

**Community Diagnostic Hubs -
a patient centred pathway through the
diagnostic journey**

**Patients from Brighton and Hove share their
experiences and views with us.**

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Thank you

Thank you to everyone who contributed to this report. Special thanks go to Fran McCabe, Healthwatch Board members, Young Healthwatch, Barbara Harris, and MindOut for helping us to gather people's stories in such a short space of time. And additional thanks go to NHS England and Innovation for working with us on this important project, and to our Clinical Commissioners for their support and willingness to engage.

Executive summary

Community Diagnostic Hubs are intended to improve diagnostics across England. This study on what patients want from a local Community Diagnostic Hub (CDH) was carried out by Healthwatch Brighton and Hove from start to finish in just two weeks (1st -14th April) in order to meet NHS England and NHS Improvement (NHSEI) deadlines. NHSEI are currently developing a model of how CDH's should operate at a national level.

The NHS Long-Term Plan made commitments to shape new services through co-production with patients, which is in line with evidence that genuine co-production of services is key to effectively designing NHS services to meet both patient and population health needs. Healthwatch endorses this sentiment.

In the short timescale available to us we spoke to 21 people from communities whose voices are often less heard: people with Black, Asian and minority ethnic backgrounds, people from the gay, lesbian, bisexual and trans community, younger people (under 25), and those with complex clinical conditions. We obtained rich stories and feedback and it is clear that there are common standards and behaviours that all people want to experience when their condition is being diagnosed. We have successfully fed local people's ideas back to NHSEI who have used these to further develop patient experience requirements or standards: in other words, what patients want to see enshrined in the design of CDHs.

Top of the list is good communications. This includes good interpersonal skills, clear information as regards the process and about their condition. Good communication needs to be an ongoing proactive process that keeps patients fully informed about what is happening to them, with whom, where, and in what timescale - and that meets their language preferences and needs. The stories people have told us about recent diagnoses describe less than satisfactory experiences, with people's lives being on hold and "in limbo".

Whilst people from the groups we spoke to did have some specifics related to their communities, their needs mostly related to been listened to, treated with dignity and their whole person being addressed. However, some people with language and cultural needs will need some additional sensitivities when arranging services, such as translators and awareness of religious needs, awareness of gender issues and the availability of sign language services.

The concept of a CDH was welcomed by the people we asked as a place where all tests could be carried out concurrently, but questions remain about where they would be, what services they would contain, and whether and how specialist advice could be on hand - and how they fitted in with 'other' services. People also mentioned wanting the option to go elsewhere if a CDH was, for instance, not an easy journey. Good public communications which define CDHs will be needed as they cannot be seen as the panacea for all diagnostics. Locally, we understand that a service model approach to

diagnostics is now being considered and certainly this is supported by the feedback we obtained (a service model is a way of delivering more joined-up services and user journeys).

A number of people spoke about the role of the GP both at the beginning of the diagnostic process and afterwards - to support and explain the implications of a diagnosis and this crucial relationship must be addressed in any CDH model.

Lastly, people had some very good practical ideas as to how diagnostics could be improved from IT solutions to incorporating preventive services into CDH's. Co-designing with users from their experiences will provide a better inclusive model for everyone.

Healthwatch has shared this piece of work with NHSEI and are pleased that it has already helped to inform draft patient standards for CDHs which will now be considered nationally before a formal policy publication is issued later this year.

We have also shared our work with Brighton and Hove Clinical Commissioners who are designing a local model for CDHs. They have warmly welcomed our findings and we will be working closely with them to ensure that the patient voice is heard at all stages of the design process. We believe the rich material we have gathered could provide a blueprint for what a good diagnostic service should look like. The case experiences in the Annex clearly highlight what is important for patients and echo other work Healthwatch Brighton and Hove has carried out.

- Fran McCabe, Chair Healthwatch Brighton and Hove

Response from the Clinical Commissioning Group

“ The Healthwatch report examining people's experiences of being diagnosed and their ideas for improving the system bring a real focus to the debates and decisions that need to be made with and on behalf of the population we serve and will help inform the next stage of planning and thinking.

At a time when the NHS is looking to bring about transformational change that is designed to increase equity of access and improve outcomes it is important to us that the patient voice is heard. We have invited Healthwatch to join our Network Diagnostic Working group and look forward to working with them to help ensure that patients are at the heart of how we design the system.

Ian Francis

*Associate Medical Director, Imaging lead
Queen Victoria Hospital NHS Foundation Trust*

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Background

In November 2020, the [Diagnostics: Recovery and Renewal review](#) led by Sir Mike Richards outlined several projects that could be delivered to improve diagnostics across England. The need for radical investment and reform of diagnostic services had already been recognised by the [NHS Long Term Plan](#) published in 2019.

One of the recommendations from the Richard's review was to create Community Diagnostic Hubs (CDHs). These would be health centres based in the community, closer to the patients, that would provide diagnostic testing for them. The goal is that patients will be able to visit this facility (or facilities) and, where possible, have all their tests done in the same place and on the same day. There are many aims for the CDHs which are still being finalised but one of the key ones is to improve the patient experience in diagnosis. CDHs could prevent patients bouncing around the system, from healthcare site to healthcare site, from specialist to specialist, and instead enable them to visit one site in one day and receive a clear and timely diagnosis.

The NHS England and NHS Improvement team (NHSEI) is designing how Community Diagnostic Hubs will work - what services they will offer, what tests will be included, and where they should be located. A big part of this Design Phase is defining what the patient experience should look like for those using the service. It is important that no matter where a patient visits a CDH in the country, they should have the same positive patient experience. Key services will operate from CDHs, although some flexibility can be applied to meet local demands and needs.

The Brighton and Hove Clinical Commissioning Group (CCG) is developing plans for how local CDHs will operate and have appointed a Community Ambassador and three Patient Champions to ensure that the patient voice is part of the design and scope of these Hubs. Though this patient involvement is extremely positive, it is not possible for a small number of patient representatives to reflect the cross sectionality of our community and especially those marginalised or often unheard from groups across our City.

Healthwatch involvement

Healthwatch were made aware of the work being carried out by NHSEI in mid-March by Healthwatch England, who subsequently put us in touch with each other. The NHSEI team advised us they had already worked with patient representatives from Age UK to draft a comprehensive set of patient experience requirements utilising "I standards" such as "*I am diagnosed in a*

timely fashion so that I have a minimal period of ambiguity and anxiety about my healthcare.”

