

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

**Patient's from Brighton and Hove share their
experiences and views with us**

**Annex A: interview notes
Annex B: demographic data**

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Annex A - anonymised interview notes

Interview number 1: an individual who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred to urology in May 2019, receiving various diagnostic tests in Haywards Heath (20 miles away from where they live in Brighton). Testing carried out in August, December, and February, with results shared in March/April 2020.

Q2. What was positive about your experience? Or why was it good?

- Staff were always very kind and caring and the patient did (eventually) receive all of the diagnostics tests that they had been referred for.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They received auto generated letters that contained inaccurate information about their referral.
- They received a number of different letters which did not explain why they were being offered an appointment i.e., no explanation as to what the appointment was for so they could not prepare.
- They were not offered a choice of appointment times or dates.
- They received multiple letters about the same referral.
- They received a letter copied from their consultant to their GP which was indecipherable to anyone who wasn't medically trained.
- They were not able to track their journey online. They ended up having to make repeated calls and send various emails to chase things up.
- They were provided with only one piece of literature to explain one of the tests they were having, and therefore were not clear why certain tests were being carried out. The person was made to feel as if they should just be grateful that they were in the system and being seen, and that it wasn't necessary to explain what was being checked. The person feels that perhaps everyone in the process assumed that someone else earlier in their journey had explained things to them, but surely, they could ask?
- They received no follow up from their GP once their test results were back. They simply felt that they were at the end of a conveyor belt and it was 'goodbye'.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- 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 to be provided with literature about my potential condition.
- I want to be given clear timescales for when things will happen.
- I want to be offered a choice around times and dates and locations of any appointments.
- I want to be given a clear explanation of what will happen at each appointment, and information so that I can prepare.
- For everyone medical professional I meet along my journey to check with me that I understand what is happening to me and to answer my questions, offer advice and support. For there to be no assumptions that someone else has carried out these checks.
- 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.
- 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.

Q5. Any other comments

- CDHs sound good in principle, as they appear to give more control to the patient.
- The idea of having standards is sound, but some common strands run throughout the entire diagnostic journey:
 - The accuracy and clarity of all info (written in a simple way)
 - The timeliness and accessibility of info (clear timescales and easy access)
 - Being given clear choices/options at each stage
 - Being given all necessary advice, information, and support
 - That checks are made by all clinicians at each stage of the journey to check patient understanding etc
 - That there is clear follow up process.

Interview number 2: an individual who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred in 2015 by GP into gender identify services

Q2. What was positive about your experience? Or why was it good?

- Good clinicians.
- Supported well by GP.
- Excellent community support.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They waited an excessive length of time before being seen at a gender identity clinic - 1.5 years from the initial referral.
- They were initially referred to psychiatric services which left the individual feeling dehumanised and traumatised. The implication was that they had a mental health problem or issue.
- They felt as if they needed to justify themselves and make themselves fit the mental health model in order to advance along the process.
- A number of tests and diagnostic procedures felt overly invasive.
- The communications the person received throughout were of poor quality.
- They felt the process was overly bureaucratic.
- They experienced a degree of ineptitude including lost medical notes and when attending one appointment the receptionist to fail to advise the Dr that the person had arrived meaning that they lost their appointment and had to wait a further 6 months.
- They experience some transphobia - the medical profession can still be very binary in its thinking.
- They felt that the system is staggered with various gate keepers involved and that they have to 'pass' one stage in order to advance to the next. The system doesn't appear joined up or fluid, rather it is staggered.
- There was a long wait before they received their medical report, adding a further delay before they were eligible to access hormone treatments.
- Their GP wouldn't let them look at their own blood tests for two months, without explanation.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want to be treated with respect and in a dignified manner.
- The onward journey needs to be better integrated.
- I would like to be given a named professional to speak with, ask questions of.
- People should receive accurate and timely communications on waiting times to allow them to plan their lives without being 'on hold'.

Q5. Any other comments

None

Interview number 3: an individual who identifies as LGBTQ+ (under 25)

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred in March 2021. GP referred the person to Hove Polyclinic for investigative tests in relation to a 2-month cough.

