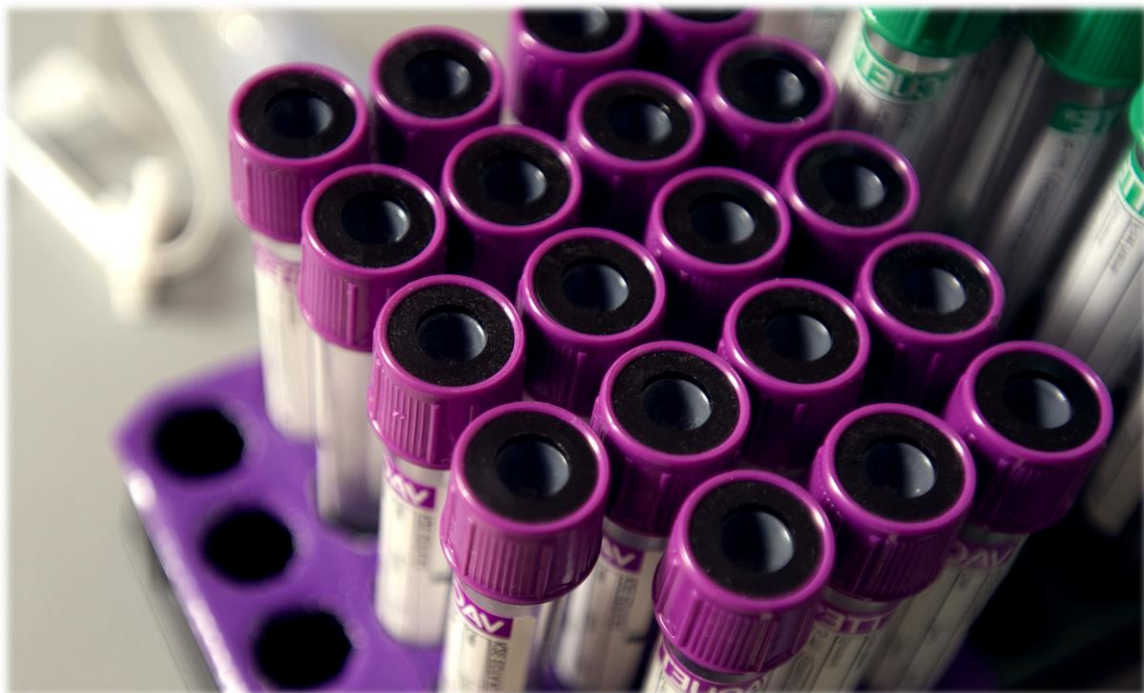


Blood Tests **in** Barnet

**A report on Patients with Learning Disabilities
and their Experience of Blood Tests in Barnet**



May 2017

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Executive Summary

It is well reported that people with learning disabilities experience worse Health inequalities than those without disabilities. Blood testing is one very important way that doctors can assess general state of health and check for infections and other issues. After hearing a number of anecdotal reports of people with learning disabilities having significant problems accessing Barnet's Phlebotomy (blood test) services, this study aimed to use Patient and GP surveys, case studies, and quality checks to examine how accessible Barnet's Phlebotomy services was for people with learning disabilities.

Our findings indicated that the majority of people with learning disabilities had had a positive experience of blood test services. There were some good examples of effective reasonable adjustments being made by Hospitals, and 65% of GP practices were providing blood tests for people with learning disabilities, especially those with higher levels of need.

The findings evidenced just how important it was to have friendly, reassuring staff who explained the blood test process to patients, and a quick easy to access service. There were many examples of this good practice from all types of services but particularly in GP practises, which received no direct negative feedback from patients.

The study was unable to determine how the Community Phlebotomy services provided for people with learning disabilities, but one case study suggested that reasonable adjustments were not being made for patients who were unable to have blood tests in Hospital or at their GP practice, but who were not eligible for a blood test at home.

Whilst blood tests services are working well for most patients with learning disabilities, there are still cases of patients with higher level needs reporting very poor experiences. Poor experiences and missed blood tests were largely caused by reasonable adjustments not being made prior to the appointment due to the learning disability and support needs not being flagged at the booking stage; or by the phlebotomists being unprepared for, or lacking the relevant experience or training, to support people with learning disabilities effectively. Improvements to the flagging and booking systems would enable staff to be more prepared, and for reasonable adjustments to be made by Hospitals and Community Clinics. This will help to reduce the number of patients who have a poor blood test experience.

Additionally more GP's offering blood tests for patients with higher level needs would also help to reduce the number of poor experiences which happened primarily in Hospitals. How GP phlebotomy services are funded may need to be reviewed in order to achieve this.

The findings and recommendations of this study are intended to be used to help by Healthwatch, NHS Health services and commissioners to further improve Phlebotomy services for people with learning disabilities in Barnet.

Introduction

Healthwatch Barnet is one of a national network of independent local charities that aim to help local people get the best out of their health and social care services. Healthwatch enables residents to contribute to the development of quality health and social care services, and to provide information on local services in Barnet. It was formed in April 2013.

Barnet Mencap was established in 1965 and is one of the leading learning disability charities in the London Borough of Barnet. Barnet Mencap provides a wide range of person-centered services which aim to respond to the issues affecting the lives of people with learning disabilities and autism and their carers.

Barnet Mencap's values are clear and work towards these in all they do: Barnet Mencap believes that everyone should have the same life chances, and the right to live and participate in their own community. To actively enable people to stand up for their rights, challenge discrimination, and to achieve this by working together with service users, carers, staff, volunteers and the wider community.

Barnet Mencap is part of the North West London Mencap Consortium - a group of 7 Local Mencap's which work together to better support the needs of people with learning disabilities across North West London.

The Expect the Best checking service is North West London Mencap Consortium Project based in Barnet Mencap. Expect the Best are experienced at quality checked a wide range of Health and Social Care services, including Care Homes, Hospitals and Activity Centres across London.

Expect the Best was asked to lead on this Phlebotomy research project for Healthwatch Barnet. The project aimed to research people with learning disabilities experiences of using Barnet's Phlebotomy (blood test) Services, and to quality check the Phlebotomy services themselves.

The project aimed to look at the patient journey from the initial referral and booking process, to having the blood test itself, and finally getting the results. We aimed to find out how easy or difficult people with learning disabilities found these different stages, and whether reasonable adjustments were being made.

The overall purpose of the project was to gather feedback and information which can then be used to make further improvements to the Blood test services for people with learning disabilities and Autism in Barnet.

Background

Barnet's Phlebotomy services was identified as an important area to research through discussions with Health professionals including the Learning Disability Team Lead Nurse, Royal Free Learning Disability Acute Liaison Nurse, Healthwatch and through feedback from Barnet Mencap staff and service users.

Anecdotal feedback from Health professionals prior to this research suggested that some people with learning disabilities, particularly those with more complex, severe and profound needs may be finding it difficult to access the Phlebotomy services, and therefore may be missing out on having blood tests.

People with a learning disability are known to experience worse health inequalities than the general population. Life expectancy is 13- 20 years lower for men and 20- 26 years lower for women. The Confidential Inquiry (CI) found that almost 40% of people with a learning disability who died in hospital died from causes that could have been prevented with good-quality healthcare. This is in comparison to just 8.8% of cases of those without learning disabilities. For these reasons it is essential that Health services are as accessible as possible to ensure people with learning disabilities and autism can access them, and receive the same Health Care as everyone else.

Blood tests are one important way for Doctors to check patients overall health and to test for specific infections. This is particularly true for patients who are unable to communicate verbally and may be unable to tell people when they are feeling unwell. Annual Health Checks for people with learning disabilities is one opportunity for eligible people to have a check-up, including a blood test, to check their overall health.

People in Barnet can have their blood tests taken in a number of different ways, including at Hospital, in a Community Clinic, or at their GP if they offer this service. Patients who are house bound may also be able to have a blood test at home by the District Nursing/Community Phlebotomy Team. The study aimed to see whether patients had a choice over where they had their blood test.