Through our conversation we learned that NHSEI has the following focus:

- To understand what is important to different patients in their diagnostic journey experience.
- To begin testing their draft patient experience requirements with patient groups.

The work that is being led by NHSEI includes a health inequalities strand that will capture the voices of marginalised groups, but at present we understand that they have limited feedback from groups such as:

1. Those who are Black, Asian, or minority ethnic (BAME)
2. Those from the Lesbian, Gay, Bisexual, Trans and Queer community (LGBTQ+)
3. Those living with complex health needs
4. Younger People (aged under 25 years)
5. Those living with poor mental health
6. Traveller communities
7. Other marginalised people, such as migrants and refugees.



Healthwatch and NHSEI are clear that patients should be at the centre of the CDH service design process. In practice, this means **inclusive engagement** with a broad set of patient groups, **understanding patient needs** across diagnostic journeys, and **co-production of services** with patients.

Healthwatch therefore offered to support the NHSEI team by gathering the views and experiences of patients from Brighton and Hove who are included in some of the above seven groups. We hoped that our insight would help to strengthen the NHSEI patient engagement & experience guidance on CDHs due to be published later this year. In conducting this work, we also wanted to identify if any equalities issues should be reflected.

Healthwatch see this patient engagement as the start of a much longer conversation. As well as sharing our findings with NHSEI, we have also shared the information we have collected with the Brighton and Hove Clinical Commissioning Group, and we are now working closely with them.

We very much welcome the openness of the NHSEI team to engage with us on this national piece of work and are pleased that our findings have already proven to be useful in strengthening the draft patient engagement & experience guidance. Examples of how our feedback has helped to enhance the draft patient expectations include:

- That people should expect to receive clear information about what tests a CDH offers, and what to expect during their visits to a Hub.

- That people should be offered a choice of whether to attend a Hub or a different medical facility where it is appropriate to do so (the draft standards now recognise that the ability to travel to a Hub should be taken into account which reflects the feedback we received from people who have complex health needs or requirements).
- That reasonable adjustments must be taken into account.
- That the role of care givers should be acknowledged (this requirement was particularly important to people we spoke to who live with complex health needs)
- That all aspects of booking appointments should be fully accessible.
- That people should expect to have their questions answered by someone at a Hub removing the reliance on GPs to perform this role (this change reflects the feedback we received from trans people in particular).
- A range of new draft standards now relate to the reporting stage of the diagnostic journey (there were none in the first draft version that we asked people to comment on). The standards now stress the need for a comprehensive, jargon-free report to be provided within a clear timescale. The draft standards also recognise that pronouns should be used and respected, and that people should be told who they can speak to should they have any questions.

Methodology for our work

Our work has been driven by NHSEI timelines:

- By May, NHSEI will have produced the next version of their draft guidance for CDHs and shared this with commissioners nationally (as this is a draft document it will not be formally published until it has been finalised).
- On 23rd April NHSEI hosted an expert group to discuss draft patient engagement & experience standards. NHSEI requested the outcomes from our work to be delivered to them by Wednesday 14th April so that they could be feed into this meeting.

Healthwatch contacted our Healthwatch volunteers, personal contacts, [MindOut](#) (a local LGBTQ+ charity) and the Head of Inclusion at our local hospital Trust. We used the first draft NHSEI standards and shared these with our contacts by email asking them to consider and comment on them i.e., could they agree to them, what was missing, and how could be improved, especially in respect of marginalised groups?

We then conducted semi-structured interviews with people using five questions that NHSEI had used as part of their public engagement with Age UK. We have captured comments from those we spoke to and inserted these throughout this

report to add context to our findings and bring the patient experience of the diagnostic pathway ‘to life’.

Alongside this, we also collected demographic data.

Due to the very tight timescales, we unfortunately had to omit some marginalised groups from our work. We are clear however that the views of these groups must also be gathered and reflected in any final guidance and the development of the CDH model. These groups include those living with poor mental health, traveller communities, migrants, refugees, and those with learning disabilities.

In this report (delivered to NHSEI on 14th April):

1. We describe our findings, and the key themes we have identified beginning on **page 8**.
2. We include a revised set of draft patient standards which encapsulates the views of the groups we spoke to (**page 23**).
3. We provide anonymised, abridged interview notes (**Annex A**).
4. We provide demographic data of the people we spoke to (**Annex B**).

Our findings

We spoke to a range of people from different communities within Brighton and Hove (see Annex B). All of those we spoke to were supportive of a streamlined process which offered the potential for multiple tests to be carried on the same day, leading to the delivery of more timely results (please see the quote, aside).

“I once had two MRIs for different parts of my body one week apart when they could easily have been done at the same time.”

The central concept of Community Diagnostics Hubs was welcomed. However, most people were unsure as to what services would be provided in a CDH, what sort of staff would be there to have a full diagnostic service, and how a CDH would relate to the wide range of other diagnostic services.

Conclusions

One of our key findings is that patients expressed a strong desire to feel empowered, and to play an active role in their own health journey - and CDHs offer the chance to help achieve this ambition:

“ *If the patient is made to feel important with a role to play in dealing with their own condition they are empowered and much more likely to take the necessary steps alongside medical treatment to achieve the best outcomes.* **”**

To achieve this sentiment, there are several components which we feel need to be built into the design of CDHs:

1. Having good communications in place will ensure CDHs are successful. There are two parts to this:

- a. Defining very clearly what CDHs can and cannot do; what services they will and will not offer. Explaining any limitations will help achieve clearer patient expectations.
 - b. Ensuring that timely, clear, and simply worded communications are provided at each stage of the diagnostic journey. These need to be made fully accessible and the only way to ensure that this happens is for the referring clinician to ask the patient what their needs are at the very start of their diagnostic journey.
- Providing patients with clear communications can reduce unnecessary anxiety, prevent uncertainty, reduce unnecessary chase-ups and free up valuable NHS staff time.
 - Digital technology can help to deliver good communications. It speeds up the delivery of appointments and diagnostic test results. People told us that they want to have online access to monitor, track, and check the progress of their referral, and to see their appointments and test results. Online options must be easy and simple to access and use. At the same time [Healthwatch](#) has previously identified how online systems must provide for those who are [digitally excluded](#).
 - Everyone who is involved in a patient's diagnostic journey must play their part in delivering good communications. This starts with the referring clinician explaining to a patient what tests they are being referred for and checking they understand. This continues with back-office staff booking appointments which respect reasonable adjustments and specific patient requirements. Next, technicians must take time to clearly explain what tests are being done. The process ends with a clear explanation of all test results (avoiding medical terminology and jargon) and offering the chance to discuss these.
- 2. Offering patients as much choice as possible is also key to the success of CDHs.** The process should enable people to choose the times, dates, and locations of their tests. People are often willing to travel further distances if it means they can be seen sooner. But at the same time, patients need to be offered a choice regarding the suitability of a referral to CDHs which matches their individual needs. The patient's individual access needs must be discussed to ensure that the Hub is the appropriate diagnostic centre for them e.g., transport options, accessibility, environment, assistance, or support required.

