Diagnostic services in Hertfordshire and West Essex Findings from engagement programme

Opinion Research Services January 2023



Prepared for:





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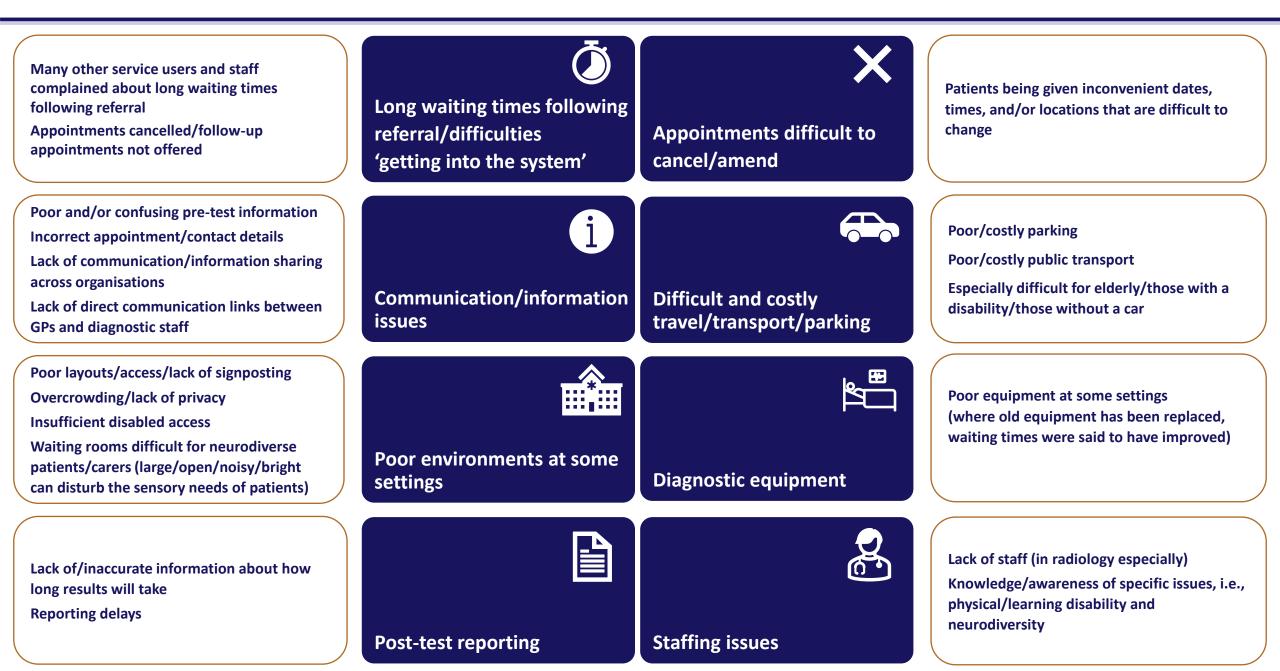
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Summary of key findings



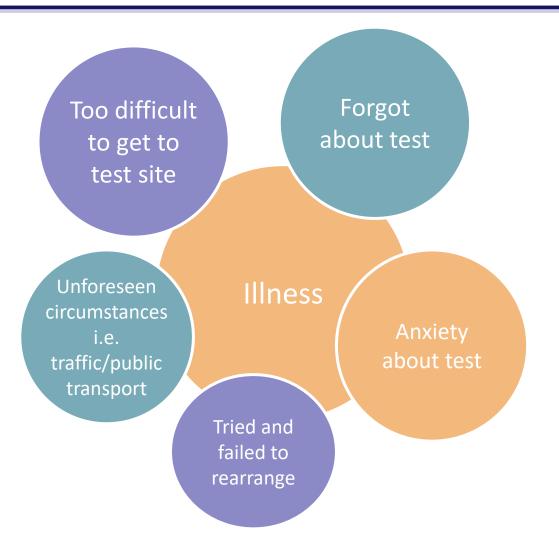
Challenges and areas for improvement in current diagnostic services



Service users' main reasons for non-attendance at diagnostic tests

Only 12% of service users responding to the questionnaire had declined or failed to attend a diagnostic test at any time in the last 5 years

The main reasons given for doing so were...



Also some specific reasons for people with additional learning needs i.e., not contacting them in the right way or not contacting their carer

An 'ideal' service?



Good access to tests location More flexible booking/appointments Greater control over booking/ amending/cancelling appointments Choice of time slots Online booking and referral technology – and other mediums for those unable to use/access online systems More walk-in provision

'Direct Access' for GPs

(i.e., MRI Echocardiogram)

More local provision/provision at a variety of locations for routine tests e.g.

GP surgeries/health centres/community hospitals/pharmacies (space and resource permitting)

Conveniently located one-stop-shops (though some concerns about distance/travel)

Non-NHS locations (i.e., supermarket car parks, retail parks, high streets, churches)

Good communication/ information provision

Adequate transport/ travel/parking options

Carefully considered environments

Pre-visit information (where to go/how long it will take) Post-visit information (results/next steps) Information must be accessible for people with additional learning needs, and English as a second language Greater choice in method/level of information received Text confirmation/reminder notifications

Good communication/information-sharing across organisations

Adequate/reasonably priced parking Adequate/reasonably priced public transport Park and ride facilities

Access for those with disabilities/mobility issues

Nicer waiting areas/better signposting

Good access to tests – opening hours

Evening and weekend appointments (if sufficient capacity available to offer them)

Enough knowledgeable /skilled staff Staff with relevant experience/training, including in accommodating special needs

Sufficient staff and other resources

An 'ideal' service?

Elderly patients Travel/transport difficulties, inappropriate facilities/support at testing locations **Disabled** patients Travel/transport difficulties, inappropriate facilities/support at testing locations, inadequate parking Inadequate consideration of needs (especially communication needs) lack of staff knowledge/awareness of Neurodiverse/ALN dealing with e.g., ADHD/ASD, restrictions on entering test rooms with patients, need carefully-designed An equal service patients and carers waiting/clinical environments Systemic inequalities, language barriers, lack of culturally-appropriate services, lack of trust in Minority ethnic services/professionals, lack of engagement with communities/community leaders communities Children and Age-appropriate service, appropriate facilities/activities while waiting, lack of (or lack of awareness of) play therapy young people Lengthy/difficult journeys by public transport, public transport often unreliable, expense of taxis, reliance on Patients who do not drive carers Essential to ask patient/carers Patients on low Cost of travel/parking, having to take unpaid leave to attend appointments incomes what works in advance of Using telephone to make/rearrange appointments, difficulties hearing names being called at testing locations, appointments and when D/deaf patients mask wearing making lip reading difficult developing new facilities and **Digitally-excluded** Disenfranchisement through being unable to access online booking systems, apps, text reminders etc. services patients **Gypsy & Traveller** Lack of trust in, and awareness of, healthcare services, literacy issues patients Patients with low Letters/online information not in easy read formats literacy skills Difficulties getting to appointments, lack of awareness of/not told about available support, particular issues for young carers (e.g., their age = less agency, knowledge/experience ignored, not properly communicated with), Carers potential for 'hospital passports' to flag additional needs, understanding about difficulty for carers to leave the person they care for to attend appointments for themselves

Most staff are aware of training / development opportunities in their role...

...but most felt there are reasons/barriers to taking part in them

KEY BARRIERS



General feeling among staff that having more training and skills development opportunities would benefit them and their patients

Specific need for training in dealing appropriately with patients with additional needs (i.e. learning disabilities/neurodiversity)



Methodology and profile of engagement participants

Methodology and response





Profile of service user questionnaire respondents

Working full time,

21%

Working

part time,

14%

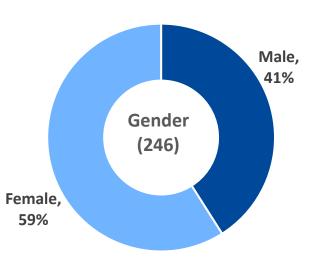
Not working for

another reason,

5%

A total of **275 individuals** responded to the questionnaire

Respondents had the option of answering several equalities monitoring questions



Working

status (247)

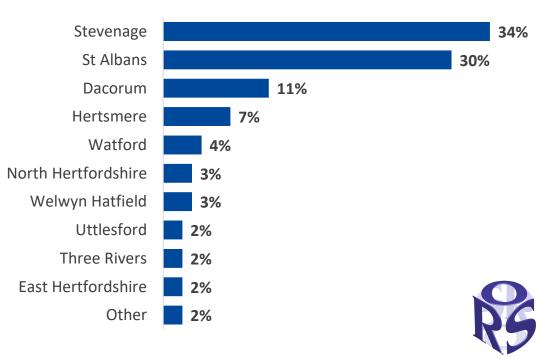
Retired,

60%

Age (247)



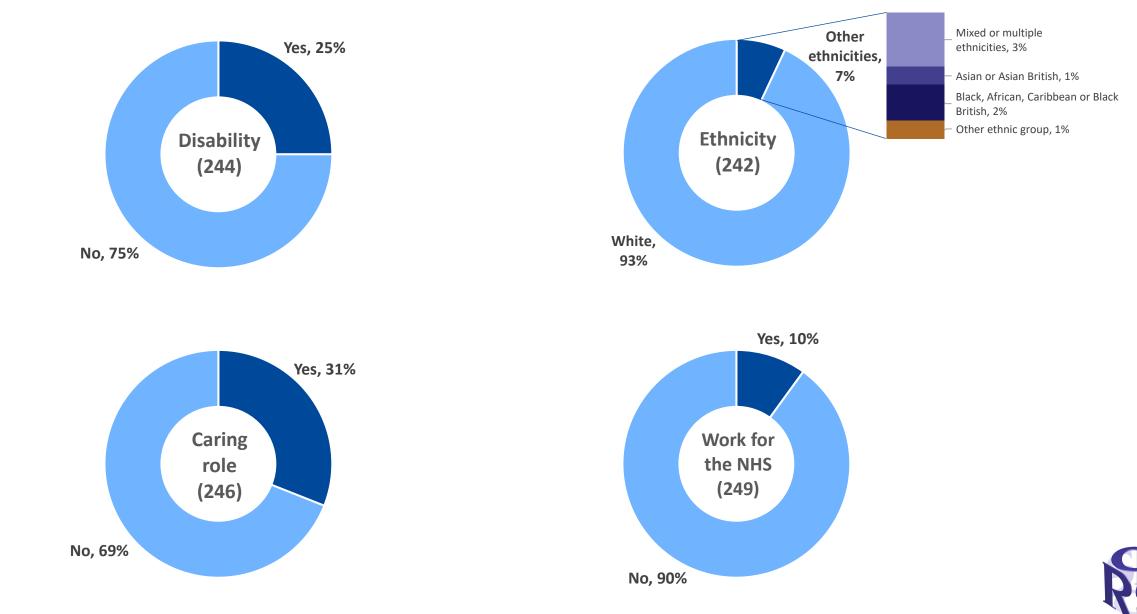
Local authority of residence* (221)



'Base' numbers of respondents who provided answers are shown in brackets

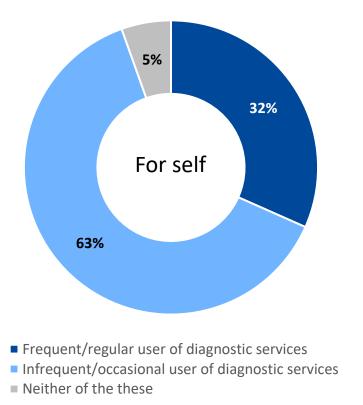
*Based on postcodes, where provided

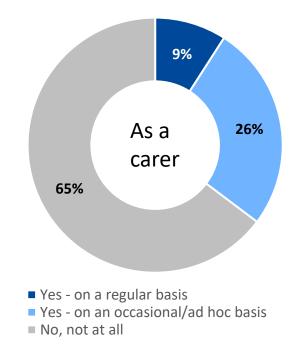
Profile of service user questionnaire respondents



Questionnaire respondents' use of NHS diagnostic services

- Around a third (32%) of questionnaire respondents have been a frequent/regular user of diagnostic services in the last 5 years. Only one in twenty (5%) respondents have not received a diagnostic test in the last five years.
- Around two thirds (65%) of respondents said that they have not attended any diagnostic tests as a carer/parent for another
 person in the last five years.







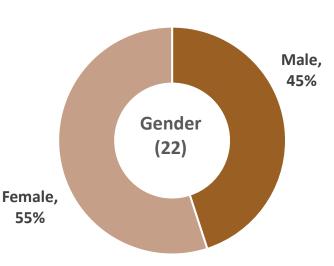
Q1: Thinking about the last 5 years, which of the following best describes your use of NHS diagnostic services? Base: All respondents (275)

Q2: And still thinking about the last 5 years, have you attended any NHS diagnostic tests as a carer/parent for another person (i.e. accompanied another person who was receiving the test)? Base: All respondents (275)

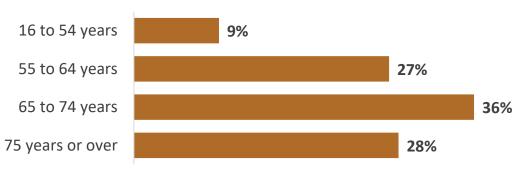
Profile of service user focus group attendees

A total of **23 individuals** took part in 3 online focus groups

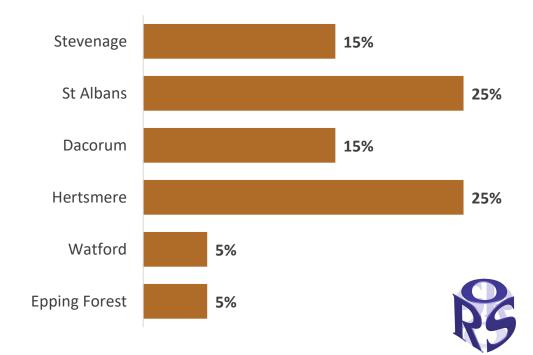
Participants had the option of answering several equalities monitoring questions



Age (22)



Local authority of residence* (20)

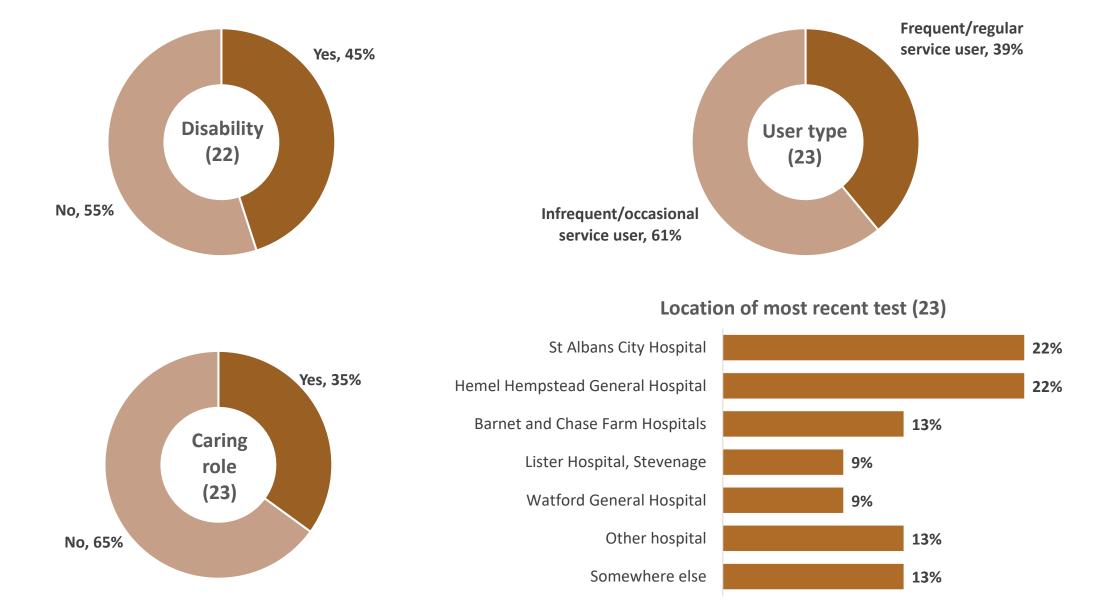


Working full time, 9% Working part time, 14% Not working for another reason, 5% 'Base' numbers of focus group attendees who provided answers are shown in brackets

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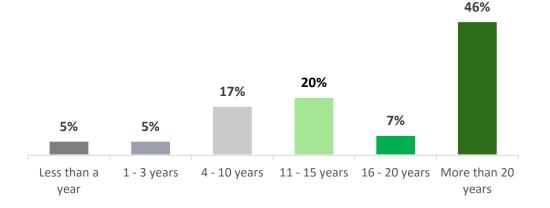
*Based on postcodes, where provided

Profile of service user focus group participants and their use of diagnostic services

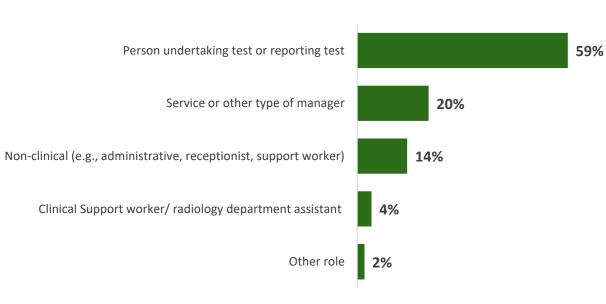


Profile of NHS diagnostic services staff questionnaire respondents

- A total of 49 diagnostic services staff members responded to the questionnaire.
- Respondents had the option of answering several monitoring questions.
- Over two fifths (46%) of staff questionnaire respondents are long serving staff members that have worked in diagnostic services in HWE for more than 20 years.
- Around three fifths (59%) of staff questionnaire respondents identify that they are the person who is undertaking or reporting the test.



Time spent working in diagnostic services in Herts & West Essex



Role in delivering diagnostic services



Q10: How long have you worked in diagnostic services in HWE?

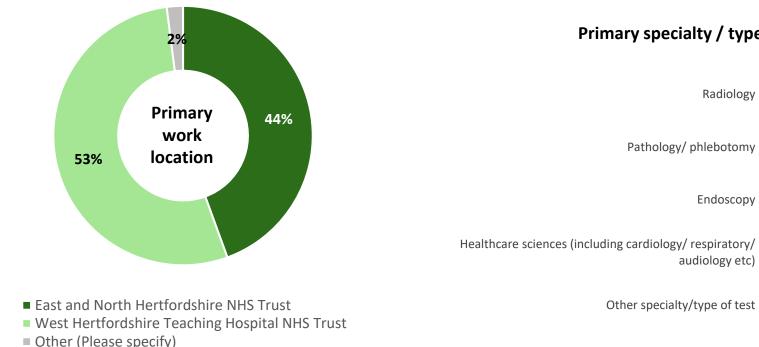
Base: All respondents (41)

Q1: What is your relationship with/role in delivering diagnostic services? (Respondents could select multiple options for this question)

Base: All respondents (49)

Profile of staff questionnaire respondents

- Over half (53%) of the staff questionnaire respondents work at the West Hertfordshire Teaching Hospital NHS Trust. There
 were no respondents from The Princess Alexandra Hospital NHS Trust.
- Over three quarters (76%) of staff respondents said that radiology is their primary specialty / type of diagnostic test that they deliver.