Accessible Information Standard

The Accessible Information Standard was introduced in 2016 and by the 31st July 2016 all NHS services should have fully implemented and conformed to it. This means that services should: ask people if they have any communication needs, record those needs, highlight these needs clearly on their file, provide information in an accessible way according to needs (including in easy read), and share this information with other NHS and social care services when they have consent to do so. This project aimed to see whether services in Barnet are meeting this standard.

Methodology

This Project utilised several different research methods to gather our findings. These included:

1. **Patient Survey: An Easy read survey assessing People with Learning Disabilities' experience of the Blood Test Services in Barnet.** (Appendix 1)

This survey was made accessible for people with learning disabilities to complete themselves or with support. Family/carers and professionals could also complete the survey on behalf of those who were unable to complete it themselves.

In addition to circulating the easy read and online survey to Barnet Mencap staff and service users, both version of survey were sent to 7 learning disability service providers in Barnet, Royal Mencap, the Barnet Parent Carer Forum, and the Parent Action Group. The survey was discussed and promoted at both parent and carer meetings and the online survey was promoted online through Barnet Mencap's and Expect the Best's social media (Twitter and Facebook).

61 responses were received between November 2016 and March 2017
39 from people with learning disabilities or autism
16 from family members or carers
6 from Professionals who support people with LD

Patient feedback on Hospitals could not analysed by individual Hospital. Hospital findings are therefore combined findings for all Barnet Hospitals which offer a phlebotomy service.

2. **GP Survey: Survey of Barnet's GP feedback on Phlebotomy Services for People with Learning Disabilities in Barnet** (Appendix 2)

The Phlebotomy research project was discussed at the Barnet GP Practice Managers meeting on 10/11/2016. All GP Practices in Barnet were subsequently sent an online survey via survey monkey which aimed to analyse what Phlebotomy services were being offered in GP practices, review the referral process, and whether reasonable adjustments were being made, and to gather feedback from GP's on how effective and accessible Barnet's Blood Test services were for people with LD and autism. 20 responses were received.

The GP Survey was sent to Practice Managers but did not record who at the GP Practice completed the survey. Responses, feedback and suggestions may therefore have been completed by either the GP Practice Manager, a GP, or other GP Practice staff.

3. **4 x Case Studies:** Additional face to face or phone meetings took place with 8 respondents, leading to 2 detailed and 2 simple case studies. (Appendix 3)

4. **Quality Check of Barnet General Hospital Phlebotomy Service.**

Expect the Best completed a Quality Check at Barnet General Hospital on 12/4/2017. This quality check utilised quality checking tools and processes developed by NHS England. The Project Manager and a quality checker with a learning disability and with experience of using blood test services completed the quality check which included the following stages:

- An observational check of the environment
- Review of a Self-assessment questionnaire which had been completed by the Learning Disability Acute liaison nurse and the Phlebotomy Service Manager.
- Role Play: The Quality Checker role played following the patient pathway through the service, speaking to the receptionist, waiting in line, and having a mock blood test with a nurse.
- Follow up Questions - The Quality Checking team spoke with the Phlebotomy Service Manager, Acute Liaison Nurse and other staff to ask general follow up questions arising from the self-assessment, environmental check and role play.

5. **Other unsuccessful research attempts**

Attempts to organise quality checks at Finchley Memorial Hospital, and several GP practices proved unsuccessful. We requested feedback and information from Barnet's Community Phlebotomy Services (District Nursing Team) however no information was provided.

Data Analysis:

Data from the Patient and GP surveys were analysed using the SurveyMonkey.com software.

Findings

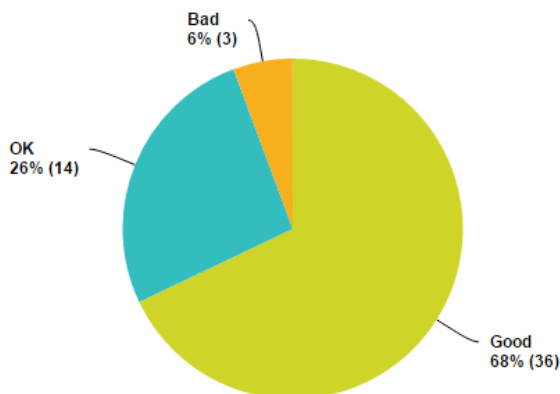
Analysis of the data and have led to the following key findings:

Overall views of Barnet's Blood test services

Graph 1: Patient Survey

How did you find the blood test service in Barnet overall?

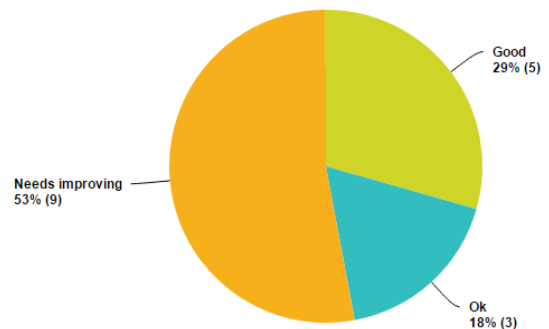
Answered: 53 Skipped: 10



Graph 2: GP Survey

Overall how would you rate Phlebotomy services for people with Learning Disabilities, autism and other additional needs in Barnet. (Answers to this question will remain anonymous)

Answered: 17 Skipped: 3



Patient Survey: Overall patients were happy with the blood testing services with 94% of respondents to the Patient Survey saying it was either Good or Ok.

GP Survey: However 53% of GP's said that they felt the Phlebotomy Service for people with LD, Autism and other additional needs needed Improving.

Findings from the Patient Survey:

Blood Test referrals process

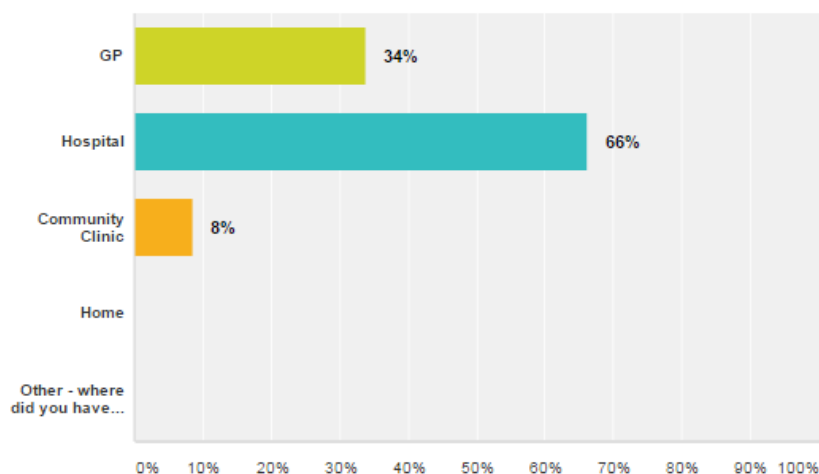
Of the 61 people who completed the Patient Survey 84% (49) of respondents had been referred for a blood test by their GP. Only 19% (11) of respondents had been referred for a blood test by a Hospital.

Where did people go for their blood test?

- 66% (39) of respondents had had their blood test in a Hospital.
- 33% (20) of respondents had had their blood test at their GP surgery
- 8% (5) had had their blood test at a community clinic
- No one who answered the survey had had a blood test at home.

Where did you have your blood test?

