their introduction. By 2022 they had only increased testing capacity by 2%, with an ambition for this figure to reach 5% within two years. With demand for tests rising by as much as 7% each year and 1.6 million currently waiting for tests, there is potential for community diagnostic centres to do much more.[8]

Political commitments to expand access to diagnostics: Ahead of the next general election, we urge all political parties to set out their vision for the future of diagnostics. Fundamentally, this should focus on how more patients can access the tests they need, but also include how technological advances will be harnessed to improve the patient experience of diagnostics. As part of our wider call for a review of the NHS Constitution, patient experiences of diagnostics and the pledges the constitution makes to them on this topic should be included in its scope.

Expand opportunities for home testing: While there are limitations on what patients can test for at home, our research showed clear desire to do so where appropriate. The Department of Health and Social Care and NHS England should seek to facilitate self-testing to determine or monitor conditions in future policy directives, where this can be done safely and effectively.

Increased transparency in waiting times: Patients should have clearer understanding of what they can expect while awaiting tests and results. This will require better use of data held by Primary Care Networks, Integrated Care Systems (ICSs) and NHS England. We urge NHS England to initiate a programme of work with local system partners that can help us reach the point where patients have a clear understanding of how long they will wait for a test to take place, and how long it will take for their results to be returned.

Keeping patients informed before, during, and after their tests: We recognise the challenges in meeting different patient expectations across the different layers of the NHS involved from the point of referral to results being delivered and explained. However, we believe that is should our ambition to notify patients when they have

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[8] The King's Fund, Why do diagnostics matter? Maximising the potential of diagnostics services, October 2022

reached a different stage of the diagnosis journey, and to flag when issues have occurred in the process. This experience should be universal. We urge NHS England and the DHSC to examine the barriers to this objective being met, and how they can be removed. While the NHS App is not a suitable mechanism for everyone, we believe it can serve as the basis to keep many patients informed about their tests and results.

the patients association
Listening to patients, speaking up for change.

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Appendices

Full methodology

This report is based on the results of an online survey that ran from 24th November 2023 to 2nd January 2024. The survey was completed in full by 1,177 respondents. The text below was included as an introduction to the survey. An initial screening question asked whether respondents have received support from the NHS in the last 6 months. Anyone who answered no was routed out of the survey. All subsequent questions are listed.

Have your say on the role of diagnostics in the NHS

The Patients Association and Roche Diagnostics UK are embarking on an exciting new project that will give patients the chance to share their understanding and experience of diagnostics in the NHS - and have their say on how access to testing could be improved. Diagnostics are tests or procedures which can be used to help healthcare professionals determine the condition or illness a person has and/or the type of treatment and care they need.

We want to hear about your experiences of diagnostics, your attitudes towards them, and your priorities for change. The results will help us raise the profile of diagnostic testing and the views of patients. They will also be used to help influence policy decisions on this important subject.

To take part in the survey, we ask that you have accessed NHS services in the last 6 months. The survey takes around 15 minutes to complete and the responses you give will be entirely anonymous.

Thank you for taking the time to share your thoughts on this vital issue.

1) Which of the following do you consider to be a diagnostic test? Please select all that apply.

- Blood test
- Nasal swab
- Biopsy
- Colonoscopy
- Mammogram
- Blood glucose meter
- Cervical Screening (smear test)
- Don’t know
- None of the above

2) Thinking about your experience of diagnostic tests, what improvements would you like to see made? (strongly agree to strongly disagree)

- More information about why I’m being sent for a test and what it will involve

- More discussion about the different types of tests I could be referred for
- Being given more options of where I could take my tests
- Receiving more clinical support while I wait for my test
- Being given a realistic timeline for my test results
- Better explanation about what the results mean for me and my treatment
- Other improvements (please specify)

3) Faster diagnosis of a condition can lead to quicker treatment and improved outcomes for patients. This can also help to reduce hospitalisation. When thinking about the challenges the NHS currently faces, which of the following statements do you agree with? (strongly agree to strongly disagree)

- Investing in testing capacity should be prioritised so that patients can receive tests and diagnosis more quickly
- Investing in diagnostics and new technology should be a priority for the NHS in the coming years
- It should be more straightforward for patients to get tests (e.g. clinicians should be able to refer patients for tests more easily).
- Testing facilities should be provided closer to patients' homes, to make tests easier to access.
- Testing and diagnosing conditions more quickly would help the NHS reduce the backlog.
- The current system to be referred for tests and getting results works well.