Primary specialty / type of diagnostic test delivered

2%

2%

2%

17%

Q8: What is your primary work location? Base: All respondents (43)
Q9: What is your primary specialism / type of diagnostic test that you deliver? Base: All respondents (42)
Please note not all %s add up to 100 due to rounding



76%

Profile of primary care service provider respondents

In order to gather the views of primary care service providers, ORS attended four pre-existing meetings to explain the engagement process, gather some initial feedback, and encourage participants to submit their thoughts in writing via a pro-forma feedback sheet containing four key questions:

- What aspects of diagnostic services do you feel work well to meet the needs of your patients?
- What aspects of NHS diagnostic services could be changed or improved to better meet patients' needs and/or reduce the likelihood of patients not attending tests?
- What particular approaches to NHS diagnostic services would benefit your patients and/or reduce the likelihood of them not attending appointments?
- If you would like to, describe how you see the role of primary care providers in relation to diagnostic services changing / developing to deliver benefits for patients.

13 written responses were received as follows:

- 11 emails from GPs (two from same practice); one from an Advanced Nurse Practitioner; one from a practice manager.
- Respondents were from Buckhurst Hill (2), Bishop's Stortford (2), Epping, Hatfield, Hertford, Hitchin, Loughton, St Albans, Stevenage, Ware, and Welwyn Garden City.
- Respondents use diagnostic services at Hertford County Hospital, Lister Hospital, QE2 Hospital, Princess Alexandra, St Margaret's Epping, and Whips Cross Hospital.



As part of the programme of engagement activities, eight in-depth interviews were undertaken by ORS researchers with Experts by Experience and representatives of several stakeholder organisations. The purpose was to gather feedback related to the specific challenges, barriers and health inequalities, and other additional needs experienced by members of several seldom-heard communities in Hertfordshire and West Essex.

Interviewees comprised:

- Staff members from the Hertfordshire County Council Adult Social Care (Learning Disabilities) team, including an Expert by Experience, involved in the management and delivery of the learning disabilities nursing service across primary and acute NHS services in Hertfordshire.
- Representatives of two organisations working with and supporting carers (Carers in Hertfordshire; Essex Carers Network) and a carer in West Essex.
- Staff members from CDA Herts' COVID Recovery Ethnic Diverse (CRED) Project, an initiative supporting people from Hertfordshire's Black, Asian and Minority Ethnic communities to access healthcare services.

It should be noted that, in addition to these interviews, ORS analysed feedback from other engagement strands to identify feedback from, and about, groups and individuals with protected characteristics under the Equality Act 2010, as well as other groups and communities faced with additional healthcare needs or health inequalities. This feedback has been incorporated into the relevant sections of this report, and a dedicated section covering issues not raised elsewhere is also included.



'Open' engagement questionnaires are, by their nature, self-selecting (i.e., rather than representing the views of the population as a whole, the outcomes reflect the views of those people who have the motivation and time to respond).

Some demographic groups are more likely to respond via questionnaires than others; in broad terms, younger people, those from minority ethnic communities and those experiencing deprivation are perhaps less likely to be represented in the questionnaire results, whereas older residents, those from more affluent areas and those with higher educational attainment (who are typically more actively engaged in public debate) are more likely to respond.

Furthermore, although NHS Hertfordshire and West Essex have undertaken a programme of promotional activities and advertising to share information about the engagement and opportunities to provide feedback, it is almost always the case that those responding via the questionnaire are already motivated to respond due to pre-existing interest or concerns around the services in question.

In this instance, the highest level of response to the questionnaire came from residents in Hertfordshire, reflecting the fact that there has already been considerable concern expressed and issues raised around the provision of diagnostic services in certain areas, as well as recent changes such as the new CDC at the New QEII Hospital in Welwyn Garden City which have raised public awareness of diagnostic services delivery.



It is important to note, however, that none of the points raised in the previous slide serve to undermine the importance of the questionnaire feedback; in fact, understanding pre-existing concerns and the views of those who feel that they are likely to be particularly affected by any changes to the ways services are delivered is valuable. In this respect, the higher proportion of responses from older residents as well as the representation of the voices of carers and people with disabilities in the questionnaire feedback is an advantage.

To mitigate for the challenges outlined above, NHS Hertfordshire and West Essex commissioned ORS to undertake additional targeted research activities, outlined on slide 21 and reported in detail in this document, to hear feedback from and about several key groups who face challenges and/or health inequalities in respect to NHS services. These include carers of adults and children, minority ethnic communities and people with learning disabilities.

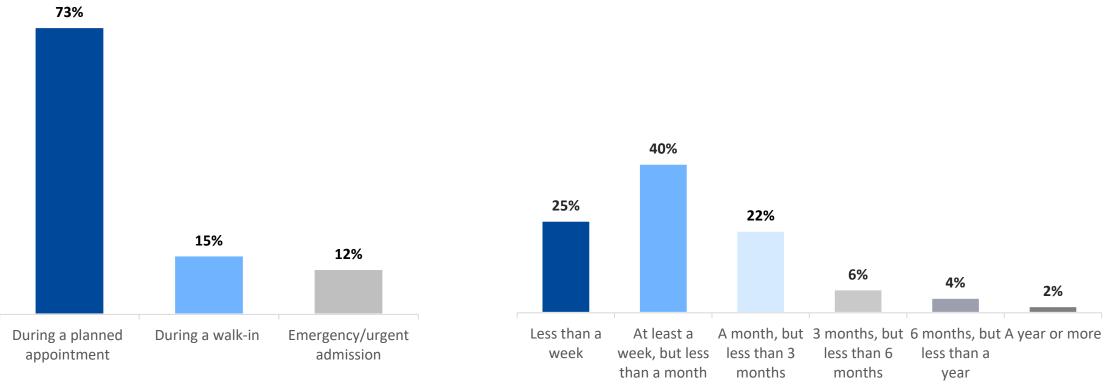
Engaging with residents and advocates in West Essex within the window of opportunity afforded by the engagement programme remained a challenge, but the welcome involvement of primary care practitioners in the area as well as input from focus group participants ensured that relevant feedback was heard. Nonetheless, an important consideration arising from this period of engagement will be how to ensure that members of the public in West Essex are able to input as the wider strategy development process proceeds.

Similarly to the main engagement questionnaire, the staff questionnaire cannot be seen to fully represent the views of the many different staff working across diagnostic services. There is no doubt that the current and widely understood pressures on NHS services across the UK will have impacted on the ability of staff to participate fully. While there was a more balanced response geographically, with responses from both NHS trusts, the highest level of response by far came from staff working in radiology departments, followed by pathology/phlebotomy. As with the wider public, consideration of the most effective ways to continue to engage with staff members across all departments would be advised as the process of strategy development continues.

Service users' experience of diagnostic services

Service user questionnaire respondents' use of diagnostic services

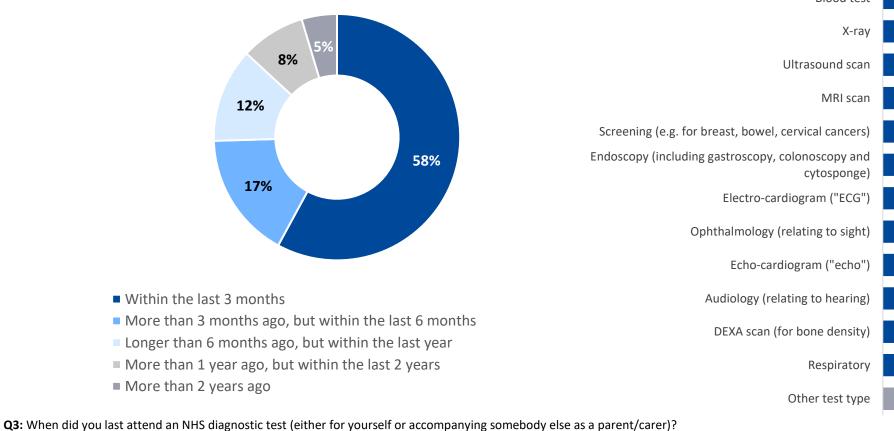
Around three quarters (73%) of respondents who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years attended the most recent test during a planned appointment. Around two thirds (65%) of questionnaire respondents said that they waited less than a month between being referred and actually being seen for their most recent test.

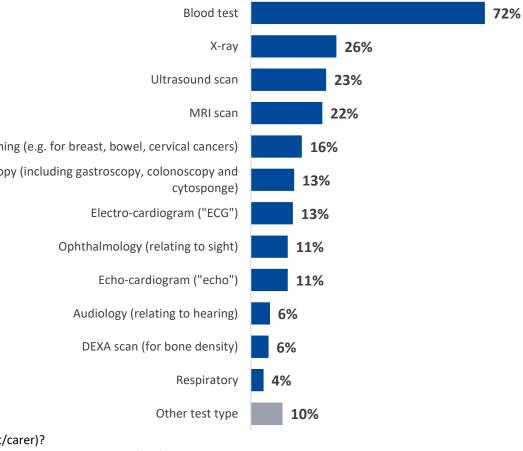


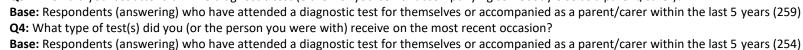
Q7: Did this test (or tests) take place during a planned appointment, a walk-in, or was it because of an emergency admission? [Respondents asked to think about the most recent test]
Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years (259)
Q8: Thinking about the period between being referred for a test and actually being seen, do you recall how long the wait was? [Respondents asked to think about the most recent test]
Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years (259)
Q8: Thinking about the period between being referred for a test and actually being seen, do you recall how long the wait was? [Respondents asked to think about the most recent test]
Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years (220)
Please note not all %s add up to 100 due to rounding

Service user questionnaire respondents' use of diagnostic services

- Three quarters (75%) of respondents who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years have done so within the last six months.
- Over seven in ten (72%) respondents who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years attended a blood test.



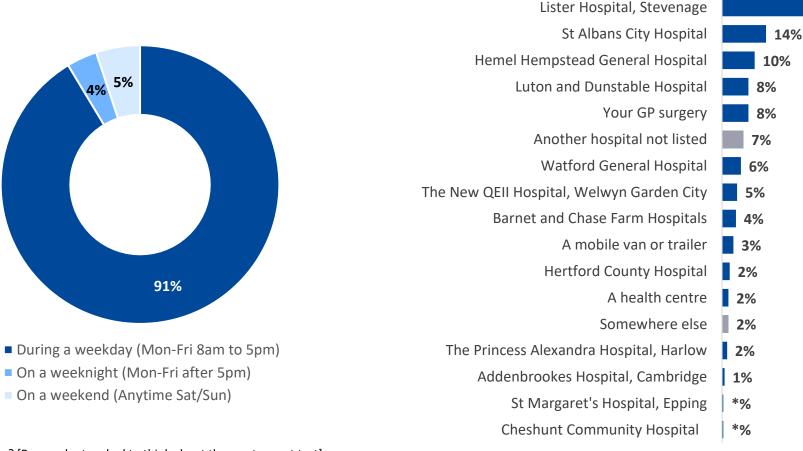


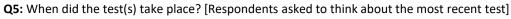




Service user questionnaire respondents' use of diagnostic services

- Over 9 in 10 (91%) respondents who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years said that their most recent test took place on a weekday.
- The diagnostic tests took place in a variety of locations with the Lister Hospital in Stevenage (26%) being the facility visited by the most number of respondents.





Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years (255)

Q6: Where did the test(s) take place? [Respondents asked to think about the most recent test]

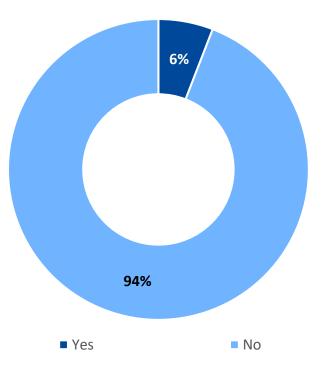
Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years (259)



26%

Service users' difficulties in arranging diagnostic test appointments

• Only around 1 in 20 (6%) questionnaire respondents who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years said that they encountered difficulties arranging the test.



Issues raised by respondents and focus group participants included:

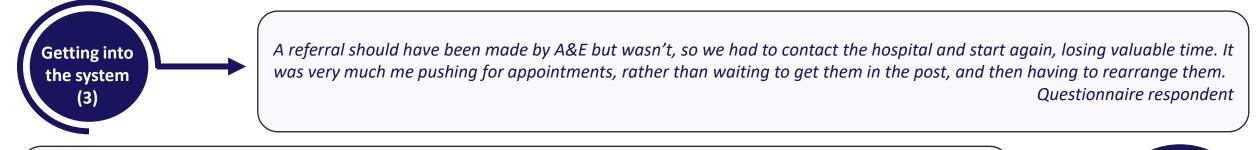
- Long waiting times following referral and 'getting into the system'
- Patients being given inconvenient dates, times, and/or locations that can be challenging to amend
- Late or incorrect appointment and contact details
- Poor and/or confusing pre-test information
- Arranging transportation



Q9A: Did you have any difficulties arranging the appointment - this might be related to language difficulties, disability, making an online booking etc.? [Respondents asked to think about the most recent test] **Base:** Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years (187)

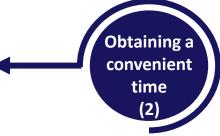
Service users' difficulties in arranging diagnostic test appointments

The questionnaire respondents who had encountered difficulties arranging their test identified several common issues.



There wasn't an option to ring anyone to arrange a date. It was a text message service and if I couldn't do the dates suggested then my X-Ray request would be cancelled. The dates suggested were all on a Sunday when I'm at work. It was pure luck that I was on annual leave on the second suggested date otherwise I wouldn't have been able to attend any of the dates suggested. There was no choice of dates or any option to call anyone to arrange a date.

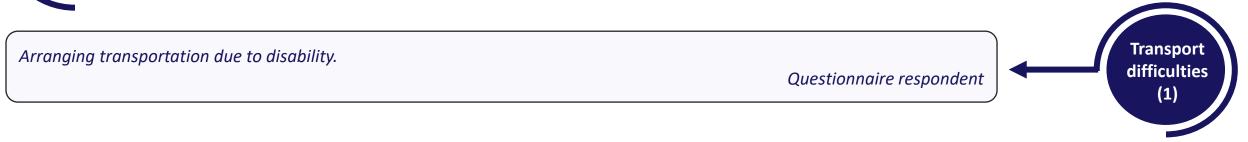
Questionnaire respondent





I was advised to book an appointment myself but every time I tried there were none available. Eventually had the test over two years after the first referral.

Questionnaire respondent



Service users' difficulties in arranging diagnostic test appointments

Focus group participants had experienced similar issues:

Long waiting times following referral

... The length of time I had to wait between my GP referral, to when I actually received an invitation to attend an appointment was several months.

Focus group participant

... You receive a letter with a date, time, and location. Its not always the easiest to change those, particular to a different location if the one they offer isn't convenient. Focus group participant Patients being given inconvenient dates, times or locations that can be challenging to amend

Late or incorrect appointment or contact details Sometimes they give you very short notice. I got one appointment ... I couldn't actually ring the hospital back because they had the wrong telephone number on the letterhead, there's a limited time you have to do these things when you have other things to do. Focus group participant

...I got this wonderful brochure and it said, 'Should you take your usual medication on the day of the test? You should continue to take all of your medications as normal, but some need to be stopped'. So, do you take all the medications or do some need to be stopped? Because both can't be true.

Focus group participant

Poor or confusing pre-test information

I have had occasions where I've had two sometimes three letters for the same appointment. On one occasion they all came on the same day in the same post delivery [...] None of that really helps the patient's confidence... Focus group participant

Suggestions to improve arrangement of diagnostic test appointments

Most focus group participants agreed that expanding and improving online booking and referral technology would improve the patient experience, while acknowledging that not all patients are able to use/access this medium.

For those that are able and wish to do so, text reminders and online referral forms were also thought to be beneficial.

I can't understand why we haven't got a much more advanced online booking system, its woeful.

Focus group participant

I'm extremely old school, I don't own a mobile telephone ... They won't
 phone me up about it, they can't send me a text so they don't contact.
 Focus group participant

...I got a text and then a link to go onto the Lister Hospital website. I was able to book a blood test and go in fairly quickly in a matter of a day or so.

Focus group participant

Any appointment coming through has always been accompanied by a leaflet explaining what the procedure is, so you know what to expect. Focus group participant Good experiences of booking tests via text, online portals and smartphone apps were shared and a few participants praised the quality of the information they had received pre-test.

It is about having the information before you go and that was positive for me for the most part.

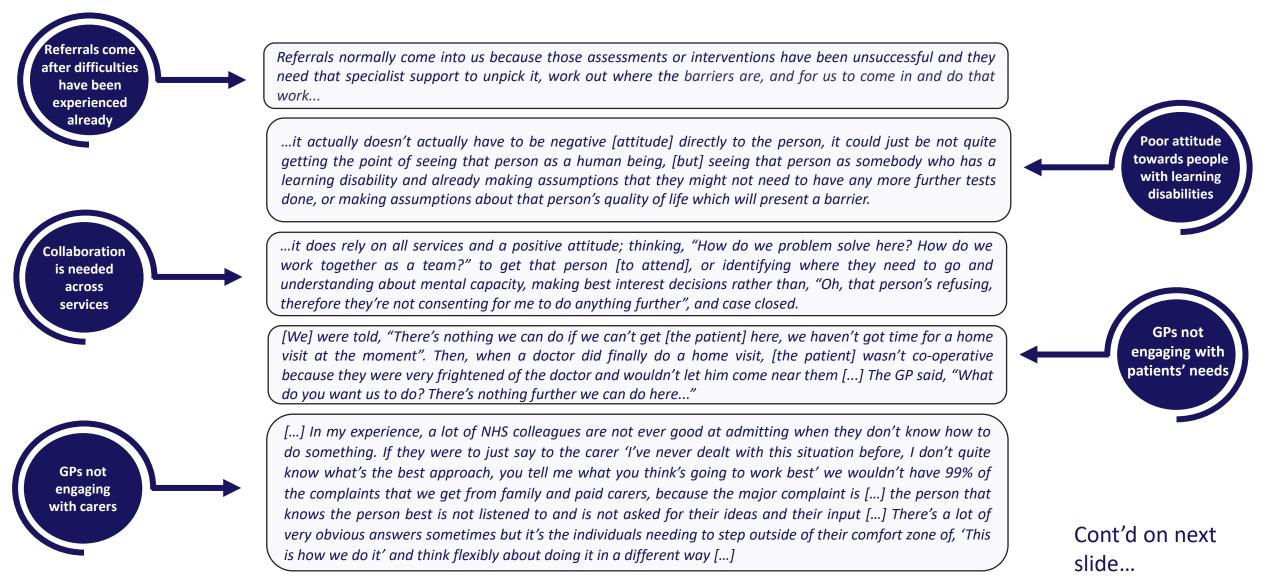
Focus group participant

There was also some praise for the ease of booking <u>urgent</u> diagnostic tests, as opposed to those that are more routine.