Answered: 59 Skipped: 3



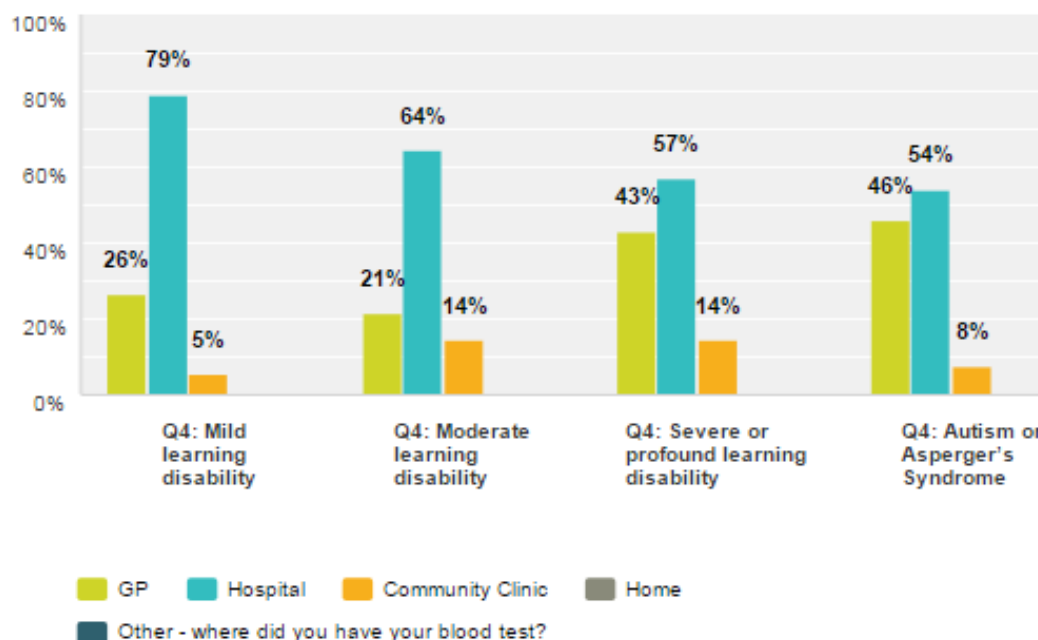
Note - Some respondents said they had had blood tests in more than one place.

Where did people go for their blood test - Compared by Disability type:

Whilst overall the majority of patients have their blood tests in Hospital. When responses are compared down by learning disability type there are some key differences.

Where did you have your blood test?

Answered: 58 Skipped: 3



40% of respondents with severe or profound learning disabilities, and 46% of those with Autism or Aspergers had their bloods taken at their GP surgery. This is far higher than those with Mild (26%) or Moderate (21%) learning disabilities.

This may indicate that some GP's are making some reasonable adjustments for patients with severe or profound learning disabilities and for those with Autism and Asperger's as these are user groups who are known to find it more difficult to access Hospitals.

Findings from the GP Survey back up this theme, as discussed in the GP Survey section (page 17).

Choice and control:

Only 47% of respondents said they were given a choice over where they had their blood test. 38% said they did not have a choice, and 15% did not know whether they were offered a choice.

However whilst less than half had a choice over where they had their blood test 95% said they were happy with where they had it. This included 100% of those who had their blood test at their GP surgery, and 92% of Hospital blood test.

One person commented that they were happy having the test at the GP Surgery because they **"know the nurse who will take my blood test"**.

Only 5% (4) were unhappy with where they had their blood test. These had their blood tests at either Hospital (3) or Community Clinic (1).

Whilst most people were happy with where they had their blood test 2 People commented very negatively about having the blood test at Hospital:

"The Nurse had absolutely no idea how to deal with my daughter with learning difficulties and who's terrified of needles"

"The person taking my blood had no thought for my disability."

There was no difference between where respondents said they would have preferred to have had their blood test taken: Respondents said they would have liked to have them at: GP (2), Hospital (2), Community Clinic (2), Home (2).

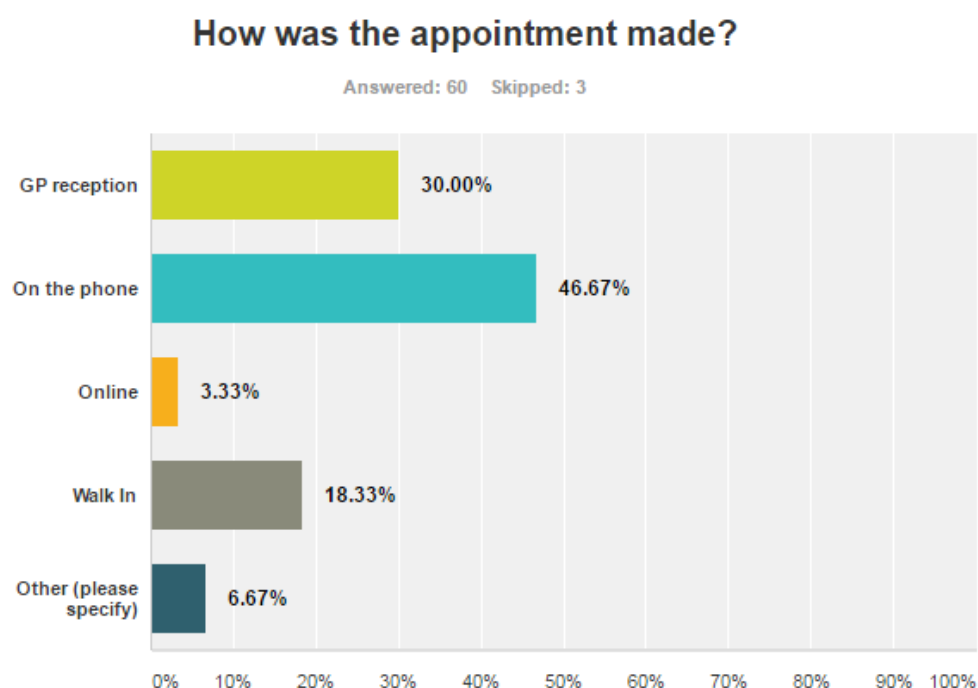
Booking the appointment:

Support from parents, carers and Support workers:

79% (45) of respondents said they had help to book their appointment. This was support was provided by parents/carers, support workers, or staff at the GP surgery. This figure is consistent with the 80% of respondents who said that someone went with them to their check. These figures may suggest that around 80% of people with learning disabilities have support throughout the blood test process.

47% (28) booked their appointments by phone, 37% (22) booked their appointments at the GP surgery (includes 'Other' responses as the narrative described GP /settings). Only 3% (2) booked their blood tests online.

There were relatively few problems with booking appointments as 89% (51) said that they found making the appointment either Easy or Ok. 11% (6) said that it booking the appointment was hard.



Key Recommendation: It's is therefore important that staff taking phone bookings ask if people have any additional needs. A flagging system is needed to ensure the Blood test service is aware of these needs prior to the blood test.

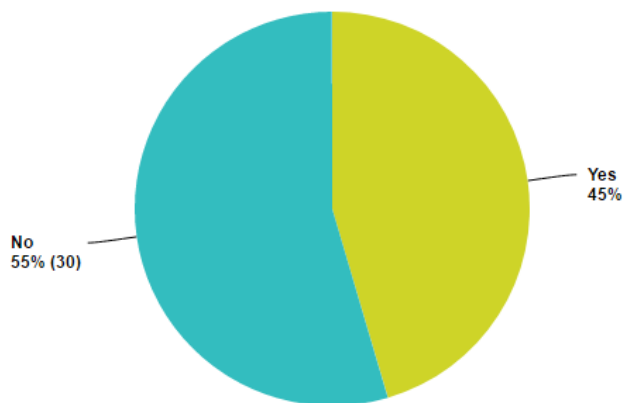
Barnet General Hospital has flagging system in place which asks whether patients have additional needs including elderly, mobility, hearing impairment and visual impairment. There is currently no learning disability flag.

Anecdotal feedback from Barnet Mencap staff has suggested that these flagging questions are not asked as standard when appointments are booked either on the phone or in person at Barnet General Hospital, or for other Barnet Hospitals.

Accessible Information and Communication

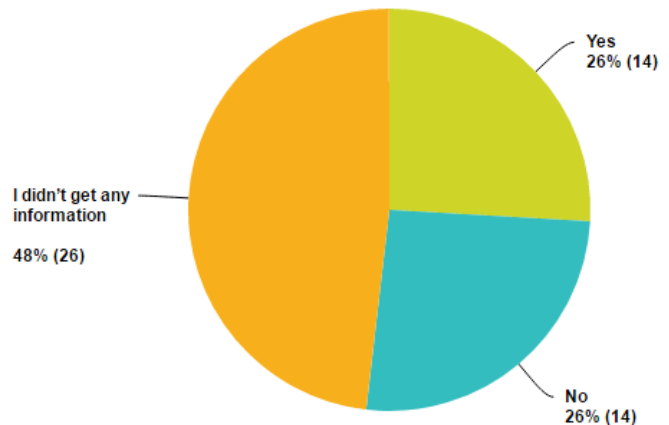
Before the appointment, were you given any information to explain about your blood test?