3. **“I Standards” for CDH’s are welcomed.** A majority of the people we spoke to were supportive of the draft standards which they felt helped to set clear expectations about CDHs. People also made suggestions to improve or enhance these. It is important that these statements are more than just words and we recommend that as local CDHs are developed that the final version of any “I standards” should be routinely referred back to by decision-makers, thus ensuring patient expectations of CDHs are at the heart of their design.

The remainder of the report is split into the following sections:

- A. Who we spoke to (page 10)
- B. Existing good practice we identified (page 11)
- C. Suggestions to streamline the diagnostic journey (pages 11-13)
- D. Suggestions to modernise the referral process (pages 13-14)
- E. Key themes we identified through our interviews (pages 15-23):
 - 1. Delivering good communications (pages 15-19)
 - 2. Providing patients with a choice of appointments (page 19)
 - 3. Incorporating reasonable adjustments (pages 20-22)
 - 4. Delivering a system people can have trust in (pages 22-23)
- F. Revised draft standards (pages 23-30)

In addition, Annex A provides anonymized interview notes, and Annex B the full demographic details of the people we spoke to (these are available as separate documents).



(A) Who we spoke to

Over three days we spoke to 21 people who had the following characteristics (see Annex B for further detail):

- The ages of those we spoke to range from 21-66, including 6 younger people aged 21-25. 17 interviewees were aged under 64.
- We spoke to 8 people who identify as LGBTQ+, including two trans individuals.
- We spoke to 5 people who are BAME.
- 9 people told us that they have a long-term a health problem or disability, and 2 people have long term multi system disabilities.
- 11 people were female, 8 male, 1 ‘other’, and one ‘not given’.



(B) Existing good practice we identified

Our conversations with patients who had been through a diagnostic journey revealed many good aspects to the current process which should be maintained as CDHs are developed:

- **Staff.** Patients are appreciative of staff who are kind, caring, professional, and empathetic to their situation; and of reception staff who are kind and helpful.
- **Assurance.** Patients appreciate being given reassurance by their referring clinician, and by those carrying out tests. They like it when the clinician or technician explains their scan result straight away, or where this is not possible, where the technician offers assurance that the scan findings or test results will be sent to the physician who had requested the scan promptly.
- **Communications.** Patients welcomed good communications i.e., where these confirmed the referral; advised patients where to attend; contained basic information about their appointment and what to expect, and also where the information was free from errors. Patients want to be clearly told what they are being referred for and why, and this is especially important when they are on a cancer pathway.
- **Timeliness.** Patients understandably prefer to be seen quickly for scans or tests. This helps negate ongoing uncertainties or anxieties caused by long delays in waiting to be seen.
- **Settings.** Patients like settings that are clean and well sign posted. They also like walk-in services, with a 'turn up' option, as this offers greater flexibility. Signage and literature should be inclusively worded/phrased.



(C) Suggestions to streamline the diagnostic journey

Our conversations with patients identified that it could be useful for the development of CDHs to view the diagnostic journey as three distinct but interlinked parts.

(1) 'Before diagnostic tests': elements of this stage could include:

- Providing a choice of dates and times that are most convenient for patients to make.
- Providing the patient with a choice of locations to seen at (where possible). If the suggested hospital, or clinic suggested time, is not convenient, then there should be an **easy way** for the patient to

reschedule. It should be explained to patients when all tests cannot take place in one place, or where limitations apply - such as where a special scan equipment is only available in one setting.

- Providing the patient with transport options - and it should be possible for transport facilities to be organised with the hospital/CDH.
- Providing the patient with clear information and an explanation about the diagnostic procedure or consultation that will take place so that they can prepare e.g., for endoscopies patients should fast on the night before, and have water only on the morning of the test etc.
- Providing the patient with a clear explanation of what a CDH does and does not offer, so that the patient's expectations are set at the right level - this is particularly important should the patient subsequently be told that they need to be sent elsewhere for further tests.
- Providing the patient with the name of someone to speak to over the phone if any written information received is not sufficient or leaves questions unanswered.
- Confirming with the patient what reasonable adjustments need to be put in place to ensure that their diagnostic journey is not slowed down later on. The patient's individual access needs must be discussed to ensure that the Hub is the most appropriate diagnostic centre for them e.g., transport options, accessibility, environment, assistance, or any support required. An element of personal choice should be incorporated into the design of CDHs, and options and flexibility need to be available for patients whose needs are not met by a 'standard journey'.

“Communication is key. I want to be told why I am having tests, when they are, what they entail, how long they'll take, how long before my results, what could they mean, what can you rule out, what can't you rule out.”

(2) 'During diagnostic testing': elements of this stage should include:

- Providing the patient with link or key person who will oversee / coordinate their care (an 'investigations and management plan'). In Geriatrics medicine for example, Comprehensive Geriatrics Assessments (CGA) are led by the most appropriate team member which could be a geriatrician, physiotherapist, or a specialist nurse and this is regarded as an effective model.
- Consultants should be on site to feed back to patients.
- Providing the patient with a clear and simply written documented account of what has happened to them during their diagnostic journey. It should be possible to share this with a named carer or family member etc, so that the patient can talk to others which in turn might help them to better understand a diagnosis and its consequences.

(3) ‘After diagnostic testing’: elements of this stage should include

- Providing the patient with a clear timeline for when their results will be ready.
- Providing results and outcomes in an appropriate way i.e., hard copies, large print, Braille, audio or electronic format, email, by phone, shared directly with a carer, or family member or companion.
- Providing the patient with information about who will communicate their results. It should be clear whether it will be a GP or a hospital/CDH staff member, technician, etc.
- Advising the patient who they can talk to about their results, or to discuss management plans or decisions that will happen after the result and by whom.