I've found personally, the most positive experience of booking has been when it's been urgent; then it seems to go extremely smoothy. Its only when its routine for me that all the problems arise.

Focus group participant

In interviews with Adult Social Care nurses, specific barriers and challenges were identified around accessing diagnostic services for patients with learning disabilities.



Cont'd...



[GPs] are not always effective in saying, 'I'm referring this guy to you, you need to engage with the carers to get him to do pre-planning', therefore the hospital just invite them as standard and then it all goes wrong. And when it's gone wrong once, it's very hard to fix [...]

Risk aversion

among GPs

[...] Has the GP got a clear record of what that person's communication needs are and do they share those with hospital? We have fantastic GPs who know that you have to talk about trains for 10 minutes before you even attempt to talk about anything else, but if they don't put that in the referral letter, [a patient with learning disabilities] might never engage with the consultant and might refuse the diagnostic tests [...]

[Another challenge] is around mental capacity; GPs might say, 'He needs to go in and have a test', and the carers will say, 'No, he'll never tolerate that'. The GP records that the tests been refused, when in fact it's not the carers responsibility or the family's responsibility to refuse. It's a clinical decision [and] they need to go through: Does the person understand? What do they need to understand? What's the risks if they don't?

[...] It's very easy from a clinical point of view to say, 'This person might have an underlying heart condition and if I give this person sedation to complete this assessment it may be harmful [...]'. The difficult bit is getting the clinicians to make the decision around the risk verses benefit [...]

In relation to the latter point, an incident was recounted whereby in a life-threatening case, "three failed attempts at A&E" were experienced because nobody had planned sufficiently and had "those conversations around [...] who do we need involved, how do we optimise the experience of this individual coming into hospital under sedation?" It was said that unless a person is under a consultant at the hospital, there is often no-one available to take responsibility for them, though some areas of the country are trialling having a specialist consultant for learning disabilities within hospitals with admitting rights for these sorts of cases.

An Expert by Experience with a learning disability also described the challenges they have faced in arranging and attending appointments due to high levels of anxiety, as well as an example of a successful adaptation to services in advance of an appointment that had helped overcome them.



I've always had a fear of hospitals; when I was growing up I had a bad experience when I was younger and as I grew older other experiences have happened where I've found it challenging [...] and I had a really bad experience a couple of years ago where the dentist just didn't understand me, he didn't understand my learning disability, he felt that I was rude and never wanted to participate in anything he asked me.

[A] blood test is actually a really long process if you're scared of needles, need a lot of understanding of why you need to have to sit there and tolerate that to accept that blood test, so it does rely on a really good individuals who are taking blood to be successful there and to really think outside the box.





I had an annual health check-up [...] and this nurse, we did everything we were there to talk about and then right about 15 minutes before the end she said 'okay, we've gone through everything else and that's fantastic, I now want to have a last 15 minute chat with you about needles' and I was literally ready to walk out of the room because that's how bad my needle phobia was and she said "look, you tell me what it is you don't like about them...I'm still scared, I don't think anything will take that away from me but because of this nurse helping me and being so positive and working with me to get me there and to get me to understand, I do feel in a way that she saved my life.

Indeed, the importance of making reasonable adjustments was also stressed by the Adult Social Care nurses, who were particularly keen to ensure these are used to ensure service integration rather than segregation.



[...] When you're talking about accessibility it's not just a ramp on the front of the building; it's the accessibility of the whole service. How can those reasonable adjustments be built into the whole pathways and structures for people with learning disabilities?

[...] We don't create separate services for people with learning disabilities, we work with the services that are there for the whole population and we look for solutions and ideas as to how that service can be made accessible for those individuals. [If] you segregate the care, you'll never provide holistic care. It has to be about how we're enabling the current services to be more holistic, not how we're providing something to make them more segregated [...]



Skills/ awareness raising throughout organisations

[...] We should not be indispensable because we should be building those skills of awareness and understanding into the rest of the structure in the hospital so that they can follow things through when we're not there, it shouldn't all hinge on an individual nurse needing to be there to make things happen.

In interviews, the potential for life-threatening outcomes in cases where reasonable adjustments have not been made for people with learning disabilities were described, including:

- Assumptions being made that patients with learning disabilities will not be able to tolerate diagnostic tests and referrals are not made unless an advocate for the patient becomes involved, which might include having to make a complaint;
- Injuries being left untreated when patients with learning disabilities experience extreme anxiety to the extent that ambulance service staff are no able to transport them to A&E;
- Late diagnosis of a terminal condition due to an apparent lack of support in place to gain an early diagnosis or life-saving treatment for someone with learning disabilities and challenging behaviour, and
- An unaccompanied patient with a learning disability finding the experience of being in hospital *"really scary"* because staff
 members administering tests did not explain procedures. The situation led to the patient agreeing to inject their own medication,
 in order to avoid having to stay in hospital overnight, without understanding why it was necessary and lacking the confidence to
 self-administer.

An Expert by Experience described visiting their GP as much easier than attending the hospital without a family member or specialist learning disabilities nurse.

Busy hospital staff, they said, do not usually recognise their learning disability, or assume their stress reactions mean the learning disability is more severe than is the case. They contrasted this with their experiences at their local surgery.

I do find going to the GPs a lot less stressful than going to the hospital and I think that's because with a GP, they get to know me; the nurses get to know me [and] if there's any new staff they've got it flagged up on the system about the reasonable adjustments I need...

Expert by Experience

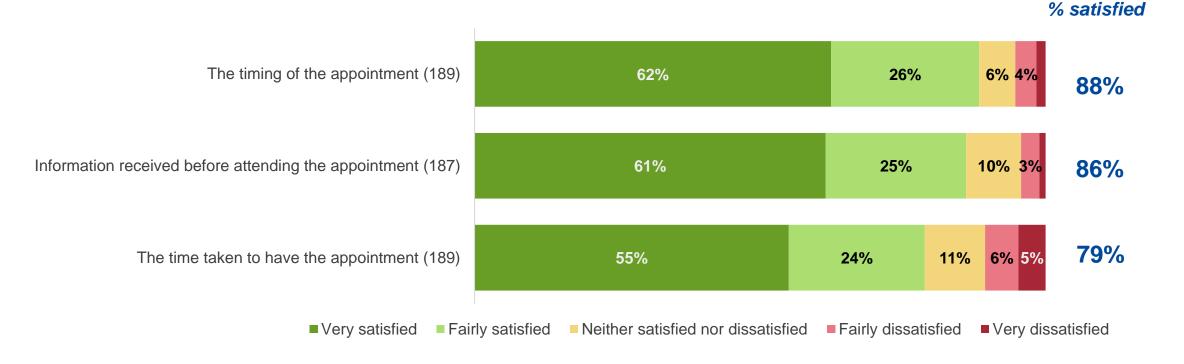


Service users' views on current diagnostic services

Service users' experiences leading up to appointments

Among questionnaire respondents, satisfaction with their pre-appointment experience was generally high:

- Almost nine in ten respondents were satisfied with the timing of the appointment (88%) and the information they received before attending the appointment (86%).
- Satisfaction with the time taken to have the appointment was slightly lower, although almost two fifths of respondents (79%) still said they were they are satisfied.



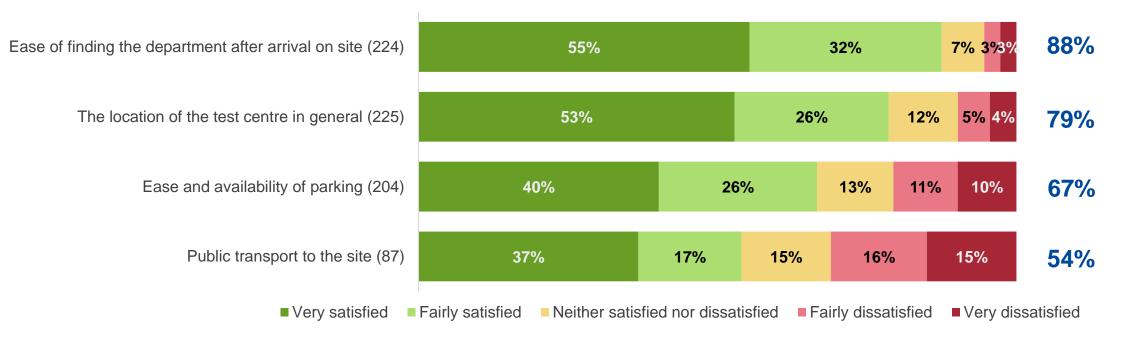


Q10: Still thinking about the appointment you were given for your most recent test visit... To what extent were you satisfied or dissatisfied with each of the following? Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years. 'Base' numbers of respondents who provided answers are shown in brace Please note not all %s add up to 100 due to rounding

Service users' experiences of accessing appointment locations

Satisfaction levels around the logistics of getting to the appointment were more varied among questionnaire respondents:

- Almost nine in ten respondents were satisfied with the ease of finding the department after they had arrived at the site (88%) and nearly four in five (79%) were satisfied with the test centre location in general.
- Views on parking and public transport were more mixed; just over one fifth of respondents (21%) expressed *dissatisfaction* about the ease and availability of parking, compared to two thirds (66%) who were satisfied.
- Almost a third (31%) of those who provided a response described themselves as dissatisfied about public transport.



% satisfied



Q11: Now thinking about where you had to go for the test... To what extent were you satisfied or dissatisfied with each of the following?

Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years. 'Base' numbers of respondents who provided answers are shown in brackets

Service users' experiences of accessing appointment locations

A number of focus group participants noted the variation in travel routes across the area, and the effect this can have on attending an appointment.

One participant noted the challenges posed by east/west journeys in comparison to north/south.

One of the difficulties I find with Hertfordshire is we have wonderful north/south journeys, main road routes etc. but, apart from the dreaded M25, we don't have particularly good east/west journeys.

Focus group participant

[...]My experience was certainly very good. That's why I made the comment that if a number of people are travelling there, maybe there is a need for a service like it in the northern area.

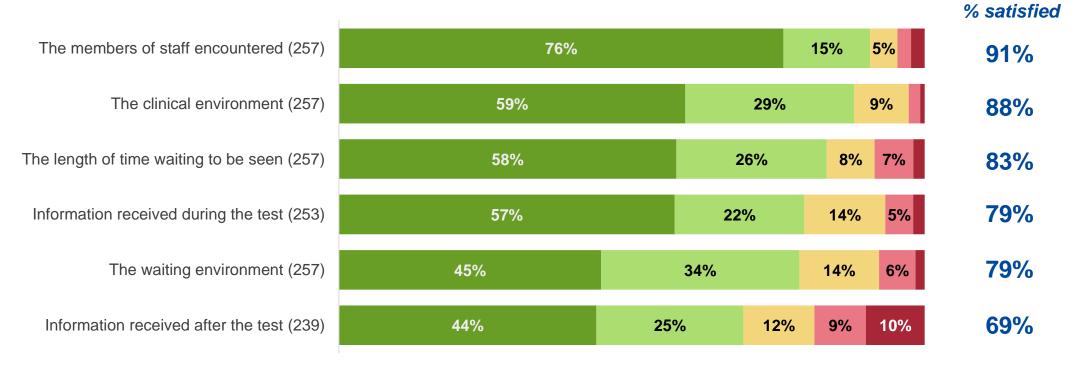
Focus group participant

... Mount Vernon [is] a big unit. Therefore, they can move patients around to capture and recover delays. It seemed to be a good operation to me ... I wonder whether some units such as that would be useful in this part, save people from this part travelling down to Mount Vernon.

Focus group participant

 A couple of participants specifically praised the scanning unit at Mount
 Vernon, noting the possible benefits of a similar facility in North Hertfordshire to avoid a challenging travel route.

- Satisfaction levels with different aspects of test appointments indicate a range of views.
- Positively, around nine in ten respondents are satisfied with the members of staff they encountered (91%) and the clinical environment (88%).
- The lowest scoring area is the information respondents received after the test, however, this score is still good with nearly seven in ten respondents (69%) saying they are satisfied.



Very satisfied Fairly satisfied Neither satisfied nor dissatisfied Fairly dissatisfied Very dissatisfied



Q12: Thinking about what happened after you arrived for the test... To what extent were you satisfied or dissatisfied with each of the following?

Base: Respondents (answering) who have attended a diagnostic test for themselves or accompanied as a parent/carer within the last 5 years. 'Base' numbers of respondents who provided answers are shown in brackets

Focus group participants described communication (and, where possible, reassurance) as one of the main influences on their experience of attending appointments. Those who experienced good communication generally felt positive about the process of diagnostic testing.

The doctor who did the scanning talked me through what she was seeing whilst she was seeing it; that was useful and helpful.

Focus group participant

They were all just amazing, especially in terms of communication, which personally I think is the key thing. You can cope with most things if people talk to you like you're a human being. Focus group participant

... a couple of times they have at least given me the assurance they're not seeing anything too sinister or of real concern. That, from a patient perspective is really helpful. There's nothing worse than going for a test and coming out having no idea what's going on.

Focus group participant

In contrast, those who received poor communication at a diagnostic test felt it had negatively impacted their experience. In one case, for example, a patient had waiting three hours at an urgent care centre only to be informed that the test she needed was not performed there.

From the moment I walked through the door, to the reception. I'm not able to follow instructions by osmosis, someone needs to tell me. To find where I need to be, I need to be told. I felt like I was being a nuisance for having to ask where I need to go.

Focus group participant

The urgent care centres need to be much clearer about what diagnostics they're able to do for minor injuries ... I got taken to QE2 urgent care centre, when I got there I waited for the best part of three hours in a lot of pain, only to be told they didn't do pelvic X-rays, which is what I needed.

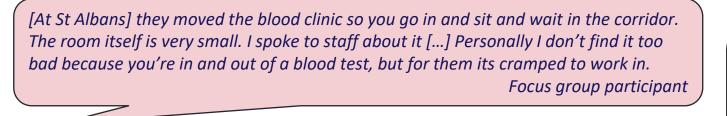
A couple of focus group participants shared their negative experiences of attending diagnostic tests in mobile units. Both tests produced inconclusive results, and there was a perception that the 'inferior' mobile equipment was to blame for this.



I did have a situation where I had a CT in the mobile unit and the results were unclear so they then referred me on to an MRI in the hospital [...] If the equipment in the mobile unit was not able to detect the issue it was meant to be looking for, then don't send me there.

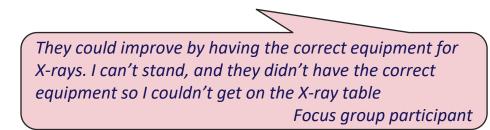
Focus group participant

There was also some sense that services generally are often overbooked and that certain facilities are unsuitable for diagnostic tests – not least as they do not provide adequate environments for staff



One was as the Lister hospital [...] they had clearly overbooked the number of people there; it was crazy. How they go into that situation, I don't know, it was chaos.

The issue of insufficient disabled access in some diagnostic settings was raised. Two participants shared their experiences of attending a test without provision being made for their physical disability. One described feeling hostility from members of staff at the facility.



They weren't very impressed with the fact I was in a wheelchair and didn't have a carer with me to help me. I went to use their changing room and [it] wasn't big enough for my wheelchair to get into. It was as if I was an absolute burden...

Focus group participant

Similarly, interviewees involved in training NHS staff and supporting adults and children with learning disabilities to access health services identified areas of concern in both the environment and the approach of some staff.

Do we need to think about [someone] becoming hyper-sensitive to noise? Do we have to think about low stimulation auditory environment? Are the lights going to trouble [someone]? You have to really think holistically about [someone] to ensure you get that outcome.

Adult Social Care: Learning Disabilities

It boils down to accessibility, flexibility and the respect of people with an intellectual disability [... People are not very welcoming [and] don't understand learning disabilities; that's a huge barrier that goes right to the top - clinicians and surgeons - all the way through to people in the café at hospitals. There's a real lack of understanding, people are more often than not frightened because of the noises or the challenging behaviours that people with learning disabilities present with.

Adult Social Care: Learning Disabilities

Despite some negative feedback, some focus group participants shared positive experiences of diagnostic tests, particularly citing friendly staff and timely/efficient appointments.

[...] the clinicians and technicians are lovely and very efficient and do exactly what is required, I've had no difficulties at all and I've had great respect for them. The test itself professionally carried out.

Focus group participant

I went to the appointment two days later at Hemel Hempstead hospital and had a fantastic experience, I was parked, in and out within 20 minutes...

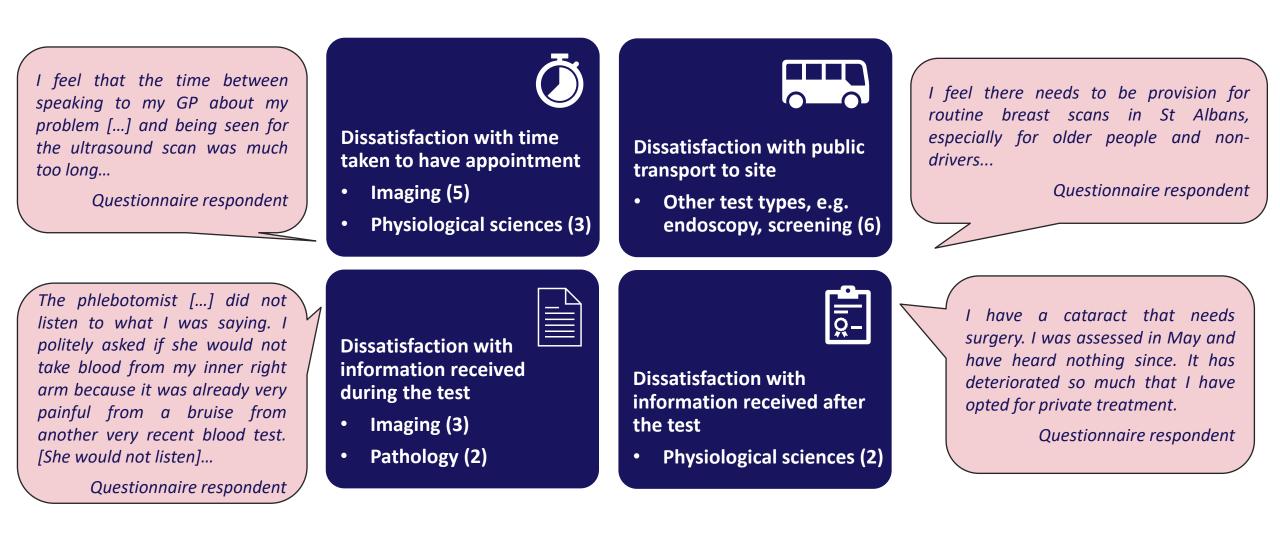
Focus group participant

In regard to the actual test, all the ones I've had recently, the timing has been very good, both in terms of blood tests and MRI tests. The appointment is at whatever time it is, I get seen fairly promptly, within five minutes of that time...