Answered: 55 Skipped: 7



Was the information in Easy Read?

Answered: 54 Skipped: 8



Only 45% (25) of respondents said they were given information to explain about the blood test, only half of this information was in easy read. 55% of respondents said they were given no information about their blood test.

Of those who were given information 76% (22) said it was easy to understand and 24% (7) said that it was not easy to understand.

One respondent who said the written information difficult to understand commented that this was due to it: **“Using medical terms that I don’t know”**

The Accessible Information Standard states that services should be giving patient’s information in an accessible way which they can understand. The findings indicate that this is not currently happening.

During the quality check at Barnet General Hospital’s Phlebotomy service staff stated that they felt that Easy Read materials needed to be given to patients by GP’s at the referral stage of the blood test process, as it was too late by the time they patients arrived at Hospital.

The Blood Test itself

Overall 95% of people said that the actual blood test itself was either Good or Ok.

The ratio was again slightly higher for GP surgeries with 100% of people who had a GP blood test saying it was Good or Ok, compared to 92% of those who had a Hospital blood test.

All 3 of the people who said that they had a ‘bad’ blood test had it in a Hospital.

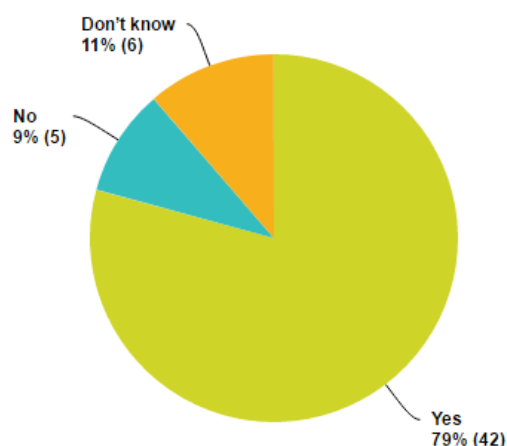
81% of people felt that the appointment was long enough, and there were only 3 negative comments about waiting times which was a positive finding.

Did People Get Enough Support?

People were asked whether they got the 'support they needed during the blood test':

Did you get the support you needed during your blood test?

Answered: 53 Skipped: 9



Overall people felt they had enough support during their blood test.

79% said that they had got the support they needed during their blood test. 9% said they did not get the support they needed and 11% did not know.

Narrative feedback from the Question: "Tell us about the Support they gave you":

What they did well:

"The nurse was nice and she talked to me with respect and I was distracted"

"The nurse was very reassuring, patient and explained what was going to happen throughout the process"

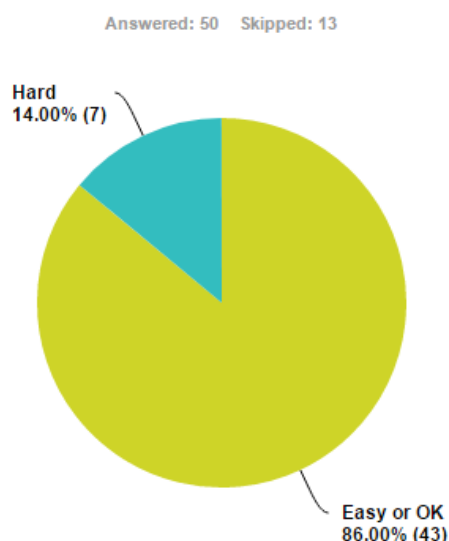
"They helped me to find the location of the clinic and they explained the blood test to me."

"Treated like any other patient, but perhaps fast forwarded in the queue"

"They took his blood while he was in the general anesthesia"

(3) of respondents said they filled in a feedback form. There were no Feedback forms available during the Barnet General Hospital Quality check at all.

Were your results easy to understand?



Results:

Respondents said that they received their results by follow up appointment (43%, 24), phone call (30%, 17) or letter (14%, 8)

86% of people found their results either Easy or Ok to understand.

Only 2 people said explicitly that they would like to have their results in an easy to read format. This low figure may be partly due to the fact that 80% of respondents are supported throughout the Blood test process by family or support workers and their results are therefore likely to be explained by the person providing this support.

Whilst the overall feedback on results was generally positive, there were 5 narrative comments which highlighted results as an area for improvement.

3 respondents stated that they would have liked to receive their results quicker. 2 referenced that they would like it in an easier to understand format and/or language and one stated that their results had been lost meaning that the blood test had to be repeated.

“Getting the results quicker and in language which we can understand and not in medical terminology.”

Patient Survey Overall Experience

What was good?

94% of Patient survey respondents said that overall the Blood Test Services were ‘Good’ or ‘Ok’.

The narrative feedback referred very positively to the **“quick”** service, and **“friendly, patient and experienced staff”**, staff **“explaining things clearly”**,

staff understanding their needs, and to being able arrange the appointment, and find the service easily.

“I know everybody at the GP service and the building is very familiar I am more relaxed”

“At my GP, it is excellent they understand my requirements”

“I did not have to wait long, and the nurse was very sympathetic to my needs and very reassuring

“Easy to arrange, not painful, not too long waiting”

What could be improved?

Only 3 respondents said that the overall Blood Test Service was ‘Bad’, all of these had had a blood test in Hospital (2) or Community clinic (1).

There were 11 narrative responses to the question: **“What would make the blood test service better?”** These included the 5 comments relating to the results referenced in the previous section.

3 patients, or their carers who had had Blood tests in either Hospital or Community Clinics made comments which suggested that they had had negative experiences overall where they felt the service was not making appropriate reasonable adjustments to cater for their needs.

One carer of someone with a severe/profound learning disability, who had had a blood test in a community clinic, commented:

“Nothing (was good) if you’re a severely disabled person who needs extra care.”

Whilst 2 more comments from those who had a Hospital Blood test suggested that the service needed to do more to make adjustments for people with learning disabilities:

One stated that the service could be improved if the service understood... **“That disabled child(ren) come with their own problems and it's not their fault”** and another said that the service needed to look at from the **“patients with difficulties angle”**.

Findings from the GP Survey (Appendix 2)

The GP Survey was sent to all GP practices in Barnet. 20 GP's completed and returned the survey.

65% (13) of those who completed the survey said they provided some level of Phlebotomy Service at their GP Practice. 12 of these (92%) were available to patients with learning disabilities, but only 50% (7) offered a service to all patients. 77% (10) of GP Phlebotomy service were available every day, whilst 23% (3) had a weekly service.

Of those 7 GP's which did not offer a blood test service, all referred patients to either 'Hospital' or a 'Community Phlebotomy Service'. Only 2 (29%) said they may refer to the 'District Nursing Team' which is available for patients who are house bound. In contrast 6 (46%) of the 13 GP's who did offer a blood test service said that they would refer to the District Nursing Team.

The survey asked if GP Practices offered an alternative to a hospital referral for people with LD/Autism who find it difficult to access hospital. Of the GP's who do not offer in-house blood tests 86% (6 of 7) said that they **do not offer** an alternative to a hospital referral for those who find it difficult to access Hospital.

Only 3 GP's said that house-bound patients would be referred to the district nursing team or community phlebotomy, and one GP stated they were **"unaware if there are any places we can send our patients with LD /autism"**.

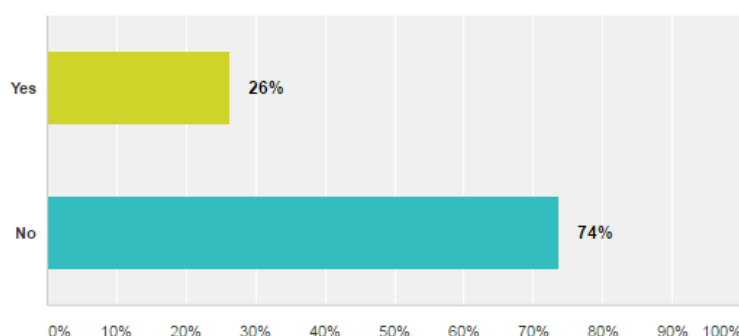
However 2 GP Practices who had previously said that they do not have a regular Blood Test service which people with learning disabilities could access, said that they would do blood tests for **"some patients with learning disabilities"** and for some **"patients who will not go to hospital to get their bloods done but need them done urgently"**.