Other suggestions made which could enhance the design of CDHs were:

- To take into account an individual’s cognitive ability to help them through the referral process. Not all patients will be able to access the service in the same way and reasonable adjustments must be made.
- To remember that for ‘healthy people’ who do not have any previous experience of the diagnostic journey or process, that their first-time experience might be particularly worrying. This underlines the importance of strong communications.

“people who do not have any experience of the diagnostic journey might be scared or frightened.”

It was also suggested that it may be useful to reflect on the design of the current 'Transient Ischaemic Attack (TIA) Clinic model' where all tests, consultation and management plan are done in one place and in one encounter.



(D) Suggestions to modernise the referral process

Patients we spoke to identified that the current system of referrals seemed quite archaic in places and that it placed too much emphasis on GPs approving a referral. Some patients spoke about the challenges or hurdles of persuading their GP’s to make referrals in the first place, whilst others (particularly younger people) felt as if they were not being listened to or were being patronised. In addition, currently in Brighton, there are delays in being able to get [GP appointments](#) and face-to face arrangements are scarce.

Patients had imaginative ideas on how processes could be improved from their perspective which might utilise other services better. They highlighted that the referral process could be streamlined in some of the following ways:

1. **GPs should not be the sole ‘gate keepers’ of the system**, and other professionals should be able to ‘direct refer’ to speed things along. For example, one patient told us that their optician could not make a direct referral for tests to be done at the Eye Hospital and instead had to pass this onto their GP (we understand in some places opticians can do this, but it would be good if this was standard practice).
2. **Direct referrals between specialties should also be possible**. This links to the point above. An example from one of the people we spoke to involved a clinician assessor who identified possible hypermobility but could not refer the patient directly onto a different specialty and had to refer them back to their GP. This backwards referral process lengthened the whole process, delaying diagnostic testing and the achievement of a result or outcome.
3. **Clinicians should have a holistic view to a patient’s health** looking across all of their conditions and not just the one they are there for that day. This could identify the need for other diagnostic testing sooner and not just treating the presenting symptom but the cause.
4. **Any encounter with a clinician should be seen as an opportunity for preventive support**. One interesting suggestion made is that patients should expect a clinician to refer them for all medically appropriate tests at the same time i.e., for specific as well as routine preventative services such as bowel screening where age is a risk factor. There was a sense here that if people are being referred for specific tests that the time could be better utilised by also carrying out routine screening at the same time to avoid future referrals (this could apply if the person is within a window period for such tests to be performed)
5. **The referring clinician must always check what reasonable adjustments the patient needs**.

It is imperative that this happens at the very first stage of the referral pathway to avoid any instances of a patient’s diagnostic journey being delayed because these checks were not made and acted upon. Communication preferences (and needs) must be recorded and applied consistently to avoid unnecessary delays and blockages occurring.

“Will all forms of communication be readily available, so my journey takes no longer than someone without additional requirements?”

(E) Key themes we identified through our interviews

The following section describes some of the key themes that our interviews with patients highlighted.

(1) Delivering good communications

The most important area that everyone mentioned was to receive quality, clear, and accurate communications throughout all stages of their journey.

Patients told us that they want to understand what will happen to them and when. They also want better access to their medical records to be able to monitor their progress. A general principle we have identified is that patients want to feel empowered in their own diagnostic journey.

Patients described to us what good communications looked like. These encapsulate a number of features which we describe below and that could be converted into “I” standards for CDHs and the other diagnostic process.

“If the patient is made to feel important with a role to play in dealing with their own condition they are empowered and much more likely to take the necessary steps alongside medical treatment to achieve the best outcomes.”

“I thought I was going for one test but on arrival was told that they were checking for other things. I did not know that I was being tested for cancer.”

It is important that the diagnostic journey starts off well. This means that the referring clinician should explain clearly what diagnostic tests they are referring people for. We heard from one person who had not had not been told they were on a cancer pathway - this is unacceptable.

It is important that all timescales are clearly communicated to patients, even if these are less than satisfactory.

Unsurprisingly, all the people we spoke to said that they wanted to get their results efficiently and to know how and when they would receive them. Having clear timescales is important so that people can plan their lives around any tests. This information also helps them to manage their concerns and anxieties. One patient told us they felt as if they had been left in limbo without anyone to speak to between tests or consultations.

“I was told the results would go to my GP but was not given any timescales for this, so did not know whether I needed to call my GP, or when to do this. Was it my responsibly to chase things up?”

“I want to receive accurate and timely information which is written in a clear way with simple explanations about what tests I am having, when I can expect to have these, where I can have these, and what they are testing for.”

“I want better communication to happen between the different healthcare systems, so that I do not have repeat my symptoms and personal story with different people. This can make the whole process quite overwhelming and brings an added stress to the process.”

It is important that patients do not have to repeat themselves. People who had been through a diagnostic journey told us that they had often had to repeat their story over and again every time they met a different clinician or technician. This made people feel as if the system was not joined up, and that health professionals were not familiarising themselves with the patient’s medical records. This can undermine patient trust but also lead to frustration and added anxiety.

It is important for patients to be provided with relevant information so that they can prepare. Patients told us that whilst some letters they had received were of good quality, others offered little information, meaning that the patient could not prepare for their tests. People often spoke poorly about the quality of any reading materials or links to online patient guidance that they had been sent. A consistent approach to all letters is needed and as a minimum these should aim to provide or include:

- An acknowledgement that a referral has been received.
- Include literature, or a link to online resources, which describes the conditions the person is being tested for.
- Include information about the types of tests the person will be having so that they can prepare.
- Clearly explain the purpose of each appointment, and who the patient will be seeing.
- Describe roughly how long the appointment will take.
- Provide details of how to easily amend an appointment (online ideally, or a number to call or email address).

“ With almost every single assessment I’ve had with the NHS I never know what’s going to happen at that appointment. I’ve repeatedly turned up to what I thought was a 15-minute consultation to find out it was a more invasive hour-long appointment, or (in this case) vice versa.”

The use of clear language throughout the diagnostic journey is imperative

Language is not just about translation and interpreting but also understanding. Much NHS material is full of jargon, acronyms, medical terms and use of ordinary language in a very particular way. This makes some material and conversations difficult to understand even when a person is very literate. Some research in the Brighton area has showed the average reading age to be the same as an 8-11 year old, so this needs to be factored into the design of local CDHs. Material needs to be pictorial, in ‘easy read’ and provided as videos and in other formats both in English and other language. BSL sign languages services should also be available.