Focus group participant

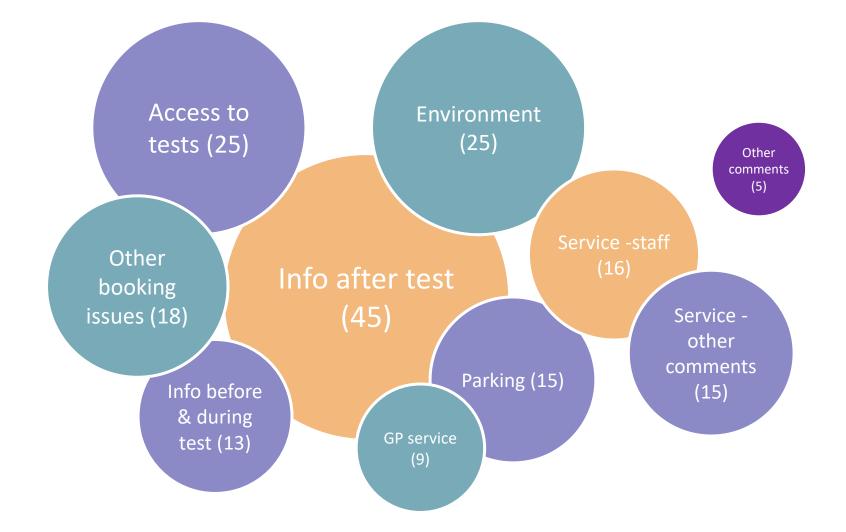
A couple of participants described notably positive environments and treatment at their diagnostic tests; in particular, they felt they were treated as 'human beings' and shown respect and kindness throughout their appointment.

I just wanted to be positive. At Hemel they have improved the service there for blood taking because what they've done is sperate the specialist clinic from the normal blood test. It used to be terrible; you'd have to wait for about an hour. The tests are separate in a big space. It was really good in Covid because there was so much space so you could be separate ... Positive about that, the experience is good. Everyone is very friendly and welcoming and reassuring.



In the questionnaire, users of NHS diagnostic services and those who had attended an NHS diagnostic test as a carer/parent for another person (i.e., accompanied another person who was receiving the test), were asked:

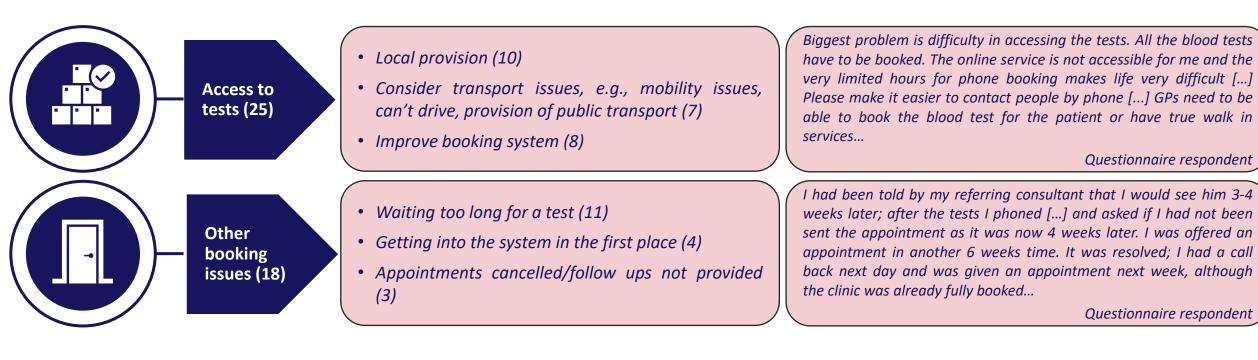
'Thinking just about this last visit, if there are any specific ways in which your experience of attending the test could have been improved'.



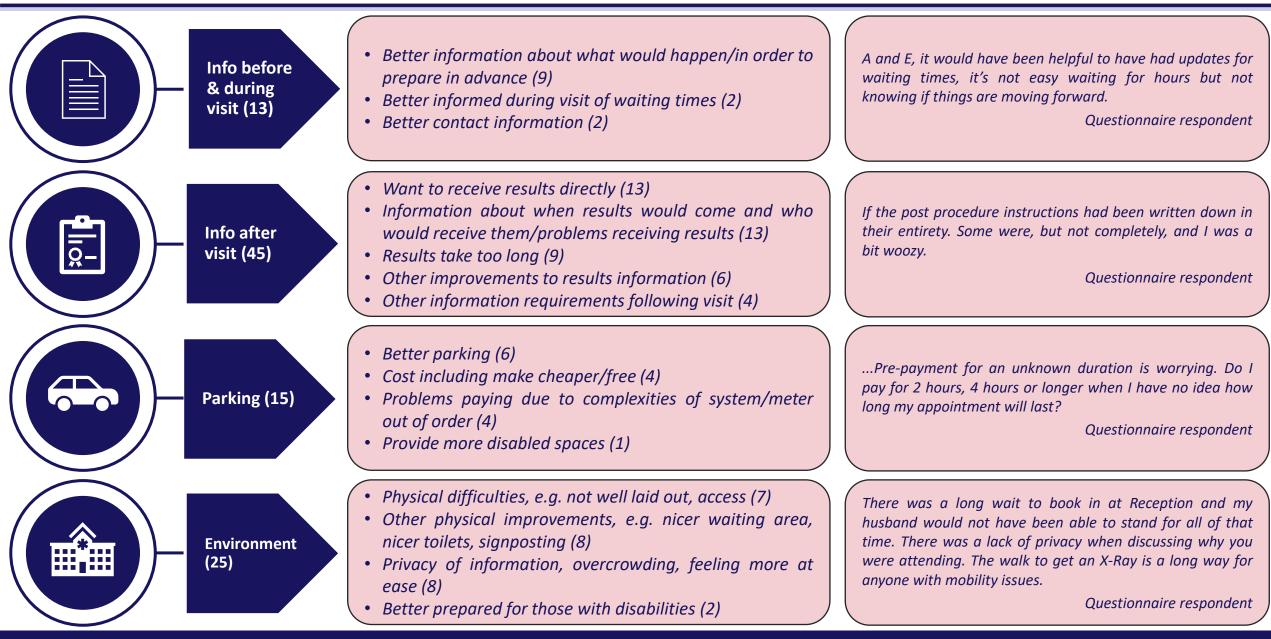
Further detail around these themes is provided in the following slides.

Of those providing a response, one of the biggest issues talked about was information received after the visit (45 respondents) which mainly related to the issues surrounding the provision of results.

This was followed by problems accessing tests (25 respondents), including difficulties getting to venues and in booking the test itself; and issues surrounding the environment of the diagnostic testing venues (25 respondents), such as the layout of the venue, how comfortable the waiting areas and facilities were and other things that would make them feel more at ease during the visit.



How the experience of attending diagnostic tests could be improved



Numbers in brackets relate to number of respondents providing comments in this category.

How the experience of attending diagnostic tests could be improved

Service - Staff (16)	 Improve treatment before visit (1) Improve treatment during visit (10) Improve treatment after visit (1) Staff training e.g. equipment, conducting tests (4) 	I took my son for blood test. He was very anxious and the phlebotomist was helpful. He did try but my son did not allow a blood test. I feel a lack of knowledge regarding ADHD/Autism is a factor as to why the test was not successful [] I did put the information regarding my son in the booking on-line. Questionnaire respondent
Service - Other (15)	 Waiting too long / more walk-in slots required (9) Share information across organisations (3) Co-ordinate tests (2) Co-ordinate between consultants (1) 	The person I saw did not initially know why I was there until I told her Questionnaire respondent
GP Service (9)	 Poor contact/communication about results (4) Not providing enough information about the test and correct documentation (3) Can't get hold of them (2) 	The follow up results information from our GP surgery is very poor. I have had no contact from the surgery post test and the only way to find out about test results is to either ring up or access the results via the NHS app [] A telephone conversation with someone who knows what they are talking about is really what is needed. Being left to the individual to find out is unacceptable, in my opinion. Questionnaire respondent
Other (5)	 Pain experienced during/after test (3) Put appropriate plan in place for after test (1) Issue with the consultation exercise (1) 	I was offered no pain relief or anything to reduce the swelling. Months later, I'm still limping badly and unable to see a GP, I paid to see a private physio [] I am still limping and still can't get an appointment with a GP. I am £1,000 pound out of pocket [] and have completely lost faith in GPs/NHS. Questionnaire respondent

Numbers in brackets relate to number of respondents providing comments in this category.

How the experience of attending diagnostic tests could be improved

Focus group participants felt there needs to be more joined up working and communication between referring GPs and other members of staff such as administrators and clinicians - as sometimes the lack of communication can cause inconvenience, frustration and confusion.

Sometimes there's misinformation and miscommunication between the GP and admin staff, that can be frustrating Focus group participant

> I have had problems where they haven't wanted to take the bloods that the GP told me I needed but didn't write on the form. I've also had problems going for scans where they didn't want to do the bits of me that the GP said I was having done. Focus group participant

... I was invited to go last Sunday. An hour and a half before the appointment I got a voicemail to say 'actually can you come in as soon as you can, we need to do some pre-tests' ... We went over and they wanted to do a [certain] test ... I told them they did them last February; I was in the very same room 6 months ago. They went through the records and saw all the results. So I didn't need to go an hour early. When they got all the results and I did see someone, the consultant said he was really sorry and they didn't need to see me because I ... need to go [elsewhere]. I said I had already been referred [there] and she said no I want to refer you to this type of [condition] ... It's confusing. Eventually I said, 'Have you got any idea when or where I'll be going and he said, 'No, ... I'm just down here for the day, I haven't got a clue'. Absolute confusion.

Receiving test results

A few participants said that they only receive test results in the event of abnormalities. Most felt that GPs should contact patients regardless of a negative or positive result. Another felt that GPs/clinicians need to be clearer with patients on how to collect test results to avoid confusion.

If you hear nothing, apparently its alright, they only contact you if there's something to say. The problem with that is you go into the whole space of have they had the results, or have I missed the contact? I just find it really frustrating...

Focus group participant

I think the communication should be either, 'We're going to contact you or you should contact us'. But I haven't received any meaningful communication either before or after.

Focus group participant

Some other participants described the convenience of accessing test results via an online portal, NHS app or text message.

I'm signed up to patient access and you can log on there and see all your results [...] and see your medication on there. My prescriptions are on there. Its quite useful

Focus group participant

I had my blood test at the GP and they texted me the results, that was very good. Focus group participant

However, online portals and the NHS app can, it was said, be difficult to navigate; and a couple of participants felt that analysing results via the app can be challenging.

... Accessing your GP information online, at my GP practice you can do that, but if you want to compare to a blood tests you had a year ago, you have to go back onto that one and jump between the two and write them down and things, it's a bit bonkers. Focus group participant

Receiving test results

A couple of participants that access their test results via the NHS app said they would prefer a face-to-face meeting with a healthcare professional to analyse them in person. This, it was said, helps eliminate anxieties around test results and allows patients to see the progression of results over time.

What I've always found is if you can get the diagnostic done before you see the specialist and they have all the information there, if you ask a question, he can look at the results and tell me if its got worse compared to last time or not. When you simply have the results, its a snap shot at the particular time, you don't know if its got better or worse than last time.

Focus group participant

When you look at them ... Of course the first thing you do is you go onto Google [and] I think, 'Oh my god have I got that?!'

Focus group participant

It should be noted that there were a few inconsistencies across the three focus groups in relation to patient technology. While some were able to book appointments and view test results online, a few others were not aware of this technology and/or did not have access to it.

I've used patient access for repeat medication and I can see my medical history, but I do not get test results from diagnostic services.

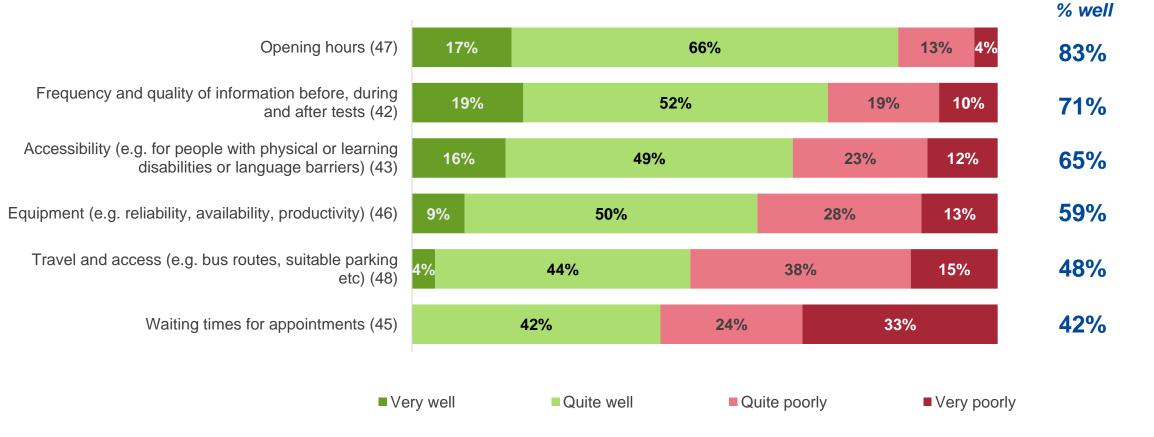
Focus group participant

There could be better communication of what's available for people. Some of the positive things out there that people aren't aware of.

NHS diagnostic services staff members' views on current diagnostic services

Are diagnostic services meeting the needs of patients?

- The six aspects on the staff survey related to patient needs show a range of views.
- Positively, over four fifths (83%) of staff respondents feel that the opening hours are meeting the patients needs well.
- However, less than half of staff respondents feel that the travel and access to get to the appointments (48%) and the waiting times for the appointments (42%) are meeting patients needs well. These results indicate areas that could be targeted for improvement.



Q2: Based on your experience, do you think diagnostic services where you work are meeting the needs of patients well or poorly in terms of ...

Base: All respondents (answering). 'Base' numbers of respondents who provided answers are shown in brackets

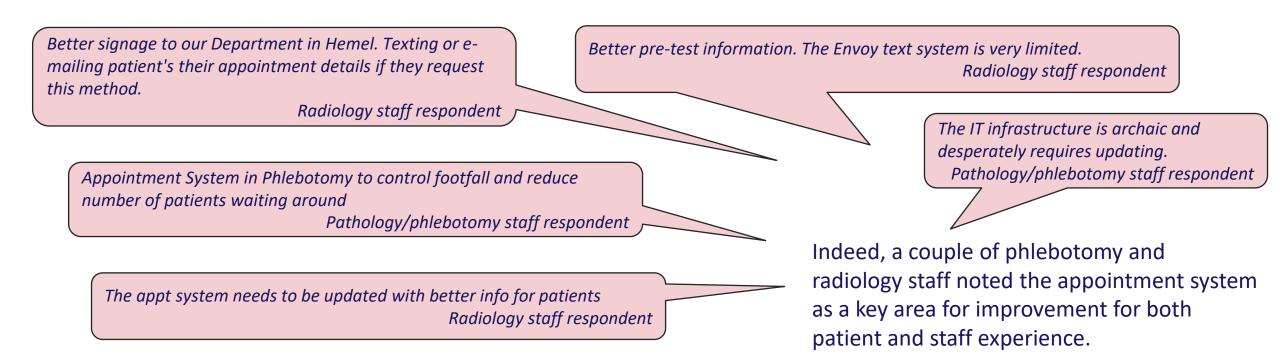
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Some staff members were positive about the pre-test process. The use of text reminders was noted as a particular positive that should be implemented more widely to improve the service.

Implementing a text reminder service for appointments to patients that agree for us to use their number. Other departments use this service and it may also benefit radiology service.

Pathology/phlebotomy staff respondent

In contrast, some felt that the pre-test patient experience could be improved.



Staff views on arranging diagnostic tests

More equipment has meant more lists being put on in and out of hours which has helped decrease waiting times caused by COVID. Radiology staff respondent

We are replacing our x-ray equipment - which is improving everything, however there is still some old equipment Radiology staff respondent

Our demand is more than our capacity. We require additional soundproof rooms, to increase capacity, which will reduce waiting times.

Pathology/phlebotomy staff respondent

Radiology staff felt that the replacement of old equipment has improved their service by reducing waiting times for patients – and that continuing to do this would lead to further improvements.

Specifically, a pathology/phlebotomy staff respondent felt that additional soundproof areas could improve the service.

I think we work well, efficiently, and are a good team.

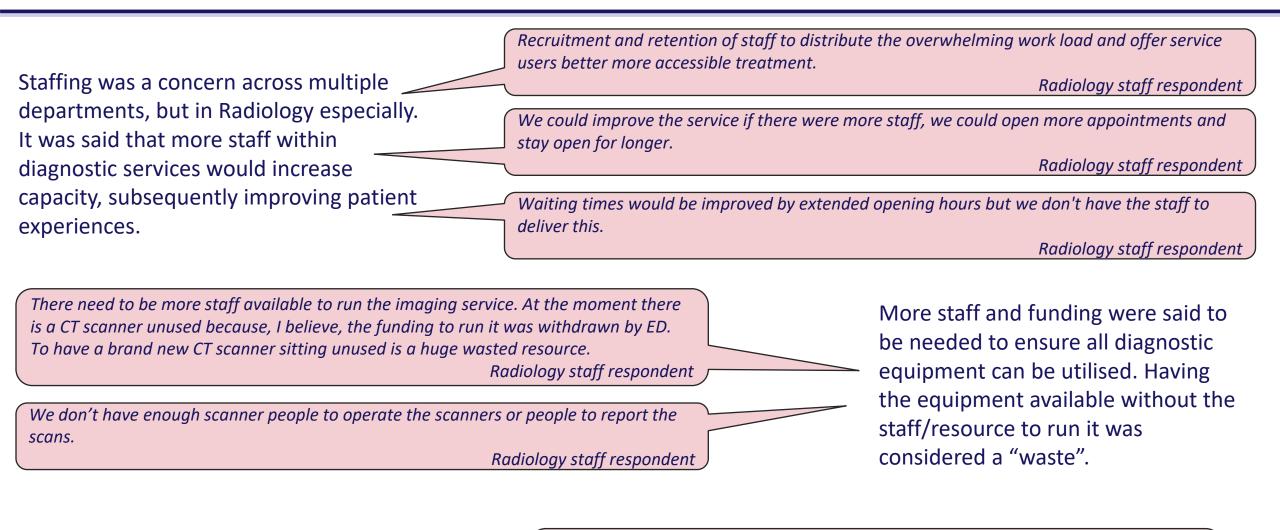
Radiology staff respondent

Radiology staff respondents were positive about the service offered to patients. It was said that staff provide as positive experience as possible for patients undergoing diagnostic tests, and typically meet important targets.