One GP said they would **"Ask if they prefer to go to a community phlebotomy, or to a neighbouring GP."**

It was positive to hear these examples of reasonable adjustments being made, however very few GP's seemed to be aware that they could refer to another local GP, or to the District Nursing Team Phlebotomy and no GP's made any reference to the Learning Disability Team, or the Learning Disability Team Community Nurses.

Do you provide any accessible information to patients with a learning disability/autism about their blood test appointment?

Answered: 19 Skipped: 1



GP Survey: Accessible Information

26% (5) of GP's said that they provided accessible information to patients with a learning disability about their blood test appointment.

4 (of the 5) of these were GP's which offered an in-house blood test. 86% of GP's which did not offer an in house Blood test said that they gave no accessible information.

The survey found that GP's who did not provide an in-house blood test were less likely to offer any support with booking appointments for people with learning disabilities who may struggle to make their own appointment; 86% of GP's with no in-house phlebotomy offered no booking support, compared to the 33% of GP's with in house services who offered no booking support.

Those that did offer booking support said that either reception staff or the GP would make the booking on behalf of the patient. Several GP's said that carers usually support people with learning disabilities and made the bookings for patients.

GP Survey: Flagging Systems

The survey asked whether GP Practices had a flagging system which informed the Phlebotomy service when a patient with learning disabilities had been referred. 54% of GP's who were referring to their own in-house Phlebotomy services did have a flagging system, however 84% (5 of 6) who were referring externally did not have a flagging system for this.

Of those who did have flagging system 3 stated that they have an alert on the record, whilst 2 stated that they would include it in the notes.

This is a key difference as the 'notes' are often not read until moments before an appointment, whilst 'alert' or flag on the record is visible without opening the record and reading the text notes, meaning that staff are more likely to notice it and prepare any reasonable adjustments prior to the patient arriving.

GP Survey: Learning Disability Awareness Training

Positively 79% of GP's said that staff had had Learning Disability Awareness training.

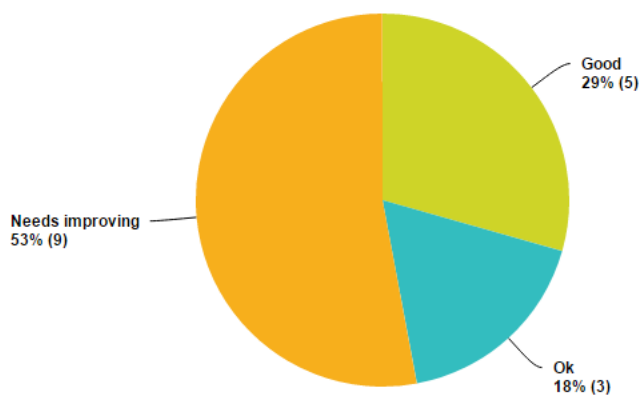
GP Survey: Overall views of Barnet's Blood Test services

Whilst overall 54% of GP's felt that Phlebotomy services for people with Learning Disabilities, autism and other additional needs in Barnet needed to improve, there was a significant difference between GP's who offered a Blood test service and those that did not.

80% of GP's who did not offer a blood test service felt that that Phlebotomy services needed to improve, and none of them rated the blood test services as good. This contrasts with the 42% of those GP's who did offer blood tests who thought the service was good overall and the 42% which felt it needed to improve.

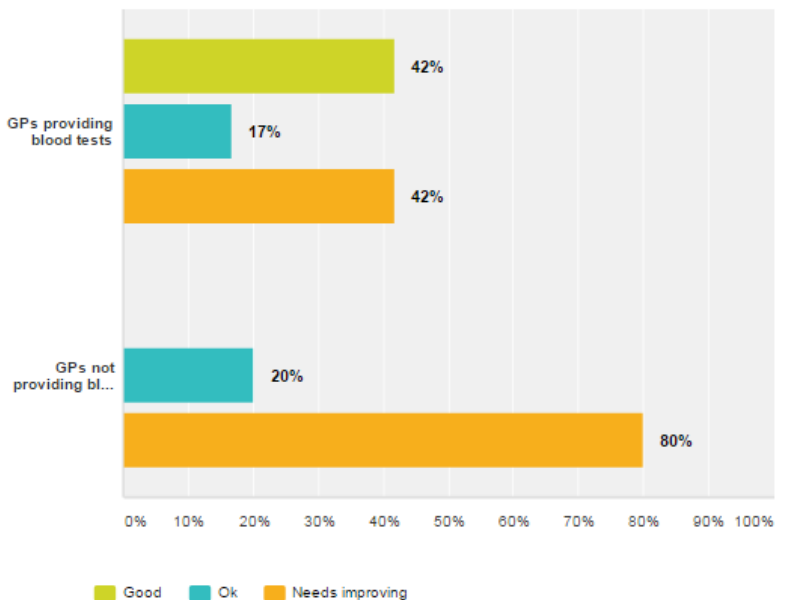
Overall how would you rate Phlebotomy services for people with Learning Disabilities, autism and other additional needs in Barnet. (Answers to this question will remain anonymous)

Answered: 17 Skipped: 3



Overall how would you rate Phlebotomy services for people with Learning Disabilities, autism and other additional needs in Barnet. (Answers to this question will remain anonymous)

Answered: 17 Skipped: 3



Suggestions for Improvements from GPs:

Narrative feedback from GP's suggested a number of different ways to improve blood test services for people with learning disabilities. These included:

Information packs for Services detailing what services and support are available for Patients' with Learning Disabilities - to be included in the BAR documents.

2 GP's referenced the fact that they are not currently funded to do blood tests. One stated that whilst they do so "for the benefit of patients" it costs the service "a lot of time and money" and "cannot continue unless funding is given to support this in house service".

Another said that they would “welcome being able to offer a phlebotomy service at our surgery” and said that if “fully funded” they could co design it with Mencap to ensure we meet the needs of our patients and especially those with special needs”.

GP’s also suggested “**more easy read materials**”, “**longer appointments and flexible times**” for patients with learning disabilities in Hospitals, and “**more learning disability awareness and dementia training for key staff**”.

Case Study findings (Appendix 3)

4 Case studies were collected through interviews with the carers of adults with severe or profound learning disabilities. All 4 reported difficulties with accessing blood test services for adults with severe or profound learning disabilities or complex needs. One patient had waited for over a year for their blood test because reasonable adjustments were not made, and 2 carers said the people they cared for were unable to have bloods taken at all due to the distress it causes. These missed blood tests increase the risk of serious illnesses remaining undiagnosed.

These case studies and feedback from the patient questionnaire indicates that whilst the phlebotomy services meet the needs of most people with learning disabilities with some reasonable adjustments being made, those with the highest needs are missing out on this service due to the difficulties they face.

Quality Check Report - Barnet General Hospital Phlebotomy Service (Royal Free Trust)

Expect the Best Quality checked Barnet General Hospital’s Phlebotomy service on 12/04/2017. This quality check was facilitated and supported by the Phlebotomy Services Manager and the Learning Disability Acute Liaison Nurse. Overall the Quality Checking team felt that Barnet General Hospital was providing a good service for the majority of patients with learning disabilities, and were making good reasonable adjustments when the service knew about patient’s needs in advance.

Key findings from the quality check are outlined below:

Barnet General Hospital - Phlebotomy Service: What was Good?