It is important that any clinician or technician the patient meets clearly explains what will be happening to them. People told us that they want every medical professional they meet along their journey to check they understand what is happening to them and to answer their questions, or to offer advice and support. There was a sense that staff further along the diagnostic journey assumed that someone else has carried out these important checks. In addition, it is important that those carrying out tests offer a clear explanation as to what was going to happen that day as we heard from patients who described their experience as “cursory and robotic”.

It is important that patients can easily track their progress. As discussed above, patients should receive assurance that their referral has been received. At present, patients have no easy way of checking this. If their referral has not been received then any time waiting to hear is effectively time lost, leading to a delay in a possible future diagnosis.

Patients also want to know how their referral is progressing as this knowledge can reduce anxiety and worry. It also empowers the patient, whilst reducing the burden on the NHS to answer routine queries

“I want to be able to track my journey online (to see its progress), but also to be able to access my records and letters and results, thus avoiding having to call up or email.”

“The time left waiting without hearing anything generates worry, anxiety and can have a negative impact on health.”

“My current experience with things like ‘patient knows best’ and ‘my gp’ style apps has been disappointing as I’ve never been able to access any results and struggle to even book appointments.”

The creation of online patient portals which enables patients to easily access their records should be delivered at the same time that CDHs are commissioned. But online patient portals must be simple and easy to use and creating an account should be easy to do.

It is important that people are contacted quickly, and better use of digital technology should be deployed to support the functioning of CDHs. Several people expressed a desire to be contacted by text, via mobile app, or by email instead of letters which take longer to arrive, and which may get lost or delayed. Patients also mentioned the preference to be able to choose appointment times that caused least disruption to their daily lives.

“If getting results via texts or mobile apps was quicker than that would be preferred, the letter isn’t any issue its more the time it takes to receive this.”

COVID-19 has shown us the practical uses of virtual consultations, with patients telling us that these save them considerable time. One patient told us that after waiting several weeks for a tonsillectomy consultation they were invited to go for an assessment appointment, only for the appointment to last 5 minutes. They felt that this initial assessment appointment was unnecessary and could easily have been done on the phone. The wait to have this physical consultation also delayed their onward referral.

Online systems should however be optionally taking account of those who may be digitally excluded.

It is important that patients receive a draft of any reports and are given the opportunity to comment on these to ensure accuracy. Patients should be asked if they want to be sent a draft report to check for accuracy. There is the potential for inaccurate or vague outcomes to be misunderstood by others which has the potential to negatively affect how someone is treated later on e.g., a report which states that someone has ‘traits of autism’ may be interpreted by others (non-medical or otherwise) as that person having autism. It is also worth remembering that it is often difficult to change medical records.

It is important that test results are clearly communicated, including being clear as to exactly what the tests show. The following comment summarises the need for this well:

“I cannot stress enough the importance of clear and concise communication as to why tests are being carried out, what the possible outcomes are and how to interpret the results received. I don’t want to hear ‘your blood work looks fine’, I want to know what exactly was being looked for and what quantifies it being ‘fine’. I have multiple friends who are sent for tests and have no idea what they were even for.”

It is important that patients receive a clear conclusion, and follow-up.

Several patients we spoke to felt that the conclusion to their diagnostic journey was unsatisfactory. Patients had not always received a letter or copy of their results, and some people were not contacted by anyone to discuss their results or what these meant, even if these were 'all-clear'. Patients should always be afforded the opportunity to discuss results with a clinician; and GPs should routinely contact patients and offer this option.

"I do not feel as if I received a satisfactory conclusion. The clinician told me on the day that everything looked fine, but I did not receive a copy of any letter that was sent to their GP, and my GP did not contact me to explain what the tests had shown, what that meant, or any next steps."

(2) Providing patients with a choice of appointment

It is not surprising that patients said they want to be given a choice of appointment times and dates. They also want to be offered a choice of locations to be seen at.

"I want to be offered a choice around times and dates and locations of any appointments."

"It would be helpful to be able to request an early morning (before work/meetings) or end of day appointment to minimise disruption and rescheduling meetings (and work around family/home needs)."

Many patients are often prepared to travel further distances if this means they can be seen sooner. As such this choice should be offered wherever possible; recognising that some tests can only take place in one place due to limitations such as where a specialist piece of scan equipment is only available in one setting - and where this is the case it should be explained to patients.

Offering patients greater choice can reduce disruption their lives and has the potential to reduce patient 'Did Not Attends' - Healthwatch undertook work in 2019/20 [reviewing outpatient appointments](#) and learnt that 1 in every 5 outpatient appointments are affected by this issue.

(3) Incorporating reasonable adjustments

One of the draft standards we have identified through this project reads:

“At the point of referral, I am asked if I require any specific adjustments which can be recorded and taken into account for the entirety of my diagnostic journey e.g., preferred language, preferred means of communication, whether I want another person to be kept notified, correct use of pronouns, any support needs, the preferred gender of future clinicians etc.”

This standard, or patient expectation, needs to occur at the first stage of the diagnostic journey i.e., when the need for a referral is first identified. Information about what the patient wants - or needs - from their diagnostic journey should be recorded and acted upon throughout the entirety of the diagnostic journey. To achieve this, the information should form the first page of any patient file, or online record, so that all staff can easily access it.

A number of patients may request that reasonable adjustments are made to facilitate their diagnostic journey, and these need to be adhered to. If they are not then appointments may be wasted if the patient cannot take part e.g., if an interpreter or signer is not available (there are many people who are hard of hearing and BSL needs to be available).

Additionally, those people with a learning difficulty may need tailored materials and help with diagnostics. For instance, people with autism find crowds and noise anxiety provoking and will need sensitive and supportive communications. These requirements need to be taken into account when arranging, booking, and holding appointments.

There are also various personal, cultural, and religious preferences that need to be factored into service design. The ones raised with Healthwatch are:

Younger people (aged under 25 years)

Younger people in particular may want to talk to and be examined by staff of the same gender (especially where the issue is sensitive) or the same or similar age. Younger heterosexual men may be embarrassed to be examined by a female doctor.

It is vitally important to younger people to be believed and some people told us that they felt patronized by clinicians because of their age with assumptions made about their levels of understanding. Staff should be mindful of this.