The radiology team provide a caring and responsive service to the patients. Cancer wait patients are always scanned inside their target of 2-weeks unless through their own choice. We provide a 48-hour abnormal chest x-ray report to CT scan.

Radiology staff respondent

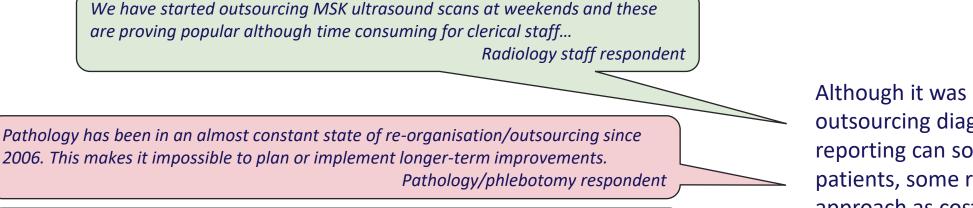
Staff views on diagnostic service resourcing



It was also said that better pay and conditions for staff would help implement service improvements. Most scanning lists only run 9-5 Monday to Friday. If we went to 7am-10pm, 7 days a week we could more than double the number of appointments available for scans. What we need is fair payment to encourage the staff to work extra lists.

Radiology staff respondent

Staff views on outsourcing diagnostic services



Stop outsourcing reporting of scans and pay your inhouse consultants to do the extra work. They are the same consultants doing it for the outsourced companies anyway. Radiology staff respondent Although it was acknowledged that outsourcing diagnostic testing and reporting can sometimes benefit patients, some respondents criticised the approach as costly and a barrier to longer-term planning

To reduce outsourcing and improve internal testing, some suggested a need for specialist staff and more training/upskilling.

I find there is a shortage of some specific skill sets for specific ultrasound scans, e.g.
 neck/thyroid aspirations & biopsies and USGIs

Radiology staff respondent

When outsourcing services to a 3rd party, make sure the whole process, including repatriating reports and images is included in the scope and price of the service. Radiology staff respondent If outsourcing is to continue, it was considered essential that the cost of doing so is carefully considered to ensure value for money.

Primary care practitioners' views on diagnostic services

What aspects of diagnostic services work well to meet the needs of patients?

- Walk-in services and same day appointments where offered (i.e., chest x-rays/fracture rule out)
- Ability to order tests online
- Easy to request / straightforward referral forms
 - Quick turnaround time for most blood test results
 - Some good communication from hospitals

Online booking of bloods is good for most patients

Advanced Nurse Practitioner

Ability to walk in for x-ray at Herts and Essex works well for patients. *Open access x-rays offer great service and prompt reporting.* GPs St Margaret's Epping for acute x-rays, good access. Patients value being able to use St Margaret's. GPs Good communication from PAH [Princess Alexandra Hospital] radiology about results. Whipps Cross are very approachable, with [extension] number provided for each of the diagnostic teams

GP

But whole system has worsened since Covid

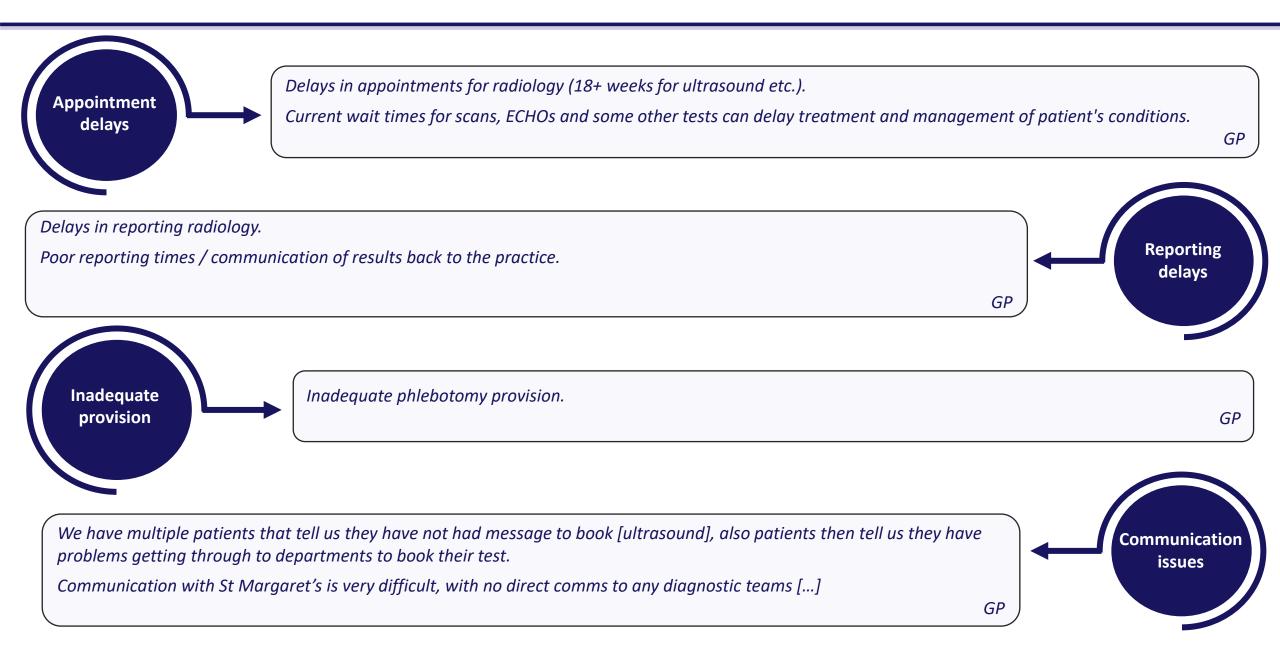
Diagnostics in most areas have been rubbish post-*Covid* [...] *and reporting is even worse. Turnaround* times are appalling

Pre-pandemic - worked well. Good range of diagnostics



GP

What aspects of diagnostic services could be changed/improved to better meet patients' needs and/or reduce DNAs



It is unclear how the patient will be contacted, sometimes rejected, if not attended but [they have] not had time to ring to book.

Difficulty in contacting radiologist / pathologist for advice.

PAH radiology seem to have high number of failed contact and then discharged patients with test not completed (ultrasounds).

We do have problems with blood test requests as even when we future date them the date on ICE is the day [the] request [was] made and this can lead to wrong tests being done and patient having to reattend. This is particular issue with care homes where phlebotomist then has to go back out again.

Invites to patients from St Margaret's expire too quickly meaning that the patient then needs to come back to the GP to have it requested again (e.g. Ultrasound).

Rejected referrals due to stricter guidelines re: eligibility (GPs need to write more).

GPs

[In West Herts] requesting runs through ICE [...] patients have the old-fashioned way of taking a pathology form in with them to the hospital blood clinic. In E&N Herts NHS Trust, they use an electronic system and appointment booking which makes it easier for a patient to arrive without a pathology form. Therefore, this means the patient doesn't need to come down to the surgery to collect a form. We can text a patient a form, but this relies on patients having smart phones and being able to print off at home.

Practice manager

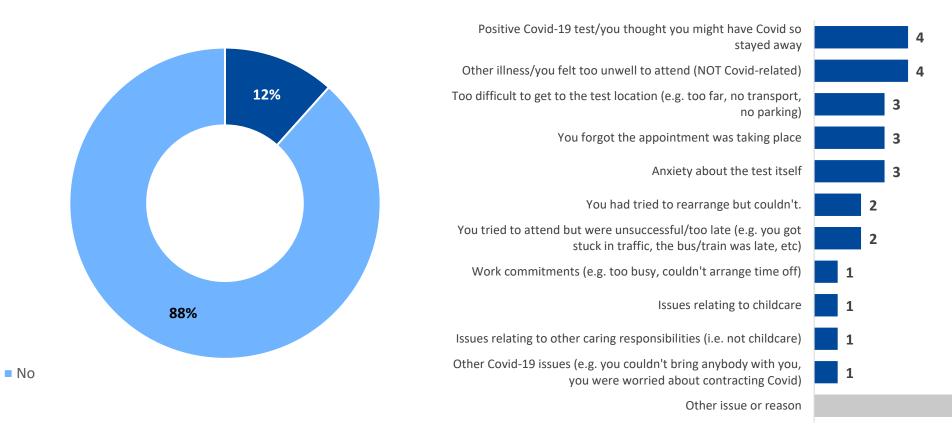


Understanding reasons for not attending an appointment

Non attendance at appointments

Yes

- Around 1 in 8 (12%) respondents have declined or failed to attend a diagnostic test at any time in the last 5 years. This excludes instances where they were able to successfully alter/rearrange the appointment in advance.
- The small number of respondents who have declined or failed to attend a diagnostic test cite a variety of reasons with a
 positive Covid test/symptoms of Covid and other illness being the most frequently mentioned reasons.





Due to the low base size,

the number of respondents selecting each option is

shown on this chart rather

than a percentage

Q14: Have you declined, or failed to attend, a diagnostic test at any time in the last 5 years? Please don't include any instances where you were able to successfully alter/rearrange the appointment in advance. Base: All Respondents (answering) (258)

Q15: Thinking about the most recent occasion where you declined/did not attend a test: what was, or what were, the reason(s) for not attending?

Base: Respondents (answering) who have declined, or failed to attend, a diagnostic test at any time in the last 5 years (29)

Non attendance at appointments



- Did not think test was worthwhile (3)
- Had had another recently/elsewhere (3)
- *Risk of procedure equal to or greater than risk of illness (3)*
- Hadn't received letters/received whilst away (2)
- Tried to cancel/rearrange, system not updated (2)
- Treatment by staff (1)

I did not want the colonoscopies offered routinely as my chances of cancer seem about the same as the risk of the procedure. I have now had the test at 75 years old as the risk seems to be lower now...

Questionnaire respondent

Rearranged with new date but

the system was not updated, so was expected on original date. Had a letter saying I'd missed it...

Questionnaire respondent

...I was fed up with repeating tests that I've already done at another hospital. They couldn't see the results because they couldn't be bothered to contact the other hospital for them. We had them on disc but apparently you can't put discs into NHS computers [...] I wouldn't have minded too much if it wasn't a huge amount of radiation. However, as a young female, it's something I wish to avoid if I can...

Questionnaire respondent

Notification received after I had left the country for a date I had warned the consultant I would not be able to attend. As no email was issued, I could not cancel and missed the appointment.

Questionnaire respondent

Non attendance at appointments

In the focus groups, poor communication was identified as the most common reason for missed diagnostic appointments.

- One participant had attempted to cancel an appointment but had been marked as a DNA.
- Another appointment was rearranged by the hospital, but the participant hadn't received the letter in time and so
 was marked as a DNA.
- A third almost missed an appointment due to miscommunication about the location of their test.

I've cancelled a test before now. They didn't get the message, so a letter went to my GP saying I hadn't attended which was annoying ...

Focus group participant

I missed an appointment because I got a rearranged appointment the day that I was actually going to the hospital. I didn't get the letter in time ... Presumably the letter came to me and I got it around 10am but I was at the hospital at 2pm so I 'missed' the appointment ...

Focus group participant

I did nearly miss one appointment ... I had a letter through to say, 'It's a telephone appointment ...' But there's no point in my having a phone conversation about my [condition] over the phone. I've always been to Watford. I phoned up and they said I could go and have a face-to-face appointment but they didn't tell me it was at St Albans. So I went to Watford and they told me it was at St Albans so I had to hot foot it to St Albans. I got there on time. I think there was lack of communication there. Focus group participant

Unreliable public transport was described as the other main barrier to attending diagnostic appointments: a couple of participants felt it was unfair for patients to be held accountable for this when it is out of their control. Furthermore, patient transport was also thought to be problematic on occasion by another participant.

... I was at Watford General and the guy there ... was expecting to be picked up at his home for his appointment ... The vehicle turned up two hours late so he missed his appointment with the consultant and had to go back the next day. If that goes down as missing appointment that's not fair because he was waiting for the transport to arrive.

Learning disabilities and non attendance at appointments

When discussing how to ensure service users with learning disabilities are not negatively impacted because they have missed appointments, interviewees highlighted the need to:

 Ensure patients understand why it is important to attend appointments that have been arranged at times when, for example, they would normally be undertaking an activity they enjoy as part of their routine.

We've had some really good success stories. Somebody has not come in for an Annual Health Check in many years, but the nurse has been to see them and [it is] actually that they didn't want to miss bingo; [the appointment] clashes and they didn't just quite understand the importance of going to the GP [...] It did need somebody to take an approach of just [going to] see them...

• Ensure understanding of why appointments might be missed, and that reasonable adjustments are made to contact service users with learning disabilities about test appointments in the appropriate way for their needs and situation.

It's not until you get to the bottom of 'How have you been contacting that person?' that they may try a different approach - trying to phone, finding that [the patient] has agreed that you're allowed to contact their carer. Sometimes it's really simple stuff [but] in the busyness, they miss it.

Adult Social Care nurse

There is a barrier in the system for the 'Do Not Attends'; the generic system is 'three strikes and you're out' or 'one strike and you're out'. There is no accounting for the people who are in the hard-to-reach patient groups; checking their flags and notifying the referrer or taking some action to follow up for the DNAs. Adult Social Care nurse For a lot of people that have mild learning disabilities who live independently [...] those letters don't get seen by anybody else [...] We've been asking for a system that can be set up so that somebody else could also be sent that letter [because] if that person doesn't communicate that to anybody they don't go to the appointment. They get two appointments and then they get put on the DNA list and [treated] as if they've chosen not to go [...] but actually the individual hasn't understood what they've been asked to go for; they haven't made an informed decision and that's where you can get a lot of delays happen and poor diagnosis. Adult Social Care nurse Encouragingly, the Adult Social Care Nurses spoke of improvements made to processes with the aim of improving communications between services and patients with learning disabilities.

We've rewritten the Purple folder, which is going to be launched this year, and it's very much focused on, 'These are my communication requirements and this is how to deal with me, these are the reasonable adjustments that work for me'. So, it's now very much written under the legal framework to empower carers to say [...] 'These are the reasonable adjustments for Bob, under accessible communication, this is how you must communicate with Bob'. So, it's more weighted as a legal document [...] More information for health professionals

Adult Social Care nurse

We try to make sure that, under the accessible information standard, every GP has got a very clear route when someone might not attend [and] they can link them to the learning disability nurse for where it becomes beyond reasonable [...] It might be that [they] have it under accessible information to always ring [Bob's] next door neighbour, because Bob gives permission and Bob's next door neighbour will knock on his front door [...]

Adult Social Care nurse

Possible changes to diagnostic services in Hertfordshire and West Essex



Numbers in brackets relate to number of respondents providing comments in this category.

Non attendance at appointments: things that would encourage attendance

 In order to improve the process of rearranging an appointment, focus group participants felt that better communication is needed between patients and booking clerks. A few said they should be able to contact someone via telephone when rearranging an appointment, as they struggle to do so currently. This, it was felt, would also benefit patients who are not able to access internet booking systems.

For anyone who can't use the internet, then you need to speak to a human being. Actually getting hold of a human being is very difficult. I think for that reason people tend to give up ...

Focus group participant

It would be good if they had numbers of people who answer the phone. Often you phone and phone and you keep getting an answerphone [...] It's about accessibility and ease of doing it, maybe there needs to be an online way and a telephone way but actually have people answering the phone.

Focus group participant

A few other participants would like to be able to rearrange appointments via text message, like they were able to do for their Covid-19 booster jab. However, it was again stressed that not everyone has access to the technology needed to rearrange appointments online or via text.

My dad, for example, wouldn't text on a mobile phone at the age of 93! Focus group participant

Non attendance at appointments: things that would encourage attendance

In the focus groups, the concept of a one-stop-shop for multiple diagnostic tests divided participants. Some supported their introduction based on positive past experiences, and others agreed that their addition would be more convenient and less costly for the service user.

... It was absolutely amazing; He had four different tests and at the end of it he went back to see the consultant on the same day to get the results and also to get the treatment. It was amazing. Focus group participant

... I'd like to see more of people ... going to a diagnostics centre which has several diagnostic instruments across multiple specialisms so that you could have many different things done on the same visit.

Focus group participant

The idea is to get a few tests done and maybe see the consultant on the same day. There are transport costs for all these appointments, there's time to fit them in. It's supposed to be less time consuming.

Focus group participant

In principle ... I would have thought the one-stop-shop is a good idea [...] It would be better going to one place when you set a day aside and you know what's going to happen, rather than ... three separate places and not know the timing.

Focus group participant

A few others also supported the concept, providing the one-stop-shop/s is/are in a convenient location (Hatfield was suggested).

...I think they need to start creating diagnostic hubs. Looking at a location, the location profile, the population density so you put these hubs in the most meaningful areas.

Focus group participant

Others, though, opposed one-stop-shops, primarily on the grounds of inconvenience. That is, they were of the view that some people would prefer to attend multiple appointments closer to home than travel a considerable distance for several in one day at a central facility. *... Yes it could be convenient as the patient only has to visit one place ... but if that one place is a lot further*

away, then they may actually prefer to go somewhere locally three times ...

Non attendance at appointments: things that would encourage attendance

There was also support in the focus groups for more walk-in centres and mobile units in convenient locations such as supermarket car parks, retail parks, high streets. This, it was felt, would remove some of the diagnostic burden on clinical settings, and may encourage attendance on the part of those who are nervous about or are too busy to make an appointment otherwise.

...When we did have the walk-in centre for triage, it didn't need me to go into the hospital but it take the burden off A&E and the general hospital. I do think we need to start looking again at having those walk-in centres again.