Q2. What was positive about your experience? Or why was it good?

- They liked that it was a walk-in service, with a 'turn up' option, as this offered greater flexibility.
- They received some good communications - the initial letter received was good as it confirmed that they had been referred to the walk-in service and advised them where to go (site location). It was accurate.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- The letter received did not provide them with any timescales, so they were unsure how long to wait.
- They did not receive any leaflets or website links to find out more about the service, or the different types of tests.
- They were not given any information about how to prepare for the tests.
- At the test itself, they were not given any explanation as to what was going to happen. The whole thing felt very cursory and robotic.
- They were told the results would go to their GP but were not given any timescales for this, so they did not know whether they needed to call their GP, or when to do this. Was it their responsibility to chase things up?
- They were also referred for blood tests but were not told if this was a fasting test or not, nor whether they could continue to take their regular medication.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- To be given clear information about how to prepare for my test, and what to expect.
- To receive leaflets that explain, step by step, the process. This is especially important for people with autism or anxiety.
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- To be given a clearer sense of timescales about my results. Waiting times are stressful for me and leave me worrying whether I should be chasing things up.
- I need to understand next steps, and my personal role in the process.
- I want to receive an acknowledgement that my referral has been received, If I don't even know if it's been received, then I have no way of checking. If it hasn't been received, then the time waiting, and wondering, is effectively time lost.
- I want to be kept routinely updated.
- I want the opportunity to be sent a draft report and to have time to check for accuracy otherwise an inaccurate or vague outcome could be misunderstood by others, with the potential to negatively affect how I am treated later on. I do not want a report to misrepresent me. For example, a report which states that someone has 'traits of autism' may be interpreted by others (non-medical or otherwise) as that person definitely having autism.
- It would be useful to have a centralized diagnosis service so that proof of a person's condition can easily be obtained. Some people struggle to maintain records and it's very easy to lose paperwork. Delays in proving that someone has a recognised condition can have serious consequences. Having online access would therefore be useful.

Q5. Any other comments

- Accessing services for trans individuals can be stressful, wondering whether they will be discriminated against, or asked inappropriate Qs.
- All those involved in the process should read key notes before seeing a person and respect the person's wishes. The first computer screen should contain details of any extra support, reasonable adjustments, or personal requirements e.g., "hard of hearing, don't call"

Interview number 4: an individual who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

Various referrals experienced, including:

- For a suspected hernia referral
- Cancer pathway referral (3 years ago)
- Endoscopy

Q2. What was positive about your experience? Or why was it good?

- Being clearly told they were being put on a cancer pathway.
- Being given reassurance by the referring clinician.
- Being seen quickly for scanning.
- Receiving letters with basic information about their appointment and what to expect.
- Clinicians were friendly and caring.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- The first hurdle is the GP and whether a referral is made can often depend on how good or empathetic they are. If the GP is not supportive or takes convincing then that can damage the relationship, and lengthen the time taken to be diagnosed.
- This patient has varying experiences of being taken seriously by their GPs.
- This initial degree of trust between the GP and patient is particularly important for men given that they are often more reluctant to go to their Dr.
- In relation to their hernia referral, they experienced a long and painful process which seemed to go on forever, which various scans and tests. Overall, it took one year from initial referral to having an operation. There was also a long wait between their diagnosis and operation.
- They were left in limbo without anyone to speak to between tests or consultations - just given a leaflet. They had no one to speak to or ask about what was going on.
- They were passed around between different departments, some based in locations far away.
- They found it difficult to physically navigate the hospital layout.
- Some consultants appeared patriarchal, disinterested, and impersonal.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- Not being left in limbo, which is especially important when placed on a cancer pathway. The time left waiting without hearing anything generates worry, anxiety and can have a negative impact on health.
- I want the whole process to be completed in a timely way and to receive a prompt diagnosis.
- I want to have all tests carried out in one place. This creates a sense of trust in the physical space.
- I want ease of access: physical access, but also access to records and information.
- I want to experience person centred care.
- I want to be able to follow my journey online.
- I want to be able to complete as much online as possible in advance of any tests or appointments to ease my journey.
- I do not want to have to repeat my story every time I see someone new.
- I want clinicians to have a holistic view to my health looking across all my conditions and not just the one I am there for that day.
- I want all reasonable adjustments taken into account.
- I do not want to receive lots of letters and want to be notified electronically or by text .