LGBTQ+ individuals

Trans individuals may want to talk and be examined by staff of the same gender, especially women where the issue is sensitive.

Individuals who are trans and undergoing reassignment may also ask to be referred to by their chosen name.

LGBTQ+ individuals may ask that their preferred pronoun (“he/she/they” etc) is respected and be used in any correspondence, or during 1:1 consultations.

Many trans patients have a negative relationship with their primary clinician (i.e., GP), meaning that requiring them to have to go through a GP-initiated CDH route, rather than a self-referral, may cause barriers to access. Likewise, requiring that any pre-referral tests occur at the GP practice could cause issues for service users that are trans because of a possible lack of knowledge in primary care about specific healthcare needs.

In general, no one we spoke to felt as if their sexuality had been an issue of concern during their diagnostic journeys, but some felt aggrieved at assumptions made by staff about the gender of their partners - staff should ask and not assume.

BAME individuals

Those from a BAME background mentioned the need for people who speak the same language to be available either from staff or interpreters. These languages will vary across the country. In the Brighton and Hove area, many different languages are spoken by some relatively small communities, so arrangements can be more complex. One of the most widely needed languages is Arabic.

When arranging, booking, and holding appointments religious events should be factored in e.g., fasting during Ramadan might create problems with some tests and Eid celebration dates means that Friday appointments should be avoided because of prayer times.

Individuals living with complex health needs

Those who have multiple conditions told us that they need a system which clearly flags people with complex clinical needs and maybe some other special needs/requirement so that reasonable adjustment can be put into place for the whole journey.

One person described their experience to us which highlights this need:

After being initially discharged from A&E following an x-ray, they were told they would receive an appointment with a chest consultant. They received an appointment a week later, but on attendance this was not with a chest consultant but an A&E doctor checking on how they were immediately following discharge. 4 weeks after discharge they were seen by their chest consultant. The chest consultant referred them to respiratory physiotherapy and for a sleep study to be carried out at home. They were discharged from the respiratory physiotherapist but kept on as an open case. A report was sent to their chest consultant. They were then sent for a follow up appointment with their chest consultant who referred them to a specialist neuro respiratory centre in London. They eventually received an appointment via telephone due to COVID-19 which resulted in referrals for their own diagnostic testing to be carried out in London (a further x-ray, specific lunge function test and blood test). They were told that local testing could not be carried out as specialist equipment was required. These tests were subsequently carried out on different days at different locations 5 weeks apart. The initial referral happened in 2019, and they are still awaiting an outcome. The length of time this journey has taken means that it is highly probable that their condition has deteriorated considerably. This may very well of been preventable.

Additionally, the patient's individual access needs should be discussed to ensure that the Hub is the appropriate diagnostic centre for them e.g., transport options, accessibility, environment, assistance, or support required. An element of personal choice needs to be incorporated into the design of CDHs and options and flexibility need to be available for patients whose needs are not met a standard journey.

(4) Delivering a system people can have trust in

The final thing we wish to highlight are examples of where the current system can go wrong. It is recognised that mistakes do happen but having adequate checks and balances in place, as well as strong professional standards, could prevent these. The design of CDHs should work to eradicate simple errors.

- “1. “I was told I hear within two-weeks of the referral from my GP, but I didn't receive anything within that time, so I phoned up and my GP who realised that the computer system hadn't processed it correctly so I had to wait another two weeks, for their appointment.”

2. “I experienced a degree of ineptitude including lost medical notes.”
3. “I attended one appointment only for the receptionist to fail to advise the Dr that I had arrived meaning that I lost my appointment slot and had to wait a further 6 months”
4. “At the test itself, I was not given any explanation as to what was going to happen to me. The whole thing felt very cursory and robotic.”
5. “I was told the results would go to my GP but I was not given any timescales for this, so I did not know whether I needed to call my GP, or when to do this. Was it my responsibly to chase things up.”
6. “I want to receive information about who I can talk to about my results or at least for my GP to contact me to discuss these even if they are all clear/negative. This would have offered reassurance, but also a chance to discuss monitoring my condition. “
7. “The tests carried out were unsuccessful and I was told, by post, that I needed to go to a hospital some distance away for further tests as they had better equipment.”



(F) Revised draft patient standards

NHSEI worked with patient representatives from Age UK to draft a set of patient experience requirements utilising “I standards” such as *“I am diagnosed in a timely fashion so that I have a minimal period of ambiguity and anxiety about my healthcare.”* These are reproduced on the next page.

We shared this first version of draft patient standards with our contacts by email asking them to consider and comment on them: could they agree to them, what was missing, and whether they could be improved, especially in respect of marginalised groups? 17 of 21 people we contacted provided comments on the draft standards.