Focus group participant

A lot of these basic diagnostics, like taking blood samples, doesn't have to be done in hospitals ... Why not move it to a facility on the side of a supermarket car park. You've got to think a little bit outside the box, not just the hospital.

Focus group participant

Perhaps it might encourage people who are nervous about seeing a doctor or making an appointment seems a hassle. Focus group participant

On a related note, the need to provide diagnostic tests at local GP surgeries where possible was noted as offering greater convenience for patients.

... I think the things happening at local GP practices, some of that has already started and that is massively useful. I've had scans at a local GP practice, not my own but they can refer within the area.

Focus group participant

Non attendance at appointments: things that would encourage attendance

Most participants felt that the addition of weekend and evening appointments would encourage attendance, particularly among those in full-time work. One participant said it would benefit them as they rely on working family members or friends for transport to appointments.

Obviously, the out-of-hours stuff is important for people who are working full-time. It's very difficult for people who are working full-time to get to appointments if its only in working hours. Focus group participant

A couple of people raised concerns around weekend and evening appointments however. One participant felt that the location of evening appointments in darkness would need planning and thought for safety reasons. Another was concerned that offering additional appointments could negatively impact existing hours due to staff shortages and capacity.

I get the impression if the equipment is running flat out and they've got staff issues, that isn't going to be easy. Focus group participant As long as its not up in some strange car park in an industrial estate. That's serious because I wouldn't want to go there in the middle of the night, it was bad enough on a Saturday morning. If I'm going to somewhere like Watford General, some of the car parks are not very nice. Those things need to be thought about as well.

Focus group participant

Although there was some objections, it was suggested that attendance could be improved by sending text reminders to patients, including the cost to the NHS if the appointment were to be missed. This, they felt, would affect patients conscience and prevent DNAs.

I received a text before I went to my appointment on Tuesday; I had the text on the Saturday. It was brilliant. It told me that not attending the appointment would cost the NHS £160. Oomph, conscience made ...

Focus group participant

Future developments: ensuring equal access to services

When asked if approaches such as Community Diagnostic Centres or walk-in clinics would work well for people with learning disabilities, there was some scepticism among the Adult Social Care nurses.

[Walk-in clinics] are rarely successful for people with learning disabilities because of the great unknown; when you've got a walk-in clinic you can't pre-plan. You can't predict the time [or] enable them to understand once they get there. [But] one size doesn't fit all [...] Again, it's individual.

Adult Social Care Nurse

Interviewees felt that they could be made to work though, providing a learning disability liaison nurse is on site at all times to ensure vulnerable people received adequate care and reasonable adjustments can be made.

Those services and centres that are being thought of and being built are absolutely great, don't get me wrong, it's absolutely needed. But we need to think more about advocating for these wonderful people, society's most vulnerable people in these settings... Adult Social Care Nurse The other thing is, when going into a hospital, to have that understanding of things [but] not have so much information thrown at you all at once; talk about one thing and then maybe progress onto the next thing and [help me] to really understand...

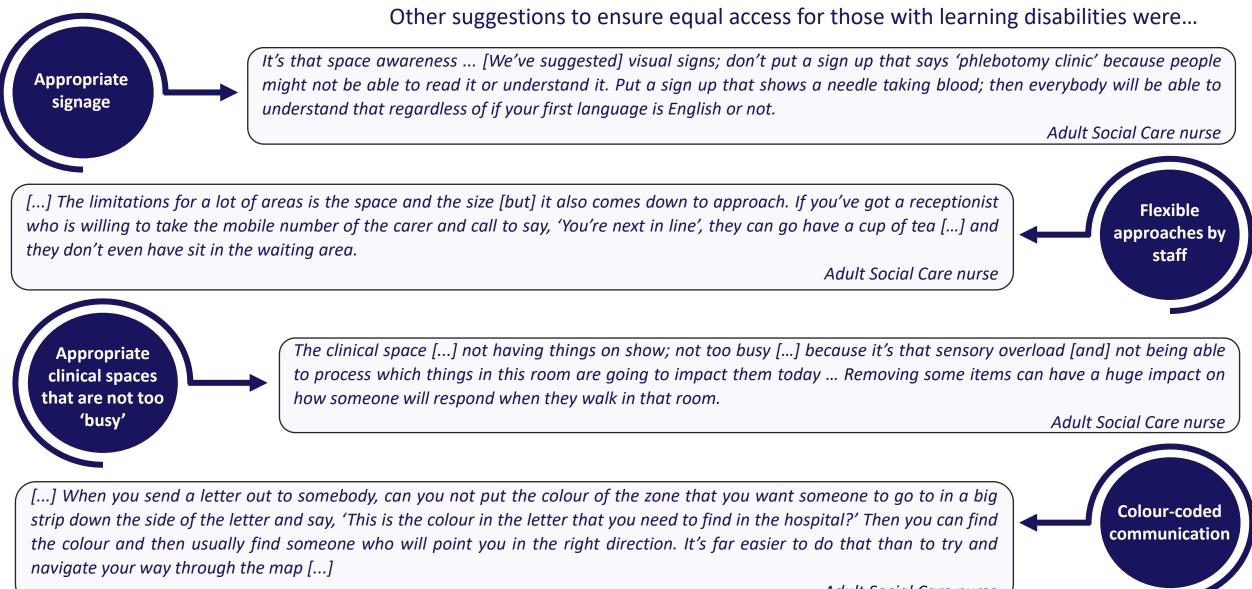
Adult Social Care Nurse

When asked whether, for example, waiting areas need to be adapted or a quiet space provided, there was a concern that people might feel that they were being told they *"need to go elsewhere"* instead of being cared for in an inclusive and appropriate manner. For this to happen, the importance of understanding the needs of this patient group must be recognised and developed so that the more often an individual has health needs, the more positive the experience will be.

I think the understanding and conversation about understanding and learning disability, neurodiverse diagnosis needs to be further up the agenda than it is currently. That for me would be a huge progressive moment.

Adult Social Care Nurse

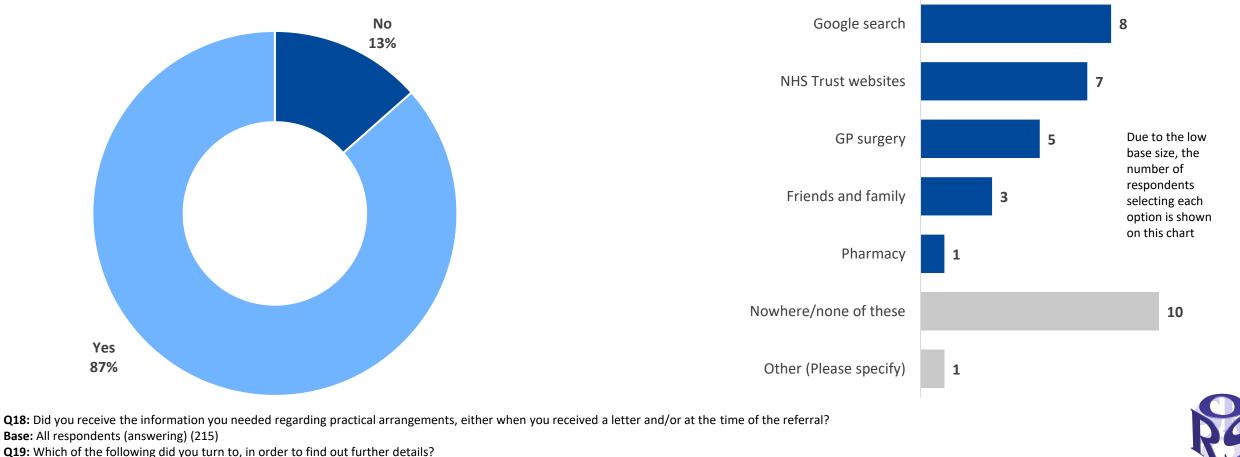
Future developments: ensuring equal access to services



Adult Social Care nurse

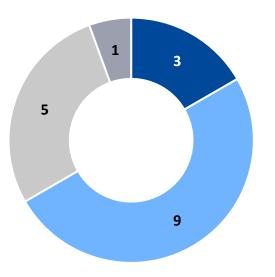
Advance information about the appointment

- Around 1 in 8 (13%) respondents say that they did not receive the information that they needed regarding practical arrangements, either when they received a letter and/or at the time of the referral.
- The small number of respondents who did not feel they received the information they needed regarding practical arrangements cited a variety of sources from which they tried to obtain this information with a Google search and NHS Trust websites being the most frequently mentioned.



Base: Respondents (answering) did not feel they received the information they needed regarding practical arrangements (28)

Of the small number of questionnaire respondents who said that they had not received the information they needed regarding practical arrangements, roughly two thirds (12 out of 18) felt that it was easy to find out the information that they needed by other means.



Due to the low base size, the number of respondents selecting each option is shown on this chart rather than percentages.

Very easyFairly easyFairly difficultVery difficult



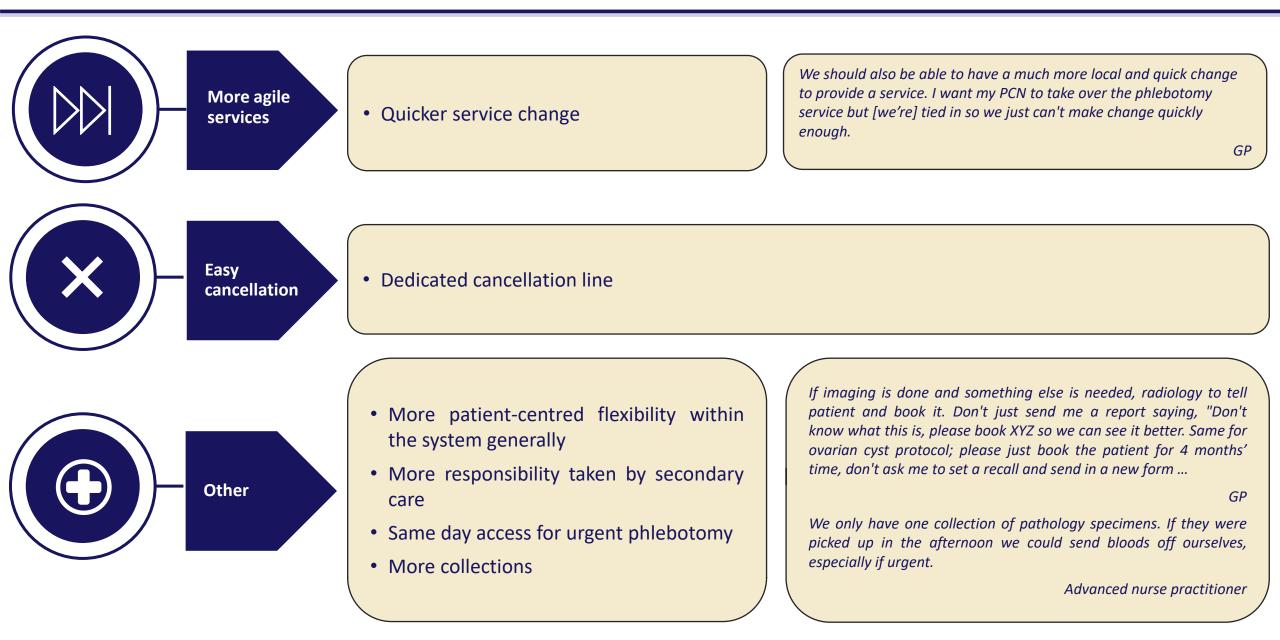
Q20: How easy or difficult was it for you to find out the information you needed? Base: Respondents (answering) did not feel they received the information they needed regarding practical arrangements (18)

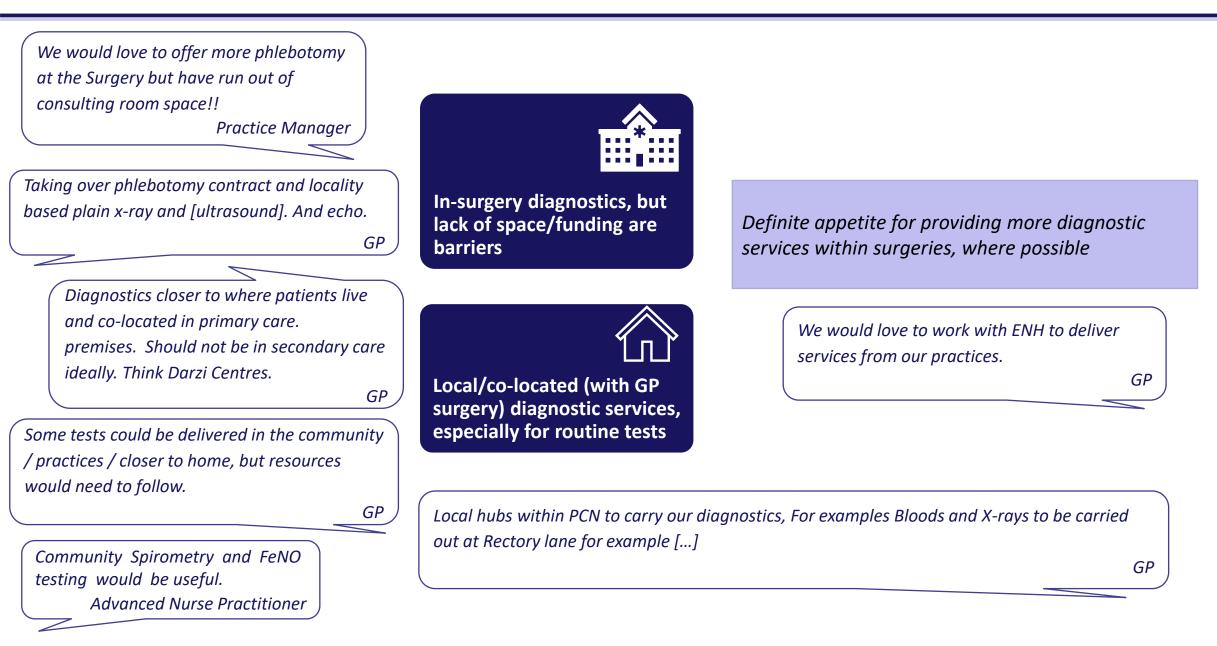
GP views on approaches to NHS diagnostic services that would benefit patients and/or reduce the likelihood of DNAs?

Appointments booked by GPs/Direct Access	 Echocardiogram MRIs (i.e., knee, neck, back) 	I would love proper direct access echo. We would love to able order direct MRI for neck especially and back as long as they fit certain criteria - this will massively improve [the] patient experience. Easier / direct access to some tests without the need for referral to secondary care could help reduce pressure on secondary care outpatient appointments. GPs
More use of technology	 Online booking systems Choice of times/'slots' Appointment reminders by text Paperless testing 	Online booking of appts [] offering a choice off appt day/time. Patient ability to select a time slot [] may help attendance. GPs BUT Need an easy alternative to online booking for elderly. Advanced Nurse Practitioner Paperless testing for all blood diagnostics, if this can be achieved at Forest Medical Centre, St. Margaret's should be able to deliver the same (time and environmental benefits) []
Walk-in/ same-day services	GeneralPhlebotomyRadiology	[] A small number of urgent walk ins at [Herts & Essex] each day would help in Stort Valley and Villages, even if the rest were booked. Phlebotomy was walk in and needs to become walk in again. So much of GP work is doing bloods and then reviewing them a week later etc. and the current delay is making us have wasted appointments. Radiology should go back to walk in for all plain x-rays. This will speed up diagnostics for patients, get rid of DNAs and will save primary care time. GPs

GP views on approaches to NHS diagnostic services that would benefit patients and/or reduce the likelihood of DNAs?

Reduced waiting times	 Reduced waiting times for appointments Reduced waiting times for reports 	[] All the data shows that the shorter the waiting time, the less DNAs there are Shorter lead time for appointments. Often patients' issues have resolved by the time the appointment comes through or it has worsened to such an extent that they have attended ED or had it done privately. GPs
Longer opening hours/more appointments	 Generally longer opening hours Weekend appointments (though some disagreement) 	Evening and weekend x-ray options. X-rays on Saturdays or evenings perhaps. 8-8 model [] for primary care. Some patient might prefer evening/weekend but actually I think if the test is important they should prioritise attending (albeit with a choice of appts during normal working hours). GPs
Information/ communication	 Clear information about what will happen post-test (for patients and staff) Generally better patient communication 	Clear advice on how they will be contacted from the hospital. When we receive [an] abnormal radiology result that recommends another test e.g. MRI we are never sure if this will be ordered by radiology or if we need to do it so would be helpful to make that clear in the report. We can then be clear in what we are saying to the patient. Ability for better patient communication experience re imaging. GPs
One stop shops	One stop shops and ability to have tests togeth reduces time that may be needed off work and	er on the same day may improve patients' ability to attend as





How could the role of primary care providers change/develop around diagnostic services to deliver benefits for patients?



Greater ability to make reasonable adjustments

Perhaps capturing the wider determinants of health could help to increase the attendance rates at the appointments by allowing reasonable adjustments to be made.

GP

GP



Clear guidance needed on any national changes

We are hearing about improved access to diagnostic tests being planned nationally prior to/instead of fast-track referrals. We would need clear guidance on timescales for testing/reporting and how it would work if patient then chooses a provider other than PAH as abnormal results would need to be transferred.

Future diagnostics strategy must include primary care, not just acute/hospitals

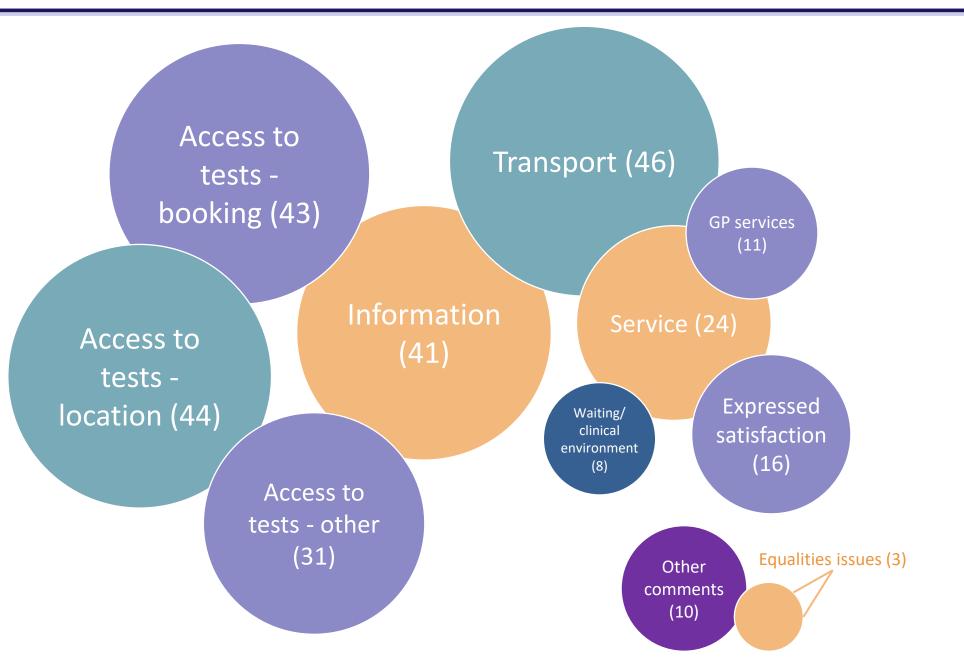
Strategy must also...