Reasonable adjustments

- Barnet General Hospital gave several good examples of where they had made reasonable adjustments for patients with learning disabilities, and the staff appeared to be more than happy to make these adjustments when they are needed. Examples of reasonable adjustments included:
 - **Booking double appointment times** for people with learning disabilities. The service was eager to inform our quality checking team that even if double slots aren't booked, the service would not rush an appointment and would take as long as was needed.
 - **Adapting the location:** The service has previously used a separate quiet area for patients who were claustrophobic. They cleared all medical equipment out of the room to ensure the setting was a comfortable and 'non-medical' as possible.
 - **Using Children's Nurses:** Patients with learning disabilities who are known to become distressed have been able to have their bloods taken in the Children's phlebotomy area by Children's nurses. The Children's nurses are more experienced at distraction techniques and use them regularly with children. These skills are transferable to making blood tests for some patients with learning disabilities easier and less stressful.
- **Prioritising patients with learning disabilities:** Patients with learning disabilities and other additional needs were prioritised to reduce their waiting times.
- **Friendly Staff** - All Staff spoken to in the Phlebotomy Service were friendly, welcoming and knowledgeable. This included reception, managers and nurses taking the bloods. The Quality Checking team were impressed with their attitudes and team spirit.
- **Learning Disability Awareness Training** - All new staff to the trust have an Induction which includes Safeguarding, Mental Capacity and Learning disability awareness training. Regular learning disability awareness training sessions are delivered by the Learning Disability Acute Liaison Nurse.
- **Openness and Transparency** - Management and staff on the day of the check and whilst organising the check were open and transparent, and appeared to be keen to hear and take on board feedback to improve the service.

Mock Blood test role play

- Overall the mock blood test went well. Both the reception staff and Nurse taking the blood test were friendly and personable.

- It was easy to know when your appointment was. The TV screen displaying patient's names was 'colour blind friendly', and names were clearly displayed.
- Quick blood test - Our appointment was prioritised and we were seen quickly but without being treated any differently to other patients.
- Other appointments were quick and waiting times were reasonable.

Environmental Observations and Accessibility:

- The Team were very impressed with the great volunteers at the Hospital reception and at the end of the Hospital corridor. Many patients fed back that they were helped by volunteers to find the right department. The team felt this helped make the process far easier and less stressful.
- The waiting area was large, spacious, clean and organised.
- The Hospital was easily accessible for wheel chair users - the ramps and lifts to the service were good.
- Whilst there were some areas for improvement around the lack of feedback forms, the Phlebotomy service knew to direct any complaints to PALS.
- The Quality checkers visited PALS and found them to be helpful. They said they would inform the Acute Liaison Nurse if patients with Learning disabilities raised a complaint. There was a visible poster on the wall in PALS to remind all staff to contact the Acute Liaison Nurse if patients with Learning Disabilities raised an issue.

Flagging Systems

- Barnet General Hospital has flagging systems in place both on the Hospitals electronic system and on the nursing handover sheets. These are used by all members of the multi-disciplinary team and indicate when patients have a learning disability or other additional needs. However these are not compatible with the Phlebotomy Service system.
- The Phlebotomy Appointment booking system does have its own flagging system which flags some additional needs such as Physical Disability, Visual Impairment, Hearing impairments, and Elderly patients. This was a very positive feature however there was no flag for Learning Disability.

Other

- Royal Free Trust website: Whilst not about Phlebotomy - The website displayed some good information for people with learning disabilities. There was a good video made by and for people with learning disabilities about how to prepare for being an inpatient at the hospital and what to expect.
- Hospital passports are used by the trust, although but not within Phlebotomy.
- Learning Disability Acute Liaison Nurse - The service gave examples of how they had worked closely with the Learning Disability Acute Liaison Nurse in order to provide a good service for patients with learning disabilities.

Barnet General Hospital - Phlebotomy Service: Areas for improvement:

Reasonable adjustments:

- **Flagging Systems:** Whilst there were some very positive examples of reasonable adjustments being made for patients already known to the service. Reasonable adjustments can understandably only be made if the service knows about needs in advance. The quality checking team felt that the flagging system and appointment booking systems could be further improved to ensure more patients with learning disabilities, particular those with more complex, severe and profound and autism were flagged as having a learning disability and given the opportunity to explain their needs and have reasonable adjustments prepared for their blood test.
- **Booking and booking System:** Blood test appointments at Barnet General can be made in person, by phone or online. When booking online people are given the opportunity to flag any additional needs (although not learning disability) however anecdotal feedback from patients and carers has been that these flagging questions are not asked when appointments are booked by phone or in person. Only 3% made appointments online meaning most this flagging opportunity was likely to be missed.
- Barnet General Hospital does not record the number of people with learning disabilities accessing the phlebotomy service.

Environmental Observations and Accessibility:

- There were no visible signs for the Phlebotomy service at reception. Our team needed to ask volunteers.
- There were no Easy read materials on blood tests available from the Phlebotomy service.
- There were no easy read materials or flyers on other Hospital services available from the Phlebotomy service.

Patient involvement and Feedback

- It was difficult to give feedback - There were no friends and family tests at the Phlebotomy service. Staff said there is usually a box at reception but they did not know where it had gone.
- PALS also had no Friends and family feedback forms, and there were no accessible easy read feedback forms available.

- Examples of the Friends and Family feedback test obtained from other wards were not in an easy read format and did not capture whether the patient had a learning disability or any other additional needs.
- There were no posters or visible information encouraging patients to give feedback or raise compliments or complaints.

Mock blood test role play

- Whilst the TV screen announcing appointments was good - the number of the cubicle on the TV display was very small. The quality checker could not read the cubicle number from the waiting area.
- The cubicles for blood tests were very small and felt cramped. It was felt that this could increase anxiety for some patients. Wheel chair users may also find it more difficult to fit in them comfortably.
- The cubicle curtain for the mock blood test was not pulled closed during the blood test. It was felt that some patients may feel uncomfortable with the curtain open, however if it had been closed the small cubicle would feel even more uncomfortable. Particularly for patients in wheelchairs.
- Whilst the nurse taking the mock blood test was very friendly and welcoming, she did not explain what was going to happen on the blood test or talk the 'patient' through the process.
- The Phlebotomy service informed us that they did not administer any emla (numbing) cream and stated that patients very rarely have this. A cold water freeze spray was suggested as an alternative however there was none available when it was requested.

Conclusions

This research project was pleased to find that overall Barnet's Phlebotomy services were working well for many people with learning disabilities. There were some good examples of reasonable adjustments being made by services, and the majority of patients said they had had a positive experience of blood test services.

Whilst there was good feedback from patients for both Hospital and GP blood tests, our findings suggest that patients are less likely to have a bad blood test experience if having a GP blood test. This is particularly true for patients with higher needs. The good news is that patients with autism, or severe or profound learning disabilities, who may find accessing a Hospital more difficult, were found to be more likely to have a GP blood test than those with mild and moderate learning disabilities, indicating that GP's are prioritising appropriately.

The study found that it was very important for staff to be friendly, to talk to the patient throughout the blood test, and to clearly explain what was happening. This helps to reduce worry and leads to more successful blood tests and positive experiences. Whilst there was evidence of this good practice in both Hospital and

GP blood tests, the study also found examples of patients with higher needs having bad experiences of Hospital blood tests. Bad experiences were largely due to no reasonable adjustments being made, staff being unprepared for the patients level of need, or staff not understanding how to support people with learning disabilities. There was no evidence of these issues in GP blood tests.

This finding indicates that people with the highest levels of need should have their blood tests at their GP practice. Where referrals need to be made to Hospitals for patients with high levels of need it is essential that these needs are flagged in advance so the staff can prepare the necessary reasonable adjustments. It was disappointing to find that 86% of the GP's who did not offer an in house blood tests had no alternative to a Hospital referral even for high need patients who they knew would find it difficult to attend a Hospital appointment. This is an area which requires improvement.

This study contacted the community phlebotomy service (District Nursing Team) to discuss the services they provide, however no comments or feedback was given.

This research project also aimed to quality check a GP Practice and a second Hospital, however the researchers were unable to organise these due to a lack of communication from services. The Quality check at Barnet General Hospital also took 5 months to arrange due to issues with gaining permission from the Hospital Trust. The researchers felt that the offer of independent peer to peer quality checking was a valuable way of supporting these services to improve, and that communication and the systems for granting permissions needed to be improved in order to take advantage of similar opportunities in the future.