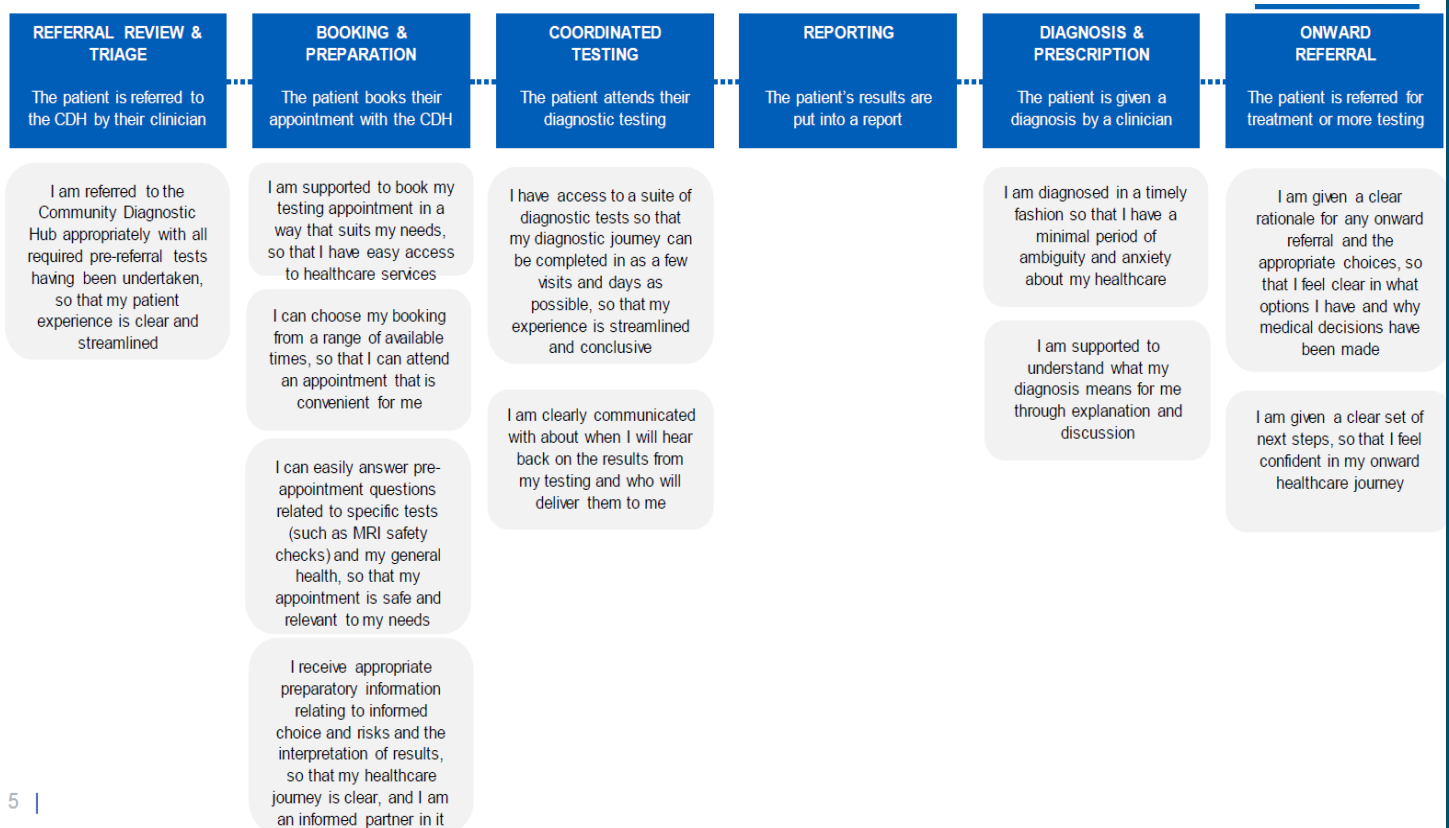
We examined people’s ideas and comments. Nine people indicated that these draft standards fitted, or fully incorporated, their current needs. The remaining 8 people offered suggestions to improve the standards.

People living with complex health needs and LGBTQ+ individuals provided several specific suggestions to enhance or modify the draft standards so that these were reflective of their needs/requirements. We have highlighted in the table below where these comments or suggestions were made.

Overall, most suggestions related to:

- Ensuring that personal choice is reflected e.g., Hubs may not be the most appropriated diagnostic pathway for everyone, and some patients may prefer to nominate carers or family members to act on their behalf’s, etc.
- Ensuring that communications throughout the entire process are clear.
- Ensuring that reasonable adjustments are recorded and acted upon at each stage of the diagnostic journey.

Below are the first draft NHSEI patient experience requirements that we asked people to comment on. These have subsequently been redrafted and shared with clinical commissioning teams for comment before a final version is published later in the year.



5 |

The table on the following pages summarises people’s views on the first draft of the NHSEI patient experience requirements above. Where possible, we have converted their ideas into additional, or revised, “I standards”.

Community Diagnostic Hubs - draft patient requirements /expectations (“standards”).

Stage 1. REFERRAL REVIEW & TRIAGE

The patient is referred to the CDH by their clinician

A question was raised about the term “pre-referral tests” and that this seems a little vague. If someone is taking tests before coming to the CDH, what are they and how are they different from going to a hospital/Hub? This underlines the importance of clearly communicating to patients what CDH’s will and will not offer.

Stage 1 should be made broader by stating that “*The patient is referred to the CDH by their clinician or healthcare professional responsible for their care*”

The first draft standard could also include reference to the fact that the patient can ‘self-refer’.

Additional standards were suggested for this stage - which is seen as being crucial in terms of setting clear patient expectations i.e., it needs to be made clear that the referral to the Hub is only a step towards an outcome which may lead to a referral to consultant, back to clinician, prescription treatment etc.

1. *“I am given a clear explanation by my clinician of why I am being referred to the Community Diagnostic Hub, what the Hub does and what tests I can expect to receive. I also want the referring clinician to confirm my understanding of what is going to happen to me.”*
2. *“I can expect the clinician to refer me for all medically appropriate tests at the same time i.e., for specific and routine preventative services such as bowel screening where my age is a risk factor.”* (There is sense here that if people are being referred for specific tests that the time could also be used to carry out routine screening to avoid future referrals (if the person is agreeable and is within a window period for such tests).
3. *“At the point of referral, I am asked if I require any specific adjustments which can be recorded and taken into account for the entirety of my diagnostic journey e.g., preferred language, preferred means of communication, whether I want another person to be kept notified, correct use of pronouns, any support needs, the preferred gender of future clinicians etc.”*

and/or “I have had the opportunity to discuss / note any access needs or issues that I may face during the testing process e.g., mental health issue, learning or physical disability, so that I can be confident my needs will be met during the diagnostic process.”

LGBTQ+ *“I am able to request adjustments for my needs such as a specific gender of staff, LGBTQ+ trained member of staff, so that I feel comfortable during the diagnostic process.”*

Those living with complex health needs: Patients must be offered a choice regarding the suitability of a referral to CDHs which match individual needs. The patient’s individual access needs must be discussed to ensure that the Hub is the appropriate diagnostic centre for them e.g., transport options, accessibility, environment, assistance, or support required. An element of choice needs to be kept and options and flexibility need to be available for patients whose needs are not met by a ‘standard’ journey.

4. *“I am provided with a letter - or other preferred method of communication - which confirms why I have been referred, and which clearly explains the next steps and timings.”*
5. *I am provided with literature or a source of information to learn more about the typical diagnostic journey, but also additional information specific to my possible condition where this is relevant i.e., where this differs substantially from a standard diagnostic journey.”*

Stage 2. BOOKING & PREPARATION

The patient books their appointment with the CDH

Stage 2 should reflect that *“The patient (or their named carer/ next of kin) books their appointment with the CDH”* as this recognises that some people cannot do this themselves

The **first draft standard** is viewed as being particularly important as all patients need to be able to access their diagnostic journey easily and fully. In this context ‘supported’ must be viewed in a wider context:

- providing additional *support* because of a language barrier as opposed to a capacity issue. That language could be BSL or overseas languages.
- to clarify that *‘supported’* means physical and emotional support - or not.
- that a patient may request that a named carer / next of kin will *support* them to book and attend appointments, and/or that they should be contacted simultaneously by the CDH.
- this first standard seems also to relate to people being given access to services that will *support* them. In which case, a possible a re-wording might be *“I am offered access to all the support I need to help me book my appointments in a way ...”*

The **second draft standard** could be expanded as follows *“I can choose my booking from a range of available times and locations...”* People should be able to choose from different locations especially if doing so means that they may get seen sooner.