4) If you knew that a specific test was available (e.g. to diagnose heart failure, which has common and vague symptoms such as breathlessness) how likely is it that you would ask for it from your GP or practice nurse?

- Very likely
- Somewhat likely
- Neutral
- Unlikely
- Very unlikely
- Only if it was non-invasive (i.e. If it didn't involve breaking the skin)
- Don't know

5) What would you like to see done to promote the benefits of faster diagnosis? Please select all that apply.

- Public awareness campaigns on importance of testing
- More information on the diagnostic tests available in my area
- More information about the latest advances in diagnostic testing
- Giving patients a clearer understanding for of how to access tests
- Other (please specify)
- Don't know

- Not applicable – I don't believe the benefits of faster diagnosis should be promoted.

6) Thinking about a time when you had difficulty accessing a test, or had to wait for test results, what were the consequences for you? Please select all that apply

- The wait made me feel nervous
- My physical health suffered during the wait
- I found it difficult to focus on things like work and family
- My mental health declined during the wait
- My long-term recovery was set back significantly
- Other (please specify).
- Don't know / can't recall
- Not applicable – I have not had difficulty accessing a test or results / there were no consequences for me

7) Would you be willing to travel outside of your local area if it meant that you were able to access diagnostic testing or screening faster?

- Yes, I would be willing to travel outside my area
- No, I would not be willing to travel outside my area
- Don't know

8) Thinking of a time you have not sought a test, or delayed trying to get a test when you have symptoms, which of the following reasons were part of your decision? Please select all that apply.

- I didn't want to waste NHS time / resources
- I didn't have time to visit my GP surgery
- There were no appointments available to get a test near me
- I didn't think the test I needed was available on the NHS
- I was worried about what the results might say
- I tried to get a test but my GP was unwilling to refer me for one
- Other (please specify)
- Not applicable – I have never not sought a test or delayed getting one.

9) Has your understanding of diagnostic testing improved as a result of the COVID-19 pandemic?

- Yes
- No
- Don't know

11) The COVID-19 pandemic saw the public self-testing at home for the virus. If this option was available for other health conditions or diseases, such as cervical

screening for HPV, would you be happy to use a self-testing kit either at home or in an alternative setting?

- Yes, at home
- Yes, in a clinical setting such as a GP surgery or pharmacy
- No
- Don’t know

12) If you faced a long wait to get tested for something on NHS, or the test you needed was not available, how likely is it you would pay to have it done privately?

- Very likely
- Quite likely
- Quite unlikely
- Very unlikely
- Not sure / don’t know

13) Tests exist for diseases such as Alzheimer’s Disease (AD), which are able to predict the probability of you developing a condition in the future, but they are not widely used as effective treatment is not yet available.

    How likely would you be to take such a test if it was offered to you, even before treatments are available?

- Very likely
- Quite likely
- Quite unlikely
- Very unlikely
- Only if it was non-invasive (i.e. If it didn’t involve breaking the skin)
- Not sure

14) If a diagnostic test revealed you were likely to develop Alzheimer’s Disease, how likely would you be to make lifestyle changes that might delay the onset of symptoms?

- Very likely
- Quite likely
- Quite unlikely
- Very unlikely
- Don’t know / not sure

15) Computer programmes can be used to detect conditions such as cancer more quickly and efficiently and can help to provide faster test results. This is known as Artificial Intelligence (AI).

How likely would you be to trust test results if they were generated using Artificial Intelligence?

- Very likely
- Quite likely
- Quite unlikely
- Very unlikely
- Don’t know / not sure

16) Which of the following measures would you be in favour of to help speed up diagnosis and reduce pressures on the NHS? Please select all that apply.