Q5. Any other comments

- It is important to take into account an individual's cognitive ability to help them through the process
- It is important to remember that for healthy people who do not have any experience of the diagnostic journey or process, that it can be worse for them as it is all new.

Interview number 5: an individual who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred by their GP for an endoscopy

Q2. What was positive about your experience? Or, why was it good?

- The waiting time was relatively short.
- The technician explained exactly what tests were being done and what they would be involve.
- The clinician told them on the day that everything looked fine, which provided reassurance.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They were not told in full what they were being tested for.
- They did not receive any information about how to prepare for the tests, meaning that they could not be done on the day and a second appointment had to be booked.
- They do not feel as if they received a satisfactory conclusion. The clinician told them on the day that everything looked fine, but they never received a copy of any letter sent to their GP, and their GP did not contact them to explain what the tests had shown, what that meant , or any next steps.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want a clear resolution following my tests including being provided with a clear set of results, and for my GP to contact me to discuss them in full.
- I want to be provided with clear information about what I am being tested for, and what that will involve.

Q5. Any other comments

None

Interview number 6: an individual who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Eye hospital referral. Need for a referral was identified by an optician who passed the request onto their GP.
- Autism referral from within secondary mental health services

Q2. What was positive about your experience? Or, why was it good?

- They were pleased to get an end result, and to be provided with knowledge about the condition and any future implications, as well as to understand about future monitoring.
- The clinicians were all friendly.
- They were grateful to have an autism referral knowing that these can be hard to get.
- They were relatively pleased with the waiting time (6-9 months).
- The assessor they saw was excellent.
- The report they received was detailed, thorough and understandable.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- The system seems quite archaic in the way referrals are made with too much reliance on GPs. The patient's optician could not make a direct referral and instead had to pass this onto their GP. Also, the assessor they saw identified possible hypermobility but couldn't refer directly onto a different speciality and also had to refer back to their GP. This lengthened the whole process.
- The limbo period created anxiety, especially concerns about missing a call, or if a letter got mislaid?
- They received no updates as to how their referral was progressing (this limbo period could have a particularly negative where the person was living with poor or challenging mental health).
- There was a lack of information provided about the process.
- They assumed that everyone in the pathway would know about their condition, and would have read their medical notes, but this was not the case and they had to explain their situation each time.
- Medical staff often made assumptions about the sex/gender of partners.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want to visit one place to for all diagnostic tests etc for all conditions.
- I want the process to be seamless, centralised.
- I want the system to apply a holistic approach.
- I want to receive regular updates about the progress of my journey, where I am in the queue or expected wait time.
- I want anyone who calls me to properly identify themselves.
- I want the option of an online portal to track progress.
- I want referral letters to have an info leaflet about the condition being tested for and tests that will happen.
- I want things explained to me as they happen to me.
- I want to receive a draft copy of the report to ensure accuracy.
- I want to be provided with a timescale of when my report will be ready.
- I want to be asked upfront about any reasonable adjustments that matter to me and for these to apply throughout the process.

Q5. Any other comments

None

Interview number 7: a young person under 25 years

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- January 2020. Referred for breast care tests and an ultrasound.

Q2. What was positive about your experience? Or, why was it good?

- Overall, a really positive experience, and all the staff encountered were welcoming and understanding, which was especially important because of a family history of cancer. Staff provided reassurance.
- The letter they received was clear and made sense. They knew what to expect from the process.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They were told they should hear within two-weeks of the referral from their GP, but they didn't receive anything within that time period, so they phoned up their GP who realised that the computer system hadn't processed the referral correctly, so they had to wait another two weeks for their appointment.
- It would have been easier and quicker if everything could have been done together on the same day (testing and consultation), rather than having to come back for different 10 min appointments.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- 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.
- I want to get a text or email to confirm appointments rather than a letter.