We recommend that the wording of the **third draft standard** is rethought. As currently worded (“*I can easily answer pre-appointment questions*”) this standard may not account for cognitive ability. It implies or assumes that patients will always understand any questions they are asked. It feels more appropriate to say: “*I can expect all pre-appointment questions to be designed and written in a simple way so that I am able to answer these ...*”, or that they are provided in an accessible way such as ensuring that any materials are translated, etc.

LGBTQ+ There should be someone connected to the CDH who is able to answer queries about the pre-assessment questions rather than the GP, as trans people can have negative relationships with their primary clinician. In addition, advocates and chaperones should be available.

In addition, it needs to be clarified to the patient what pre appointment questions they will be asked: are they basic health and access requirements or do they relate to previous medical history, or both?

The **fourth draft standard** might benefit from being simplified:

“I can expect to receive preparatory information so that my healthcare journey is clear to me, and I feel fully involved in it. I can expect the information I receive will enable me to make informed choices about my ongoing care, and that this information will help me to understand any associated risks with my tests and to interpret any results.”

Stage 3. COORDINATED TESTING

The patient attends their diagnostic testing

Stage 3 should reflect that the “*The patient attends (in person or virtually) their diagnostic testing*”

We recommend that the **first draft standard** is revised. “*I have access to a suite of diagnostic tests*” implies that the patient can make a choice as to which tests to have which we suspect in most cases will not be the case. The word “*suite*” is not a widely accessible term. We would also shy away from saying “*conclusive*” as an initial batch of tests may lead to further tests or examinations, and some people might interpret the use of the word ‘conclusive’ to imply that the test results themselves are conclusive (final). We would suggest this standard could be simplified to:

“I can expect to be referred for all appropriate and necessary tests at the same time so that my diagnostic journey can be completed in as few visits as possible, so that my experience is streamlined”

Those living with complex health needs: The concept of a suite of testing facilities may work for basic testing but will not work for very specific specialist tests. The wording is not an issue; it is the concept of what tests will be carried out in the Hubs and how specialists or patient specific these can be made. This includes how knowledgeable Hub staff and technicians will be.

An additional standard was suggested to capture the patient expectation that specialists will be fully briefed on their whole medical profile, removing the need for the patient to answer the same questions several times or at each testing point.

Stage 4. REPORTING

The patient's results are put into a report

Stage 4 should include standards which reflect the fact that *“The patient's results are shared with / communicated with the patient and / or their next of kin.”*

It is important that standards exist under this stage, and we would suggest some of the following:

1. *“I am given access to my report within agreed timescales and am kept notified of any delays or change.”*
2. **LGBTQ+** *“I can expect that any language used within a report will respect my preferred pronoun and gender identification and avoid presumptive language about my gender.”*
3. *“I am given access to a report which is comprehensive explaining all of my different tests and results; is written in a simple and jargon-free way so that I can engage with the contents and understand the results; and so that it can be kept for personal record and reflection.”*

This standard is particularly important as currently patients are often copied into consultant letters sent to their GPs which are technical and opaque in nature. This lack of transparency can generate additional concern and stress on the part of the patient.

Part of the last draft standard included at Stage 2 (the booking and preparation stage) also applies seems applicable here i.e., *“I receive appropriate information relating to informed choice and risks and the interpretation of results, so that my healthcare journey is clear, and I am an informed partner in it.”*

4. *“I am given access to a report which explains next steps, and who I can speak to discuss things.”*
5. *“I want to be provided with a report that is easily accessible, and also available online, and that it forms part of my medical profile that I can access at any time. I want to be able to access any photos of my x-rays and any other details collected i.e., the same medical information that would be available to any specialist.”*

6. People also said that they want to know who is making the report and diagnosing their condition? Is it the person that took the tests or a specialist in the medical condition being investigated?

Those living with complex health needs It needs to be clear who will be diagnosing me and how this diagnosis will be made if I am not previously known to the clinician or specialist in question. Will this clinician have knowledge of the patient’s previous medical history etc? How can a clinician support the patient adequately if there is no established trust and rapport? So, there is a potential standard here which could encapsulate these points.

Stage 5. DIAGNOSIS & PRESCRIPTION

The patient is given a diagnosis by a clinician

Stage 5 should reflect the fact that *“The patient is given a diagnosis (or a management plan) by their clinician or healthcare professional responsible for their care”*

Additional standards were suggested for this stage:

1. *“If a diagnosis is taking longer than initially anticipated I want that delay to be communicated to me in a timely manner without having to chase results.”*
2. *“I am signposted to services to support my emotional health so that any feelings relating to my diagnosis can be explored.”*

Stage 6. ONWARD REFERRAL

The patient is referred for treatment or more testing

Stage 6 should reflect the fact that *“The patient is referred for treatment or more testing or is discharged, and if discharged, there a clear forward plan that the patient (and next of kin) is aware of.”*

We recommend that the **first draft standard** is simplified, and the wording switched around. We also advise substituting the word ‘explanation’ for ‘rationale’ as it is more obvious to patients what this means.

“I am given a clear explanation for any onward referral and why medical decisions have been made and am provided with clear options so that I can make an informal choice about my healthcare.”

For the **second draft standard** it feels that an aspect of ‘timeliness’ should also be included.

Additional standards were suggested for this stage:

1. It was suggested that this stage could also incorporate an opportunity for a newly diagnosed patient to discuss with other patients that have the same condition. This would allow the newly diagnosed person to have conversations about what it is like to live with the condition and how treatment feels.
2. As with Stage 5, people said that they want to know who is making the decisions regarding their onward referrals and journey. It needs to be made clear if it will be a clinician/specialist or purely the technician that makes these decisions. **So, there is a potential standard here which needs to encapsulate these points.**

How to contact Healthwatch

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