Recommendations

1. GP's to give Easy Read information on blood tests to patients with learning disabilities at the referral stage. www.easyhealth.org.uk is a good source of free, easy read materials
2. Easy read materials on blood tests to be made available at the Hospital Phlebotomy sights.
3. All Phlebotomy and other Health services to ensure they are conforming to the Accessible Information Standard.
4. Patients with higher levels of need should have their bloods taken at their GP practice where possible.
5. More GP's to offer blood tests to people with learning disabilities, particularly those with higher needs. Currently 35% of GP respondents do not offer a blood test service.
6. District Nursing/Community Phlebotomy Teams to provide home or community blood tests as a reasonable adjustment for patients who are

not house-bound but find it very difficult to attend Hospital or GP blood tests due to their needs.

7. Funding for GP Phlebotomy services to be reviewed. Many GP's are not currently funded to deliver blood tests and only do so as an additional free service for patients, which one GP said was unsustainable.
8. Patients with higher level needs who are referred to Hospital for a blood test need to be flagged at the booking stage to ensure Hospital staff are prepared, and reasonable adjustments have been made.
9. Booking Blood test appointments - Reception staff for all services taking bookings by phone or in-person should ask there are any additional needs and if so if any reasonable adjustments are required. This should be asked as standard for all patients and recorded on the system as a visible flag.
10. All services to ensure staff have learning disability awareness training, and that staff are reminded how important and impactful it is to be friendly, and to talk patient's throughout their blood test, explaining the process.
11. Services to record the number of patients with learning disabilities using Phlebotomy services.
12. Feedback forms to be made easy read, more easily available, and to capture whether patients have any additional needs.
13. Services to promote the use of feedback forms, and to promote accessible ways for patients to leave complaints and compliments.
14. Trusts to review their governance procedures regarding how permission is granted for services to work with independent quality checking projects.
15. Barnet General Hospital Phlebotomy Service to review and act upon the areas for improvement highlighted in the Quality Check section of this report.
16. All services to continue working to make Phlebotomy services accessible to people with learning disabilities and to share best practice whenever possible.

Acknowledgements

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Accessible Information Standard Specification (2015):

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Appendices

Appendix 1 - Patient Survey



Easy Read Blood Test Survey

Do you have a learning disability or autism?
Have you had a blood test in Barnet in the last few years?
Expect the Best would like to hear how it was!



Expect the Best is a quality checking service run by Barnet Mencap. We are working with Healthwatch Barnet.

We want to find out how good or bad the blood testing service is for people with learning disabilities in Barnet.

We have made this questionnaire so people with learning disabilities and autism can tell us how it was when they had a blood test.

All your answers are confidential, and we will use them to try and make the blood testing service better.



Family, carers, and professionals can also use this questionnaire to tell us their experiences of supporting people with learning disabilities to use the blood testing service in Barnet.

If you would like to take part then please answer the questions on the next page.

You can also do this survey online at:
<https://www.surveymonkey.co.uk/r/WDWW7K8>

Section 1: About You

1. Are you answering these questions:
(please circle your answer)

 a.) About yourself	 b.) About a family member or someone you care for (family/carer)	 c.) About someone you support (as a professional)	 d.) Other
---	--	---	---

If you are a family carer or professional, please answer the following questions about the person with learning disabilities that you support.

2. What gender are you?

 Male	 Female
---	---

3. How old are you?
(please write below)

4. Would you describe yourself as having:

<input checked="" type="checkbox"/> Please tick	<input type="checkbox"/> None
<input type="checkbox"/> Mild learning disability	<input type="checkbox"/> Don't know
<input type="checkbox"/> Moderate learning disability	<input type="checkbox"/> Other
<input type="checkbox"/> Severe or profound learning disability	
<input type="checkbox"/> Autism or Asperger's Syndrome	

5. Do you have any physical disabilities?

Yes No

6. Do you need any extra support?
or example a wheelchair or mobility aid, or
help to communicate?

Yes No

If yes, please tell us what extra support you need

.....

.....

Section 2: Booking your blood test

7. Have you ever had a blood test? (if no, skip
to section 7 on Page 10)

Yes No

8. If yes, how long ago did you have it?

In the last year Over a year ago

9. How often do you have a blood test?

Every month Every 6 months Once a year Other

.....

3

10. Who sent you for your blood test?

GP Hospital consultant Other

11. Where did you have your blood test?

GP Hospital Community clinic Home Other

If 'Other', where did you have your blood test?

.....

12. Did you have a choice about where to have
your blood test?

Yes No Don't know

13. Were you happy with where you had your
blood test?

Yes No

14. If No, where would you have liked to have your blood test?

GP Hospital Community clinic Home Other

If Other, where would you have liked to have your blood test?

.....

4

15. Did someone help you to make your
appointment, or make your appointment for
you?

Yes No

If Yes, who helped you?

.....

16. How was the appointment made?

GP reception On the phone Online Walk In Other

If Other, how did you make your appointment?

.....

17. How easy was it to make your appointment?

Easy Ok Hard

18. How long after you made the appointment
did you get the blood test?

Same Day 1 day 5 days 1 week 2 weeks Other

.....

5

Section 3: Accessibility

19. Before the appointment, were you given any
information to explain about your blood test?

Yes No

If yes, what information were you given?

20. Was the information easy to understand?

Yes No I didn't get any information

Why?.....

21. Was the information in Easy Read?

Yes No I didn't get any information

Why?.....



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Section 4: On the day of the Appointment

22. Did you take anyone with you for support?

Yes No



23. Was the building easy to access?

 Yes  No




If No, why?

.....

24. Were the reception staff friendly?

 Yes  No

25. Did you get the support you needed during your blood test?

 Yes  No  Don't know

26. Tell us about the support they gave you:

What did they do well?




.....

What did they need to improve?

.....

7

27. How long did you have to wait for your last appointment?



 10 minutes  30 minutes  One hour

Over one hour - How long?



.....

Section 5: About the blood test

28. Did the nurse/doctor explain what was going to happen?

 Yes  No



29. Did you understand what the nurse/doctor said to you?

 Yes  No

Why?

.....

30. Did you feel worried about the blood test?


 Yes  No

Why?

.....

8

Appendix 2: GP Survey -



Expect the Best. GP Survey - Phlebotomy Services for People with Learning Disabilities in Barnet

GP Services Questionnaire - Quality Checking

Expect the Best is a quality checking service run by Barnet Mencap. We work with organisations to monitor and improve services for people with learning disabilities, autism and other additional needs.

We are currently working with Healthwatch Barnet to look at the experience of people with learning disabilities using Phlebotomy services in Barnet.

Part of this work involves finding out where in Barnet offers a phlebotomy service, and whether any reasonable adjustments are offered for people with learning disabilities.

It would be really helpful if GP Practice Managers could complete this short survey to help us build a picture of what services are offered across the Borough. If you have any other comments or feedback about what works well or could be improved in relation to Phlebotomy Services for people with learning disabilities then please add this to the end of the survey, or feel free to contact matt.gamble@barnetmencap.org.uk and we would be very happy to speak to you.

1. Details of GP Service

Practice Manager's Name:

Name of GP Surgery:

Locality:

Postcode:

Email Address:

Contact Number:

2. Do you provide a Phlebotomy Service at your GP Practice?

- ☐ Yes
- ☐ No

3. If Yes – How often is this service available?

- ☐ Everyday
- ☐ Weekly
- ☐ Monthly

Please give details:

4. Who is the Phlebotomy Service available to?

- ☐ All patients
- ☐ Children
- ☐ Pregnant women
- ☐ Older people
- ☐ People with learning disabilities
- ☐ People with physical disabilities/other additional needs
- ☐ Carers
- ☐ Other (please specify)

5. Where are patients referred to for a blood test?

- ☐ GP Practice
- ☐ Hospital
- ☐ Community Phlebotomy Service
- ☐ District Nurse Service
- ☐ Other

Please give details:

6. Do you offer an alternative to a hospital referral for people with learning disabilities/autism or other additional needs who may find it difficult to access the Hospital Phlebotomy Services?

- ☐ Yes
☐ No

Please give details

7. Do you provide any accessible information to patients with a learning disability/autism about their blood test appointment?

- ☐ Yes
☐ No

Please give details

8. After a referral has been made, how does the patient make their appointment?

- ☐ Telephone
☐ Online
☐ Walk in
☐ Other (please specify)

9. Is there any support available for people with learning disabilities/autism or additional needs who may struggle to make their appointment on their own?