- ...be developed in partnership
- ...be clear on who will deliver it
- ...outline how primary care can deliver at scale
- ...be clear on what GPs can access

Service users' views on potential improvements to services - common themes arising

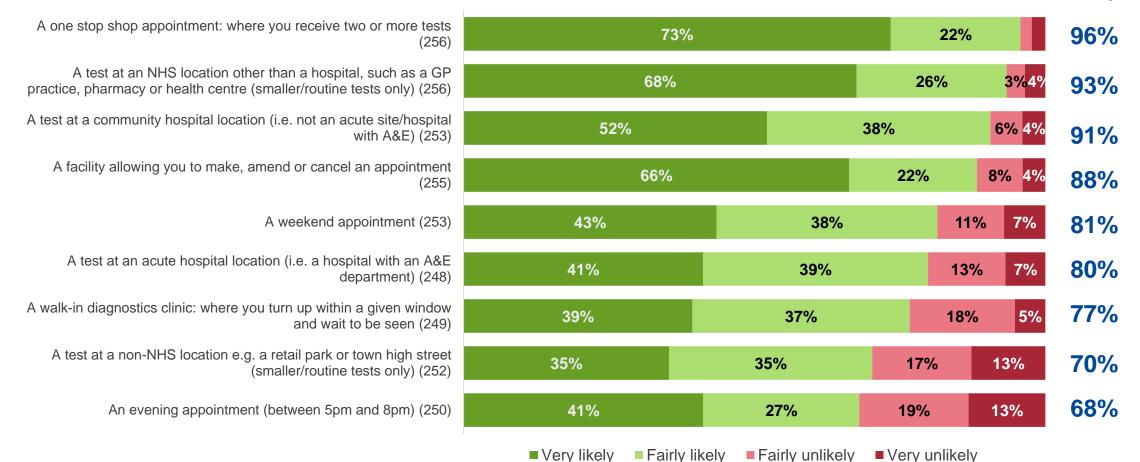
All respondents to the service user questionnaire were asked:

'If you have any further comments to make about diagnostic services in Herts and West Essex (including any suggestions around possible improvements or factors that might make people more likely to attend a test)'.



Likelihood of attending different appointment options

- For each appointment scenario, over two thirds of respondents say they are likely to choose it if it was offered to them.
- Over nine in ten respondents would be likely to go for a test at a 'a one stop shop appointment' (96%), an NHS location that isn't a hospital (93%) and a community hospital location (91%).



% likely

Q17: Please imagine a scenario where you (or somebody you care for) needed a diagnostic test(s). How likely or unlikely is it that you would choose the following, if they were offered to you? Base: All respondents (answering). 'Base' numbers of respondents who provided answers are shown in brackets Please note not all %s add up to 100 due to rounding



Service user questionnaire respondents' views on potential improvements to services

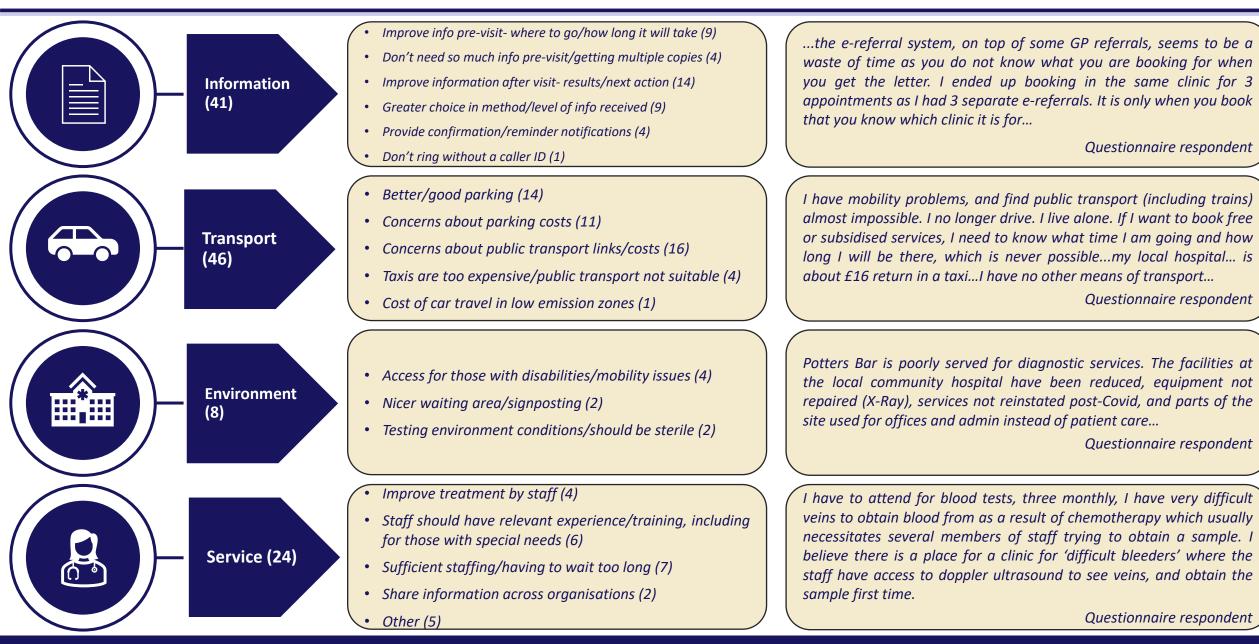
Of those providing a response, the biggest issue talked about was access to tests (118 respondents in total). This was followed by problems surrounding transport (46 respondents) and concerns about information provided (41 respondents).

Further detail is provided in the following slides.



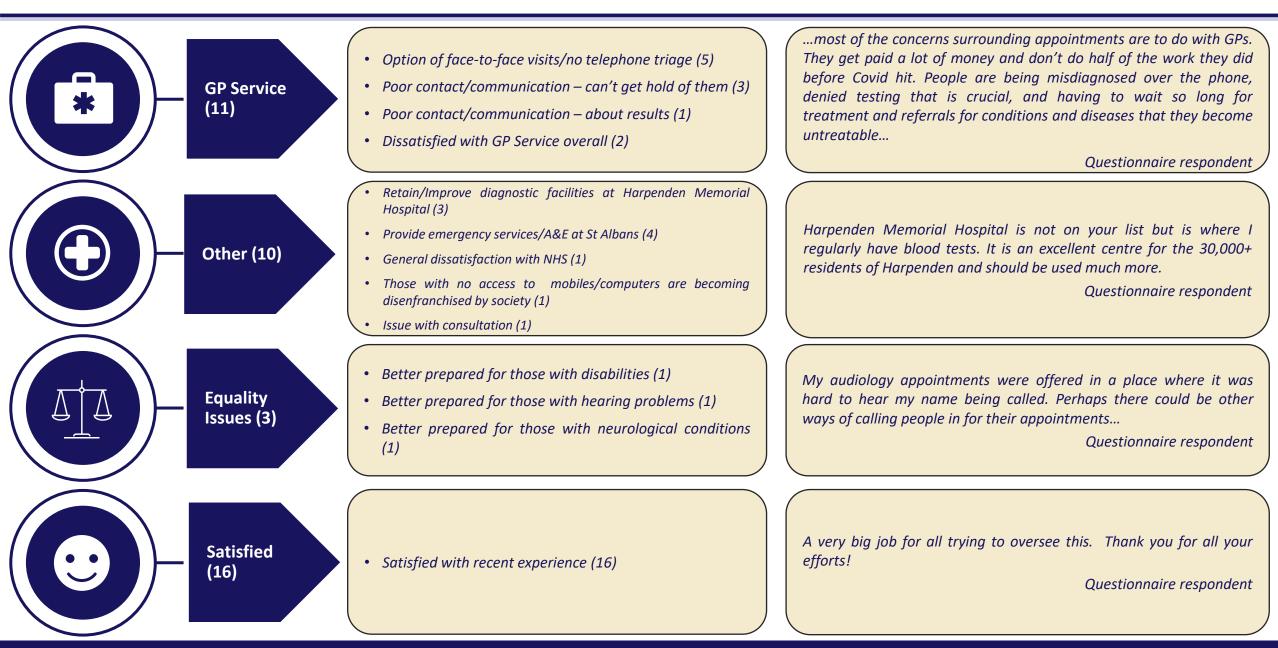
Numbers in brackets relate to number of respondents providing comments in this category.

Service user questionnaire respondents' views on potential improvements to services



Numbers in brackets relate to number of respondents providing comments in this category.

Service user questionnaire respondents' views on potential improvements to services



Numbers in brackets relate to number of respondents providing comments in this category.

Service user focus group participants views on potential improvements to services

The general feeling in the focus groups was that better communication and administration (both within and across Trusts) would solve many of the challenges currently faced by patients in arranging and attending diagnostic tests.

The communication is always the hardest and the biggest thing... unfortunately the NHS isn't getting it right.

Focus group participant

... The communications on the admin side for diagnostics is not good between Hertfordshire and Bedfordshire and Luton and Dunstable ... For example ... I'm under a consultant at L&D, I always take the trouble to write to him to give him the results because I can't rely on whatever the system is to get the results to him. Focus group participant Communication, clearly, is one of the really fundamental issues to do with anything like this in the NHS or any other major institution. Its an incredible failure to streamline communication. That's why, for example, tonight people have said we need to take charge because my GP surgery has gone from contacting me about results and now it just doesn't happen.

Focus group participant

It was also said that patients need more basic education, and the NHS needs more funding and resource, if any future changes/initiatives are to be fruitful in facilitating system change.

... Some people don't know how or when to access services and they access the wrong services which creates a burden. I think with any of these initiatives, there needs to be a drive on basic health education with the population because it can get confusing; people get anxious and people might not choose the right things. There are services that are currently being overused because people don't understand what those services are for or when to access those services.

Focus group participant

... I think resource will be the biggest problem Focus group participant

Staff views on potential improvements to services

Staff suggested some ways to further improve the patient experience of diagnostic services. One suggestion was better transport and parking facilities. Transport links are always challenging to patients. A park and ride for them would be excellent if it was efficient and low cost.

Radiology staff respondent

Better & free car parking.

Radiology staff respondent

Consider elderly, infirm and neurodiverse patients when planning diagnostic services. Services specifically for young people and children is sadly lacking. For example, colour blindness in signs, avoid slopes and provide short-term parking for disabled/infirm patients.

Pathology/phlebotomy staff respondent

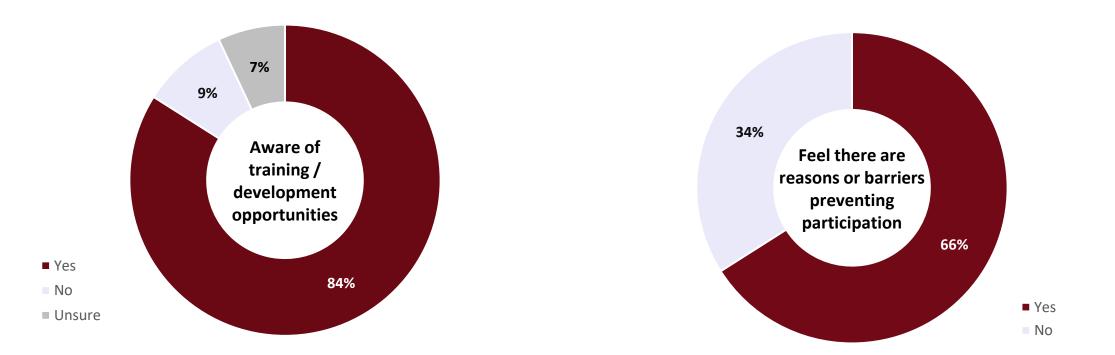
With the introduction of facemasks I feel deaf people are at a disadvantage. Personally I have done a short course to introduction to sign language to try and navigate this but that is a personal choice. There are entire communities like the deaf community that we are unable to communicate with so more funding and time for courses to help with this could be beneficial.

Radiology staff respondent

Some also felt that more consideration is required for specific patient groups such as neurodiverse, elderly, infirm, and disabled people – and children and young people. Giving thought as to how the barriers these groups face could be mitigated is, it was said, essential.

Training and development opportunities

- The vast majority (84%) of staff questionnaire respondents are aware of training / development opportunities in their role.
 Only less than one in ten respondents (9%) say they have no awareness of these opportunities.
- Two thirds of staff respondents (66%) feel that there are reasons or barriers that are preventing them from taking part in training opportunities.





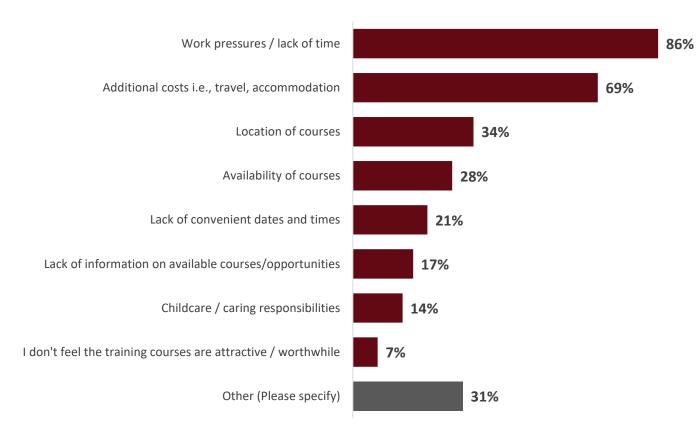
Q5: Are you aware of training/ development opportunities within your role?

Base: All respondents (44)

Q6A: Are there any reasons or barriers that prevent you from taking part in training opportunities? **Base:** All respondents (44)

Reasons / barriers for attending training and development opportunities

- The staff respondents who felt that there are reasons or barriers that were preventing them from taking part in training opportunities were then asked what these reasons or barriers were.
- A variety of reasons or barriers were cited by the staff respondents. The most common reason / barrier was work pressures and a lack of time (86%) and the additional costs of the training opportunities (69%).





Q6B: What types of reasons or barriers are these?

Base: Respondents who feel that there are reasons/barriers that are preventing them from taking part in training opportunities (29) (Respondents could select multiple options for this question)

When asked about training opportunities, radiology and pathology/phlebotomy felt there are different opportunities for different staff groups. This causes divisions and feelings of unfairness.

Trusts treats different classes of staff in different ways. Our TPs (classed as nurses) got funding to travel to and attend SHOT this year but our BMS staff did not attend it even though very highly relevant to them because it required long-distance travel within the UK and overnight accommodation, which was not funded for non-nurses. We feel like a lower class of staff, not valued at all.

Pathology/phlebotomy staff respondent

Getting training for some courses seems to be driven by something other than ability. Some people get better opportunities than others.

Radiology staff respondent

Funding for courses is limited.

Radiology staff respondent

Others attributed funding and a lack of financial support as key barriers to training opportunities in diagnostic services.

We don't get much financial support / often requests for study leave are ignored and then we miss out.

Pathology/phlebotomy staff respondent

Managers don't authorise the expense.

Pathology/phlebotomy staff respondent

Limited capacity to demonstrate skills post-training was also raised as a barrier to development.

Lack of support after training to implement the skills gained. No point in gaining skills or knowledge you're not going to use...

Pathology/phlebotomy staff respondent

Certain departments have travel & accommodation expenses for courses covered by the Trust whilst Pathology for the same course do not.

Formal training in performing breast biopsies. I would need the department to finance the course and also require support with study time. Also adequate training and support in performing fetal medicine ultrasound scans.

Radiology staff respondent

Staff felt that having more training and skills development opportunities would benefit them and their patients.

Some again noted the importance of fair financial and other support for training and development.

It was suggested that a more proactive approach to training is required, especially with respect to filling expected vacancies as a result of retirement. Training people to take over from retirees should, it was felt, begin years in advance.

We do need to consider replacing staff close to retirement on a buddy system, about 3-*4 years before staff are due to retire. Reactive (wait until vacancy) instead of proactive.* Finance arrangements do not help, e.g. funding not approved until vacancy, we should be able to recruit when notice served., not after they have left.

Pathology/phlebotomy staff respondent

Pathology/phlebotomy staff respondent

More leadership training for new managers especially would, it was felt, be beneficial. Health and Safety courses, Leadership, recruitment, Budget control/finance, Conflict management - more courses to be provided. Trust don't provide enough courses and they get full so fast that you don't have a chance. Webinars/courses that we can complete when it is convenient. I tend to prioritise work over self development and miss out on growing myself especially as a new manager.

Pathology/phlebotomy staff respondent

Want to support my team undertaking JETs and pre-assessment course. would want trainee nurse endoscopists to have same access to immersive training in the academy as junior doctors.

Endoscopy staff respondent

A member of staff from Endoscopy noted the importance of equal training for trainee nurses and junior doctors.

Business case writing Healthcare sciences staff respondent

Chest x-ray reporting Radiology staff respondent Other staff members had more specific suggestions for training improvements...

Reporting qualification Pathology/Phlebotomy staff respondent

CT guided biopsies

Radiology staff respondent

To attend the national professional forums like BMUS, ISUOG, FMU etc- to be at the forefront of change Radiology staff respondent

Additional feedback related to protected characteristics groups and health inequalities

An 'ideal' service?