Q5. Any other comments

None

Interview number 8: a young person under 25 years who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- N/A

Q2. What was positive about your experience? Or why was it good?

- N/A

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- N/A

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want all staff to be accommodated in the same place.
- I want to be given a date of when I will get my results, because this will ease any worry or anxiety.
- I want to receive a text or email rather than a phone call and a letter, because if you are moving around, you will not miss the result.
- I want to receive clear information to help me understand any possible condition and clear steps on treatment and what is going to happen.

Q5. Any other comments

- CDHs area a good idea, as it keeps everything in one place.
- The idea of trying to ensure that all testing and consultations happen in one day is a good one as it makes it easier to organise my life around it.

Interview number 9: a young person under 25 years who identifies as LGBTQ+

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- October 2016. Referred for pain assessment

Q2. What was positive about your experience? Or why was it good?

- Pain clinic were good. All the departments were OK.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They experienced a lot of pain and underwent 3 years of various tests and operations, but nothing could be identified - they eventually received a letter from the hospital saying they could not help. They were then referred to the pain clinic.
- They were never phoned about their results; just received letters to return to the hospital. Overall, the communications they received were poor.
- They made lots of visits, where it would have made sense to have several tests etc done on one day.
- They had a feeling of being dismissed, and clinicians did not take the time to answer their questions.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- Clear communication is important.
- Being told in advance what the outcomes could be, and what the next steps are.
- If getting results via texts or mobile apps was quicker then that would be preferred; the letter isn't any issue it's more the time it takes to receive this.
- I want clinicians to display empathy and take time answering my questions.

Q5. Any other comments

- Happy with standards.

Interview number 10: a young person under 25 years

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- N/A

Q2. What was positive about your experience? Or why was it good?

- N/A

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- N/A

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- The most important thing for me in a diagnostic journey is to have clear communication so that I understand what will happen.
- I want to get results efficiently and know how I will receive them.
- It would be good if these appointments could all be set up by text or on an app rather than letters.

Q5. Any other comments

- Standards are exactly what needs to be practice.

Interview number 10: a young person under 25 years

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred by GP about 9 months ago with concerns about having constant headaches. Referred for a blood test

Q2. What was positive about your experience? Or why was it good?

- It was helpful to eventually speak to the doctor
- It was good to finally get a diagnosis.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- It was difficult to book in for a blood test as they worked 7am-3pm Monday-Friday and after 3 o'clock it was too late for the bloods to be sent off, so they had to wait a while to book in to have the test done as they only did blood tests on Saturdays every now and then.
- After they had the blood test, they received a telephone call to call someone back regarding the results which made them feel anxious. They booked in for a call back with a doctor but never heard back. They called up and were told their appointment had never been booked which left them feeling stressed. They were away at the weekend and needed the results before then so their weekend wouldn't be ruined. They had to book in for call when they were at work to take the call, and their employer was not understanding, which added to the stress as the phone call was also late.
- The poor communication could easily have put them off continuing with their diagnostic journey and their problem could have gone on untreated and gotten worse.
- No follow up appointment was recommended when they had finished treatment.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- To be kept in the loop.
- To not be patronised
- To have concerns taken seriously for example, follow up appointments - to feel heard is important.

Q5. Any other comments

- The idea of having somewhere specific to go to for tests etc, is good as this would lead to increased support.
- It would be good to possibly have all tests out of the way in one day, as this could decrease anxiety and waiting times.

Interview number 12: a person who is BAME

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred for a smear test by GP

Q2. What was positive about your experience? Or why was it good?

- It gave them a chance to talk about something that is quite sensitive.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They had to undergo many tests to check if there was anything else.
- 3 weeks down the line they phoned up to ask where their result was and were told that the hospital had misplaced it meaning they had to repeat the tests over again.
- They thought they were going for one test but on arrival were told that they were checking for other things. The patient did not know that she was being tested for cancer.
- Their GP did not have the test results when she rang. They are still waiting and unclear when they will hear.
- Communication is the biggest issue, at the start it was good, but it went downhill, so better communication would have shaped the journey better. More explanation about what is being done because they had a different understanding of what tests were happening compared to what actually happened. Nothing was explained in the letter they received. It is important to make sure that patients understand what the treatment is or next steps.
- The letter they received was confusing, saying one thing and hospital staff saying other things.
- They were reluctant to go for the test and now nothing has been done - why bother to go in?