- ☐ Yes
☐ No

Please give details

10. Do you have a system which flags to the Phlebotomy Service when a referred patient has a learning disability or autism and may require additional support on their blood test?

- ☐ Yes
☐ No

Please give details

11. How are the results of the blood test delivered to the patient?

- ☐ Telephone
☐ Letter
☐ Follow up appointment
☐ Other (please specify)



12. Does the GP service offer training to its staff around learning disability awareness?

- ☐ Yes
☐ No

Please give details

13. Overall how would you rate Phlebotomy services for people with Learning Disabilities, autism and other additional needs in Barnet. (Answers

to this question will remain anonymous)

- ☐ Good
☐ Ok
☐ Needs improving

Please give details:

14. If you have any other feedback or information on how the Phlebotomy Service works for people with learning disabilities, or any suggestions on how things could be further improved then please tell us here:

(Answers to this question will remain anonymous)

Thank you for taking part in this survey and for helping to improve services for people with learning disabilities.

If you would like to give any more information or feedback on this area or to discuss this survey further then please contact
matt.gamble@barnetmencap.org.uk

Thank you

Appendix 3: Case Studies

Detailed Case Study 1 - Mark and Simon.

This case study reported by Phone interview on 19/12/2016 by Simon, who is the brother of Mark, a man who has Profound and Multiple Learning Disability, and no verbal communication.

Both names have been changed for anonymity.

Mark's brother Simon had been arranging blood tests for Mark for last 15 year since 2002. These blood checks took place every 2-3 years. Simon first started requesting regular blood tests for Mark in 2002 after Mark had been losing weight and a Psychologist recommended a blood test to monitor his health. As Mark has no verbal communication skills he may be unable to indicate that he is feeling unwell.

Mark finds going to a hospital extremely distressing and so blood tests at a hospital setting was not possible. Mark's GP does not offer a blood test service. Simon spoke to Mark's GP Practice and discussed the options. The GP was very helpful, and contacted an assistant Psychologist within the Learning Disability Team to discuss how they could facilitate a blood test for Mark.

It was agreed that the best place for Mark to have his blood test was at his regular day service, where he felt relaxed and at ease in familiar surroundings and with familiar staff. It was agreed that a Phlebotomist from the District Nursing Community team would travel to the day service at an agreed time to complete the blood test. It was also agreed that Simon would also be present to support Mark and that would administer a mild sedative 2 hours prior to help prepare Mark for the blood test. On the day of the blood test Simon, day service staff and the phlebotomist all worked together to distract Mark and complete the blood test. This was very successful and the blood test went well.

This was an excellent example of a reasonable adjustment working very well, and was repeated successfully for Mark's blood tests every 2-3 years between 2002 and 2012.

However in Dec 2014 Mark was not very well and had diarrhoea. After visiting the GP it was decided that Mark needed a blood test. Simon asked that the GP request the blood test through the system that had previously worked.

In January 2015 the GP made the request, however they were informed that the District Nursing Team could no longer carry out the blood test as whilst Mark's disabilities were severe and profound, and unable to attend a Hospital blood test he not house-bound, and that changes to CLCH meant that the District Nursing Team could only visit house bound patients.

Simon was informed that Mark would have to go to Hospital for his blood test. This was despite it being known that Mark found Hospitals extremely distressing. As there was already a very successful tried and tested system for Mark having a blood test, Simon felt that this should have been a reasonable adjustment to make.

Over the next 17 months Simon contacted his GP, the Learning Disability Lead Nurse, the Learning Disability Commissioner and the Phlebotomy Services at CLCH to ask for reasonable adjustments to be made, but were told that these were not possible.

The Community Phlebotomist did then arrive at Simon and Mark's house with no prior warning to do the blood test. However neither Simon nor Mark were prepared for the check as the sedative had not been prescribed or administered. Whilst this miscommunication was frustrating Simon was pleased that the Community Phlebotomist now appeared to be able to come to the house for the blood test. However when Simon tried to rearrange the blood test at home he was told that the Community Phlebotomist should not have gone to the house at all, and that this had been a mistake. They

reconfirmed that the community phlebotomist would not be able to do return to the home or go the day service for the blood test.

Simon then says he spoke to the the Learning Disability team and was told that the blood test would have to be done at Barnet General Hospital or not at all. It was also suggested that Mark may not need the blood test any more. This was despite a referral being made by the GP, and the fact that Annual Health checks, which include blood tests, are recommended as People with learning disabilities often have difficulty in recognising illness, communicating their needs and that regular health checks for people with learning disabilities often uncover treatable health conditions which would otherwise go undetected.

Mark was re-referred by his GP in February 2016 over a year after his originally referral. After further 4 months of continued pressure from Simon, Mark had a Health review with his GP, and it became apparent that there had been some mis-communications between several health professionals and they had thought the blood test had already taken place.

In early June 2016 after further discussion the blood test, with reasonable adjustments, was finally agreed, and took place at the end of June 2017 - 17 months after Mark was originally referred.

The blood test itself went very successfully, it was carried out by the District Nursing Team at the Day Service exactly as had been done previously.

Simon found the process very draining and frustrating and felt Mark's health was not treated as a priority throughout the process, and reasonable adjustments were not made.

Simon's main fear was that serious Health issues could have been missed in the 17 months wait for the blood test, and that other parents and carers would not be able to navigate the confusing and complicated system. Simon felt that this would lead to people with similar disabilities missing blood tests and health checks, which could lead to serious health issues not being diagnosed.

Detailed Case Study 2 (Janek and Ana)

Expect the Best spoke to a Mother (Ana) whose child (Janek) is aged 14years old with complex learning disabilities and is a wheel chair user. They had an appointment to go to Edgware Hospital to the Phlebotomy department for Janek to have a blood test.

Ana explained that there were 6 blood test stations at the hospital all with curtains; Ana felt that the setting was very open and lacked privacy. On arrival the family were told to wait for their appointment time, and were not prioritised. The wait was long, and Janek had started to get distressed by this.

When Janek was called to the cubicle for his blood test, the Mother felt that the nurse did nothing to try and make him feel calm and relaxed. No private room was offered and the nurse did not apply any numbing cream on him.

Ana stated that the nurse who was taking the bloods seemed inexperienced and kept repeating that Janek needed to be still in order for her to take the bloods from the arm, but did nothing to help calm him. Due to Janek's distress Ana could not keep him still.

Ana felt that the staff member was rude to them, and was so furious at their behaviour that she asked to see the manager and to have someone who understands the needs of someone with a disability to take Janek's bloods.

Ana was advised to go and have a coffee and take their son away for a while to help calm him down and then come back and another attempt will be made.

After returning calmer Janek was prioritised and the blood test was successfully taken by another member of staff who seemed more experienced and helped to keep Janek relaxed and calm.

Ana explained that the whole experience felt awful, humiliating and very upsetting. Ana said that both her and Janek were exhausted by the process.

Ana suggested that reasonable adjustments could be made by the hospital by having a separate section for people with a learning disability when bloods are taken. She felt that staff should have more awareness of people with learning disabilities, and that numbing cream for their son should have been prescribed and used to make the process less painful for Janek.

Simple Case Studies 3 and 4.

In a group interview setting with parents and carers, 2 parents of adults with severe learning disabilities and complex needs told of their similar experiences of trying and failing to have blood tests:

Both parents had been referred for a blood test by their GP and had attempted to have these blood tests at Hospitals in Barnet. Neither was successful in having the blood test. In both cases Hospital staff had been patient, supportive and helpful, however they were unable to take any blood due to the patients being very distressed by the experience. They had both tried to have the blood test several times but their adult sons and daughters had been far too distressed by the setting and experience.

Both had subsequently tried to have the blood test at their GP surgery and also failed, however they had been unable to have a blood test at home.

Both parents said that they had not been able to have a blood test for over 5 years as a result of these difficulties.

One parent stated that they had previously had one blood test successfully completed as it was done whilst their adult child was under anaesthetic for a separate Hospital procedure.

Both parents were concerned that missing blood tests could lead to medical conditions remaining undiagnosed.



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