Across the feedback from all engagement strands, the need to consider specific groups of service users was highlighted, with some referring to specific areas of concern or challenge

Elderly patients	Travel/transport difficulties, inappropriate facilities/support at testing locations
Disabled patients	Travel/transport difficulties, inappropriate facilities/support at testing locations, inadequate parking
Neurodiverse/ALN patients and carers	Inadequate consideration of needs [especially communication needs], lack of staff knowledge/awareness of dealing with e.g., ADHD/ASD, restrictions on entering test rooms with patients, need carefully-designed waiting/clinical environments
Minority ethnic communities	Systemic inequalities, language barriers, lack of culturally-appropriate services, lack of trust in services/professionals, lack of engagement with communities/community leaders
Children and young people	Age-appropriate service, appropriate facilities/activities while waiting, lack of (or lack of awareness of) play therapy
Patients who do not drive	Lengthy/difficult journeys by public transport, public transport often unreliable, expense of taxis, reliance on carers
Patients on low incomes	Cost of travel/parking, having to take unpaid leave to attend appointments
D/deaf patients	Using telephone to make/rearrange appointments, difficulties hearing names being called at testing locations, mask wearing making lip reading difficult
Digitally-excluded patients	Disenfranchisement through being unable to access online booking systems, apps, text reminders etc.
Gypsy & Traveller patients	Lack of trust in and awareness of healthcare services, literacy issues
Patients with low literacy skills	Letters/online information not in easy read formats
Carers	Difficulties getting to appointments, lack of awareness of/not told about available support, particular issues for young carers (e.g., their age = less agency, knowledge/experience ignored, not properly communicated with)

Stakeholders representing minority ethnic communities: systemic issues

An interview was undertaken with three staff members from a community organisation working with patients from diverse communities with, e.g., diabetes, heart conditions etc., to understand what may need to change in health and voluntary sector to ensure access to services.

Some of the main themes that arose were around systemic issues such as:

People being described as 'hard to reach/engage' when inequalities are stopping them getting support, not that they don't want/need it.

Too many clinicians telling patients that 'they are the professionals' and a lack of trust in healthcare services (especially among Gypsy & Traveller communities).

Language related inequalities, and a lack of community involvement in decision-making.

A lot of it comes down to [...] the terminology the NHS use [...] It's very clinical, then trying to translate that to communities who perhaps don't have English as a first language or do but perhaps are illiterate or haven't had the greatest education [...] in a simple, easy format to then share. Stakeholder (representing minority ethnic communities) It [...] just means perhaps they can't get there, transport may be an issue, finances [...] Working two or three jobs, larger families, more likely to be carers [...] All these kinds of barriers in place that would stop them getting to that appointment [...] Not being aware of the signs to look out for in the first place because it's all written in English [...] Stakeholder (representing minority ethnic communities)

The Gypsy and Traveller community [...] There is the issue of trust and [...] maybe there's a bit of literacy as well. Also, there's that lack of awareness. Stakeholder (representing minority ethnic communities)

We don't really feel like there's a two-way system [...] 'We're going to suggest this for you', but where were we in that decision? [...] You're not asking these communities specifically what they need, just guessing [...] We are doing to them not with them.

Stakeholders representing minority ethnic communities: accessing diagnostic services

Referral pathways were considered too difficult for those with complex/additional needs – ______ and not sufficiently explained.

[...] It's not a straightforward pathway for clients that have [an] added level of barriers [...] Two mothers with children of a similar age have the same condition [...] They had been invited to come along for tests and nobody had really taken the time to sit and go through the pathway with them. They were automatically expected to show up and understand [...] Stakeholder (representing minority ethnic communities)

I think a new group of people that we're working with are the Ukrainian refugees. Their needs are very different, because they don't understand the system, it's too complex. Stakeholder (representing minority ethnic communities)

A lack of flexibility for elderly patients/carers/ those with large families was alleged (awkward times/locations of appointments for example).

Some of these communities will have one or two jobs [...] sometimes full-time parents or carers and all sorts. So being a bit more flexible. The other day a client's parent had an 88-year-old father with severe mobility issues and his appointment was something like 8:05 in the morning [...]

Stakeholder (representing minority ethnic communities)

A lot of elderly clients are getting appointment letters left, right, and centre that they have to go to. There's no transport, they can't drive, taxis cost an arm and a leg so trying to find them transport is somewhat impossible. And for an appointment at eight in the morning it's not going to happen [...]



Ensuring certain cultures are offered and able to access specific services, such as female doctors for female patients (Asian, Muslim and Gypsy & Traveller women)

Gathering information about a person to determine their needs, giving them control over their healthcare



Educating and empowering people to take control of their health and wellbeing



Including visual aids in appointment letters to describe tests and processes (i.e., a "visual of a machine") I know it's hard because you're sending out multiple appointment letters to multiple people and you just want to get people in and out [...] but just being a bit more mindful and taking that extra 10 minutes to look at the client quickly, any additional needs they may have [...]

Stakeholder (representing minority ethnic communities)

We're talking diagnostics [...] Your GP may have this information about you because they see you in person and they refer you to the hospital. The letter comes from the hospital and they're not going to have that opportunity to see you, to work out '[Name] is a black female' [...] Is there something here about making sure we gather as much information about a patient, and it is shared [...]? That may mean a connection between the primary and secondary sector to know that 'this is a female that would prefer a female doctor ['. [...] It could be the difference between someone attending their diagnostic appointment to not [...]

Stakeholder (representing minority ethnic communities)

Education is a real tool [...] If you get people to come and debunk some of the myths going around that really does help [so] it's important for health professionals to come to any community and group events and provide that information to them.



Raising awareness of healthcare issues by 'piggybacking' onto existing community events

Undertaking tests in frequently-visited locations (i.e. faith-based locations, shops, supermarkets, town centres, healthy hubs, food banks)

More one-stop-shops



More flexible appointments

[...] Take specific health-related information or people to their already set up sessions [...] and say 'Hey, we want to talk to you about this today, get a bit of a Q&A, and if you want to have a test then have a test'. It worked perfectly [during Covid]; people were out there getting their vaccines because they felt comfortable; it was in their space; around people they trust and know. They were able to ask the questions they needed to before making that decision rather than it being shoved in your face [...] Then in future once you've made that connection, built that trust, they can come to you [...]

Stakeholder (representing minority ethnic communities)

The hospital in Welwyn Garden City; I think it's a brilliant idea and it would really be good if that could be extended to other areas [...] Essentially, it's that one-stop-shop [...] It also folds into that mode of making every contact count [...] I go there one day, I might travel far but at least when I get there I can get a couple of things done.

Stakeholder (representing minority ethnic communities)

Just being a bit more flexible [...] Saying, 'What is going to be best for you? I have a few options and if none of those work we will try to find something within your timeframe, but it may not be within the next few weeks. Are you happy with that?', rather than 'Here's your appointment, you didn't come so you'll get cancelled, back on the waiting list, see you in eight months'. That's not helpful and it's not going to make people feel good about getting support with their health; they're just going to avoid it.

People [...] respond better to experiences rather than statistics and data [...] People don't want to be scare mongered into doing something; they just want to hear it from someone else that it was an ok experience, it wasn't too anxiety provoking, it was quick, and they explain things to you, they took time and answered questions. People want that connection rather than data and statistics [...]

Stakeholder (representing minority ethnic communities)

[...] It would be good to provide that immediate response, 'I just had this test done [...] and it was actually a good, straightforward process and the experience was good' [..] You can incorporate it into the actual appointment. When you're first sitting down, 'Would it be ok if I just get feedback from you throughout this appointment that I can use anonymously [...]?' Stakeholder (representing minority ethnic communities)

[...] There seems to be a very direct disconnect between professionals and the community or the community's needs [...] and I think a lot of it is that lack of cultural awareness. People need to be educated or trained on the etiquette on connecting with each person in that holistic way or in that particular community [...]

Stakeholder (representing minority ethnic communities)

[...] Even just the data being collected, it's not representative of who you're supporting therefore you can't then go on and do the training or necessarily research to find out about specific cultures and ethnicities and protected characteristics [...] A lot of organisations still go by the government guidelines of ethnic monitoring forms which is totally out of date [...] Stakeholder (representing minority ethnic communities)

Educating staff to ensure they offer culturallyappropriate services, informed by appropriate data collection

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Using experiences (gathered from patients) rather than statistics to encourage take-up of/attendance at diagnostic tests

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Engaging/visiting communities directly (i.e., Q&A sessions, the Covid-19 vaccine bus)

One of the communities had [...] an Ask a GP session [...] This GP was from a black African background so [they] felt comfortable asking simple questions and getting the information they needed. Something like that maybe where GPs are able to come to these groups [...] stops the taboos; it allows the communities to feel a bit more confident in what they're going for [...] Stakeholder (representing minority ethnic communities)

A really effective thing [...] was having that little vaccine bus that went to those communities [...] So, a little tour bus that goes around and does these checks for you [...] would be quite helpful and effective. It's taking that service to the community, saying to them 'Don't worry about trying to fit us into your day; we're going to fit into yours'.

Stakeholder (representing minority ethnic communities)

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Engaging faith/community leaders to gain trust and foster confidence

Making every contact count

Communities really trust their faith leaders, so involving them [...] is really important [...] to meet people's needs [...] The engagement is slow [...] but I think it's the only way for us to really influence the systematic change we're talking about.

Stakeholder (representing minority ethnic communities)

We should be supporting the person [through] a person-centred approach holistically, openly, making every contact count, no wrong door [...] Stakeholder (representing minority ethnic communities)

Carers: views on diagnostics appointments

Carers shared concerns around the growing use of online portals for booking diagnostic tests. One interviewee explained how booking diagnostic tests for additional needs children can be difficult, as there are no options to cater an appointment to specific needs online.

Despite this negative feedback though, it was said that the online booking system is more accessible for young carers.

I called up, and I spoke to somebody because obviously I couldn't use the online booking system because it's only for people who are neurotypical and want something straightforward, you can't add anything to the online booking system which is frustrating but I get that it caters for the majority of people.

Parent/Carer

[...] before we can even get to booking a test it's getting those referrals. Getting an appointment with the GP, the GP having an understanding of the family, the young person, the adult with learning disabilities and why these referrals need to be done. For example, a lot of families have felt they can't get an appointment and if they have managed to get an appointment and they see the GP, the GP lacks understanding of the young person's needs. So there [is] a severe lack of training.

Parent/Carer

It goes back again that hospital staff, whether it's the nurses or consultants, don't have the understanding of the people they see so it's a case of they don't read the notes before they're going to see the patient to have an understanding of, 'Right, this person doesn't like eye contact' [...] One rule does not fit everyone. I suppose it goes back to learning about your patient, especially when they do have additional needs. It was also said that there is a lack of understanding around patients with learning disabilities and additional needs. This can again make the booking process more difficult for carers, as staff are often unaware of the support services available.



Parent/Carer

Carers suggested hospital passports or a system whereby staff are informed of patient needs and their access to a carer ahead of an appointment. This could mitigate the stress of explanation upon arrival.

The play therapist was there and she brought her things she knew she wanted because she saw her name on the list and she knew who she was, she remembered her. She's been to appointments with both of my neurodiverse children and she's fantastic. She's there, but no one, even people in the hospital seem to know she exists. The parents don't know because the hospital doesn't tell them. So you have all of this wonderful infrastructure, but if you want to do anything other than a straightforward, neurotypical appointment it's very hard.

Parent/Carer

...but it's having that service more readily available because that can make the appointment a much more positive experience for the young person and the family, and doesn't then become an off-putting situation especially if some families have to have recurring appointments every 6 months, or a year or 3 months. I know the hospital is moving all of their records into an electronic system, I don't know what the timescale is for that. But part of that electronic system will flag up if the patient has additional needs. So in the event they did, perhaps an email could be sent out to them to say, 'How would you like this done?'. Maybe a tick box thing, just something simple to then feed back so people know how that's going to work.

Parent/Carer

Play therapists were noted as one key positive of diagnostic services. Carers praised the support from this service in entertaining and calming children with additional needs or learning disabilities during a test.

Despite this positive feedback, carers felt that this service is not used to its full potential as staff may be unaware of it and therefore not informing patients or carers of its availability when booking appointments.



There are apparently gaps between children and adult services that cause issues for patients with additional needs and learning disabilities. Carers struggle taking patients aged 16 and over to services that no longer cater to their ability or needs. Lack of support can lead to traumatising experiences.

The anxiety [a traumatic experience] brings for next time and future appointments is awful and the prep work that goes into supporting the person they care for because it is going to bring anxiety, and you want your child to be seen as well but you know when you get there it's going to bring a whole heap of challenges. Parent/Carer

[...] There's a massive grey area [...] because from 16 they go into adult A&E or adult wards [and] those settings are not suitable [...] the whole situation is incorrect because the person by law is an adult but doesn't have that mental capacity of a [16+] year old [...] Obviously a [16+] year old doesn't look like a 6 year old, so people have a lack of understanding unless they are in a wheelchair or whether they've got Down Syndrome where you can physically see that someone has got additional needs.

Parent/Carer

[...] All of those areas of diagnostic services would be an issue. Like for example, the x-ray the parent can't go into the room. If the child can't sit still but needs to be x-rayed, then it's not going to happen, the x-ray wouldn't happen, it's the same with the MRI [...] Then that brings a whole heap of anxiety for the family of having sedation and things like that.

Parent/Carer

Another concern for parents and carers is the restriction on entering the test room with the patient. Often this has not been an option, causing difficulty for both patient and carer.



Carers: views on diagnostics appointments

Waiting rooms are often difficult for carers and patients. Certain waiting environments that are loud, bright and open can disturb patients sensory needs and negative impact their experience.

Carers suggest separate spaces for additional needs and learning disability patients to wait that would reduce the risk of disruption. The ability to leave and come back if there are delays would also improve the service. [...] she will suddenly just jump up and run away. She's fast. But if we had a room that was controllable, I would feel a lot calmer. If I'm calmer, she's calmer. Parent/Carer

Having a quiet room where you can go and sit, because a lot of waiting areas are open and for me that's a risk.

Parent/Carer

So things like giving us the opportunity if they're running late to go away and come back. Even if it's a walk around the hospital, or a trip to the café and a cake instead of sitting in a waiting room for 45 minutes.

Parent/Carer

A lot of families, depending on what type of appointment and what type of diagnostic services they have access to, then they've had to wait another 6 months or 12 months for another appointment and in that time the problem that they've gone in with has got worse. Then there are now more problems because they've not been seen when they should have been, not by the fault or anybody really but just the fact that the appointment couldn't be completed how it needed to be.

Parent/Carer

Failure to attend or complete an appointment means having to wait a long time before a patient is seen again which can result in worsening medical conditions and outcomes. This issue was further exacerbated during Covid and the resulting clinic backlogs.



Carers felt that opportunities such as extended appointment hours, more local services, and 'one-stopshops' could benefit certain patients and carers depending on their needs. However, some felt that these service developments would not suit all, therefore carers and patients should be asked beforehand what works best.

The way it works for my daughter isn't the way it works for everybody else. So I'm not saying, 'no we don't want it that way, we want it this way', what I'm saying is there's got to be a way to ask that question, particularly if it's obvious that the person in question has additional needs.

Parent/Carer

Especially if it's somewhere like a GP or local community hospital, the young person or adult would be more familiar with the way the hospital looks or how rooms are because they would've done multiple visits. Same with families, a lot of families would use visual aids, so they will go beforehand or go on the internet, take pictures or ask for photos so they can explain 'this is where we're going, this is the procedure'...

Having additional resources for families that care for somebody, whether it's a child or adult, available for families whether that's on their website or sending through the post would be beneficial Parent/Carer Preparation tours for patients with additional needs and learning disabilities could also improve services and experiences. These would offer the opportunity to familiarise patients with test environments.



Carers said/say that they often neglect their own health at the expense of focus on the health and wellbeing of their loved one.

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The first barrier for carers is having the test for themselves at all. Carers don't look after their own health. They will move hell and high water to get the person with the care needs for their tests, they will deprioritise their own test generally speaking [...] the sorts of things carers told us is that people don't appreciate how much effort it is to get there, how much has to be done before you get to the hospital door.

Parent/Carer

There's still that element that health professionals say, 'Carers are very important, but they're somebody else's job', 'Social Care do that don't they?'. Actually, if you don't address it then health professionals then you are going to end up with more patients... Unfortunately we see carers dying of things because they've left it too late [to go for diagnostic tests].

Parent/Carer

This, it was said, needs to be addressed in a 'whole system' way to ensure carers are having the tests they need in a timely manner.



Carers: views on diagnostics appointments

Younger carers were said to face unique challenges and to experience worse health and wellbeing outcomes than older carers, possibly because:

- They face a lifetime of caring for someone.
- Their age means they have less agency.
- Their own situational knowledge is not considered in terms of their lived expertise.
- They are not adequately communicated with about their loved one's condition or the role of health professionals involved in their care.

[] Often if you're going in for a diagnostic, someone will say to you 'is there
somebody that will be there for you when you go home?' They won't ask 'are
they an adult?' necessarily, and are they going home to a 15 year old who's
going to look after them? Because some will be. Are they missing school in
order to do that? Is that an appropriate thing to do? A lot of the time I talk
about it, being professionally curious about things which is a big phrase which
is used a lot in social care but is probably not used nearly enough in healthcare
[] Who's going to be looking after you? What are they going to be giving up
to look after you.

Parent/Carer

Especially younger carers who are balancing work, school, lack of knowledge and all those things alongside it. I do think language is another big one actually, that would be the other thing [...] In health and social care, we all speak a different language [...] I know I get a different response if I talk the language of the health service. Carers need to be listened to and spoken to, particularly younger carers. They need plain English.

Parent/Carer

Another issue is that it is assumed a patient is being cared for by an adult and that there is not enough professional curiosity among healthcare staff when asking whether someone has a carer at home and who that might be.



An interviewee stated that "the two big challenges for carers are around time and travel" - as well as accessibility, parking and getting into the centres if the person they care for has a disability.

However, if the tests can be done quickly and thoroughly with support in place for both the carer and their loved one, it will make the effort to attend worthwhile. Obviously what's always going to trump that is having the right equipment and the least possible tests.... So, actually if you say being able to combine any tests using time efficiently and effectively. But then also combining with that making sure it's got the wrap round offer of support.

Parent/Carer



Carers: importance of staff training and development

In interviews, it was felt that many challenges facing service users with learning disabilities arise because of poor communications and a lack of understanding on the part of some staff members delivering diagnostic tests.

[...] people just don't understand our patient group. They don't understand how to communicate with somebody who is nonverbal. They don't know what resources are available, they don't know some of the times we're available or other specialist services or clinicians are available to support that patient during that journey to go and get that outcome...

Adult Social Care Nurse

While there were positive comments that specialist learning disabilities nurses and experts by experience are able to give training to NHS staff...

[...] we provide a lot of education to GPs and staff in acute settings to think about people with an intellectual disability and what their additional needs are, to ensure that we are successful with the outcome...

Adult Social Care Nurse

...there was also deep-rooted concern that the amount of training undertaken is falling short of what is needed to ensure that the needs of vulnerable service users are being met.

I was asked to talk to trainee consultants one day [and] I was gobsmacked to find out that only one day of their sevenyear training programme [was] in relation to learning disabilities; [to] society's most vulnerable people!

Adult Social Care Nurse

These trainings should be mandatory; if you're going to work in the NHS, you've got to take this training. And it shouldn't just be an hour and a half talk about why it's important for someone with a learning disability to do it, it should be full on training all the time [...] Expert by Experience

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