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want communication to be clear and accurate and to explain what will happen and help me to understand what I can expect.
- I expect the process to be efficiently managed (so that tests are not lost or need to be repeated)
- I want to know when and how I get results.

Q5. Any other comments

- Standards are exactly what needs to be practice.

Interview number 13: a person who is BAME

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred for a cardiac scan in Lewes Victoria Hospital

Q2. What was positive about your experience? Or why was it good?

- They were late arriving, but called the department informing them and they were very understanding and reassuring. Although they arrived about 20 minutes late, they were nevertheless accommodated which was most appreciated.
- The cardiac technician was very professional.
- The technician explained the scan result straight away - which was very good. The technician was knowledgeable and assured the patient of the scan findings and promised to send the report straight away to the physician who had requested the scan. It was a prompt service with the result communicated promptly.
- The setting was clean and well sign posted.
- Social distancing was well observed.
- The reception staff were kind and helpful.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They found it stressful to get to the hospital as there were many road diversions. It would have been easier if the scan had been done at a local hospital that was much closer to where the person lives.
- The technician was not empathetic enough. The patient is struggling with Long-COVID and would have benefitted from being accompanied in the scanning room rather than being on their own.
- While they were waiting, there was relatively personal information discussed in the open between clinical staff and patients.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want my scans and tests carried out at a location closer to where I live.
- I want the clinician I see to be professional and empathetic.
- I want to receive the results from my tests promptly and for these to be shared with my GP in a timely way.
- I want to be accompanied by a friend, partner, or support person during my tests if safe to do so.
- I expect all staff to maintain confidentiality at all times.

Q5. Any other comments

None

Interview number 14: a person who is BAME

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- October 2019. Referred by GP at A&E to gynaecologist at local hospital.

Q2. What was positive about your experience? Or why was it good?

- They were pleased that the Dr in A&E had referred them. She was thinking of sending them back to their GP surgery until she realised she was part of the same GP network.
- They received good information about logistics and what would happen at the appointments.
- Super surgeon and after care .
- Very pleased they had the option for a general anaesthetic.
- Information provided in a letter was comprehensive about what would happen at the appointment and where to go and what to wear etc

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- All communications were very slow as they used post.
- No choice on appointment was offered.
- They were disappointed that the Gynaecologist had not reviewed previous gynaecological information and only had the information provided by A&E .
- They found it frustrating not to have access to ‘all’ of their health records.
- The tests carried out were unsuccessful and they were told, by post, that they needed to go to hospital some distance away for further tests as they had better equipment.
- The test conducted was very painful and the person doing the tests said she was being trained. Overall a horrendous experience.
- The tests results said they were still unsure and that they had arranged for an operation. All again done by post.
- From the beginning of the visit to A&E to the end of successful operation took about 10 weeks - a long time.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

1. The speed of the service
2. Accurate tests conducted first time rather than having another test on a better machine.
3. Communication online via email would make the whole process easier and faster.

Q5. Any other comments

None

Interview 15: A person with complex long term multi system neurological disabilities and a 24 hour a day care package

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Initially referred in February 2019 but ongoing in respect of sharp pain in ribs. Referred for x-ray. Subsequently referred on for physiotherapy, and then for additional tests in London.

Q2. What was positive about your experience? Or why was it good?

- Happy with the quick action of their GP.
- Reassured by their established relationship with both their GP and London neurologist.
- Positive experience / treatment at A&E.
- On being discharged the hospital checked that all their needs would be met at home

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They experienced a disjointed journey. After being initially discharged 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 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 neuron respiratory centre in London. They eventually received an appointment via telephone due to COVID which resulted in referrals for their own diagnostic testing to be carried out in London (a further x-ray, specific lung 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 location 5 weeks apart.
- The misreporting of x-ray results. After the initial scan, a report was sent back to their GP stating no further actions necessary and which contained no flags. The

pain continued to worsen and 10 days after having the chest x-ray, they were starting to struggle to breathe and to sit up. Their GP examined them at home and examined the chest x-ray only to find that it indicated a severe chest infection. The patient suffered a total collapsed lung on one side, and they had an emergency chest drain inserted.