- Making use of new technology such as artificial intelligence (AI) in diagnostics
- Being able to access more medical services in one place
- Making testing facilities available in the community (e.g. shopping centres)
- Expanding the opportunities for patients to test themselves at home
- Introducing testing for common conditions such as flu
- Introducing more screening programmes for more conditions for the wider population
- Don’t know
- None of the above

17) We’d like to hear more about your experience of diagnostics and thoughts for how they could be improved both for patients and to reduce pressures on the NHS. Please use the space below to tell us more.

- Open text

Demographic information

Demographic information on our sample is provided below.

18) Which if any of the following conditions have you received care or treatment for in the last 6 months?

Heart conditions (e.g. heart failure, heart attack, hypertension)	20%
Cancer	12%
Chronic respiratory disease (e.g. COPD, asthma)	17%
Neurological conditions (e.g. epilepsy, multiple sclerosis, Parkinson’s disease)	7%
Women’s health (e.g. PCOS, HPV screening, pre-eclampsia, endometriosis)	18%

Men’s health (e.g. Prostate cancer)	5%
Urological conditions (e.g. kidney or bladder issues)	13%
Eye conditions (e.g. cataract, glaucoma)	11%
Gastrointestinal disease (e.g. irritable bowel syndrome)	18%
Dementia	1%
Diabetes	11%
Musculoskeletal conditions (e.g. arthritis, fibromyalgia)	20%
Mental illness (e.g. depression, schizophrenia)	13%
Don’t know	1%
None of the above	18%

19) How old are you?

Under 18	0%
18-24	3%
25-49	42%
50-64	27%
65-79	22%
Over 80	5%
Not known	1%
Prefer not to answer	0%

20) What is your Sexual Orientation?

Heterosexual	85%
Gay	1%
Lesbian	1%
Bisexual	3%
Asexual	2%
Pansexual	1%
Prefer not to say	5%
Not known	1%
Other sexual orientation	1%

21) Are you a carer?

Yes	27%
No	71%
Prefer not to say	2%
Not sure	1%

22) Which of the following best describes your gender?

Male	30%
Female	67%
Non-binary / Third gender	1%
Not known	0%
Prefer not to say	1%
Prefer to self describe	1%

23) Is your gender the same as you were assigned at birth?

Yes	96%
No	2%
Not known	0%
Prefer not to say	2%

24) Which of the following best describes your ethnicity?

White English/Welsh/Scottish/Northern Irish/British	84%
White Irish	2%
White Other	3%
White Gypsy or Irish Traveller	0%
Mixed/multiple – White and Black Caribbean	1%
Mixed/multiple – White and Black African	0%
Mixed/multiple – White and Asian	1%
Asian/British Asian – Indian	2%

Asian/British Asian – Pakistani	1%
Asian/British Asian – Bangladeshi	0%
Asian/British Asian – Chinese	0%
Black African	1%
Black Caribbean	1%
Black British	1%
Any other ethnic group or background	1%
Prefer not to say	1%
Don't know	0%

25) Where do you live?

East Midlands	7%
East of England	9%
London	15%
North East	5%
North West	10%
South East	24%
South West	8%
West Midlands	7%
Yorkshire and Humberside	6%
Wales	4%
Northern Ireland	2%
Scotland	4%
Outside the UK	0%

26) Do you practise any of the following religions?

Buddhist	2%
Christian	44%
Hindu	0%
Jewish	1%

Muslim	3%
Sikh	0%
No religion	40%
Prefer not to say	7%
Other religion	2%

27) Do you consider yourself to have any of the following disabilities?

Learning disability e.g. dyslexia and dyspraxia	5%
Autism	7%
Both	2%
Neither	87%

28) Do you consider yourself to be disabled for any of the reasons outlined below?

Yes (no specificity)	5%
No	60%
Yes, physical impairment e.g. mobility difficulties	19%
Yes, sensory impairment e.g. hearing or sight	8%
Yes, mental health conditions e.g. depression or obsessive-compulsive disorders	12%
Yes, genetic and progressive conditions e.g. motor neurone disease or muscular dystrophy	4%
Yes, conditions characterised by a number of cumulative effects e.g. pain or fatigue	16%
Yes, hidden impairments e.g. asthma or diabetes	11%
Yes, history of impairment e.g. no longer disabled but met the definition in the past.	1%