- The amount of chasing up they had to do regarding appointments and referrals.
- The lengthy time that it has taken to reach this point (they still have 6 weeks to wait for their diagnoses appointment).
- The lengthy time this journey has taken means that it is highly probable that their condition has deteriorated considerably. This may very well of been preventable.
- They now have an appointment at the end of May in London to see a consultant of respiratory medicine. At this appointment test results and medical history will be discussed, and an ongoing treatment plan put in place.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want 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.
- I want any diagnosis to be accurate given the implications of receiving a wrong diagnosis
- I want clear information about appointments and what these are for.
- I want to be given a choice of diagnostic venues.
- I want a streamlined process which avoids delays and drift, which can result in a deterioration in health.
- I want to receive timely regular updates to avoid my having to chase to get information.

Q5. Any other comments

None

Interview 16: A person with complex long term multi system neurological disabilities

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

Referred for various tests due a variety of different symptoms including:

- Bladder urgency, referred to urologist
- Foot drop/poor balance, referred to orthopaedic consultant who had performed a hip replacement
- Numbness in arms and legs - referred to specialist ECG
- Extreme tiredness, review of work /life balance
- Eventually referred to a neurologist

Also, blood tests resulted in a referral to a haematologist.

Q2. What was positive about your experience? Or why was it good?

- Little positive about their MS diagnosis
- MDS - Haematologists were very sympathetic and reassuring. Consultants provided a very clear explanation of the likely journey and information about their support, and reassurance about future contact.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- For their MS diagnosis they felt there was a lack of empathy from the clinicians: each were prepared to do their job and carry out their own tests, but none looked at the bigger picture or took the time to discuss intelligently what might be the problem. The delivery of their diagnosis was handled insensitively by the consultant who failed to provide any treatment or reassurance - left the patient casting about in the dark with lots of wild fantasies.
- For their MDS, there was a lack of explanation from their GP as to what their blood tests were for or what the results might mean.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want to be treated as an individual. Information is knowledge which enables judgements to be made and choices. People can then own their condition. Without this, people are simply treated as statistics and not as human beings.

Q5. Any other comments

- It is important to centre treatment around the patient rather than the hospital or department. 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.

Interview number 17

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred for various tests including colonoscopy, MRI, CT scan and stool sample. April to July 2020.

Q2. What was positive about your experience? Or why was it good?

- Following the detection of an abnormal stool sample, various further follow-up tests were carried out at regular intervals.
- Under the circumstances the service received was excellent.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- Not knowing whether I had a cancer was a terrifying experience so a quicker diagnosis would have been beneficial.
- They found it frustrating not knowing what was happening.
- It would have been helpful to have someone guide them through the various steps that would be taken before a diagnosis, and a timeframe. No support was available until the point of diagnosis.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- I want tests to be carried out as quickly as possible.
- I want to be kept fully informed of results by letter or email.

Q5. Any other comments

None

Interview number 18

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred for Ultrasound (abdominal)

Q2. What was positive about your experience? Or why was it good?

- Their referral happened quickly - didn't wait more than a couple of months (this was a much better than prior experiences waiting for scans).
- Everything was clear - and good reminders and confirmation of their appointments were received by text message.
- Despite the lockdown/COVID-19 restrictions, the scan was quick and efficient, and the radiologist provided an initial / likely diagnosis based on what she saw. This was confirmed when the Dr called with results.
- The process was very reassuring

Q3. What were the moments of frustration? What was bad? How could it have been improved?

N/A

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- Speed - I want to find out quickly and to be provided with a diagnosis. I want to have this knowledge soon and then work out what I need to do / what (if any medication) is needed.
- Local / Convenience - I want to be able to get to the locations quickly - so prefer local hospitals / GPs.
- Booking / calendar - it would useful if there was a way to easily (online perhaps) book in tests around a busy calendar? 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).

Q5. Any other comments

None

Interview number 19

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- 2019, after a hospital admission with tonsillitis, I was referred to ENT

Q2. What was positive about your experience? Or why was it good?

- This was a bad experience all round.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- They were advised that they needed a tonsillectomy. After waiting several weeks, they were invited to go for an assessment appointment. The assessment appointment lasted 5 minutes and consisted of being asked 'do you want your tonsils out?', to which they responded 'yes'.
- They were placed on a waiting list and offered an appointment 4 months later.
- They suffered the loss of a parent and needed to reschedule. When they called to reschedule, they were told that they would lose the appointment. After explaining the exceptional circumstances, they were offered an appointment a week later which was turned down as it was still too soon. They were then told that they had lost their place and would need to get re-referred, go for another 'assessment appointment' and go back on the waiting list.
- The initial assessment appointment was unnecessary and could easily have been done on the phone. Or they could have better explained what the appointment would entail.
- With almost every single assessment they have had with the NHS they have never known what was going to happen at that appointment. They've repeatedly turned up to what they thought was a 15-minute consultation to find out it was a more invasive hour-long appointment, or vice versa.
- They could have said they would call them in a month or two to schedule another appointment as opposed to making them go back to the beginning of the process again and waste everybody's time.
- They felt there was a lack of compassion at a difficult time.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- 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.
- I want any information about me to be shared with me by medical professionals.

Q5. Any other comments

None

Interview 20

Q1. Tell us a little about your diagnostic journey i.e., what diagnostic tests were you referred for, when was this, where did you go for your tests (location name/hospital etc)?

- Referred locally for blood, ultrasound, and cystoscopy test and to some hospitals in London for MRI scans, in respect of tumours growing on their bladder.

Q2. What was positive about your experience? Or why was it good?

- Throughout the process, most doctors and nurses were supportive of their situation and took the necessary time to go through things slowly and made sure they understood their options of potential treatment and their effects.

Q3. What were the moments of frustration? What was bad? How could it have been improved?

- When a local GP mis-prescribed drugs as they thought they were in a depressive state.
- They felt the GP did not believe them. It took a personal call from another doctor, for their GP to take the situation more seriously.

Q4. What is important to you in a diagnostic journey i.e., this is the journey starting at the point you are referred on for tests, to having tests carried out, to receiving results and any further treatment

- When it comes to my diagnostic journey, I feel it is important to have communication and reassurance throughout the whole process. Normal people, who do not have any experience of the diagnostic journey might be scared or frightened.
- Support is also needed when a patient gets a test result confirming their illness or diagnoses.

Q5. Any other comments

None

Annex B - demographic data

The ethnicity of respondents		The gender of respondents									
Ethnicity	Number of respondents	Gender	Number of respondents								
White British	14	Female	11								
White any other	1	Male	8								
BAME (all groups)	5	Other	1								
Other	0	Not given	1								
Not given	1										
The ages of respondents		The sexual orientation of respondents									
Ages	Number of respondents	Sexual orientation	Number of respondents								
18-25	6	Heterosexual	12								
26-34	2	LGBT	6								
35-44	4	Other	2								
45-54	4	Not given	1								
55-64	1										
65-74	3										
75+	0										
Not given	1										
<p>Respondents with a long-term health condition, and carers</p> <p>Nine people identified themselves as having a long-standing health problem or disability</p>		<p>Respondents who are carers</p> <table border="1"> <thead> <tr> <th>Carer?</th> <th>Number of respondents</th> </tr> </thead> <tbody> <tr> <td>Yes</td> <td>0</td> </tr> <tr> <td>No</td> <td>20</td> </tr> <tr> <td>Not given</td> <td>1</td> </tr> </tbody> </table>		Carer?	Number of respondents	Yes	0	No	20	Not given	1
Carer?	Number of respondents										
Yes	0										
No	20										
Not given	1										
Respondent's religious belief's											
Ages	Number of respondents										
None	12										
Christian (all denominations)	4										
Buddhist	0										
Hindu	0										
Muslim	2										
Jewish	0										
Any other	1										
Not given	2										

How to contact Healthwatch

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