



Annual health checks for adults with learning disabilities

About Healthwatch Newcastle

Healthwatch Newcastle is one of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act 2012.

Healthwatch Newcastle is an independent not-for-profit organisation. We help children, young people and adults to have a say about social care and health services in Newcastle upon Tyne. This includes every part of the community, including people who sometimes struggle to be heard. We work to make sure that those who plan and run social care and health services listen to the people using their services and use this information to make services better.

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Introduction

During 2021, Healthwatch Newcastle received feedback from a local voluntary sector organisation that supports people with a learning disability. The feedback suggested engagement with annual health checks for people with learning disabilities hadn't been successful locally.

Under the NHS Long Term Plan, targets were introduced to ensure GP practices offered an annual learning disability health check service and improved access to healthcare for people with a learning disability.

The annual health check targets for people in this group and on a GP practice learning disability register (a list of all patients registered at a practice with a learning disability) were 75% by 2023–2024. There were further aims of raising the level of awareness and understanding across the NHS, to best support people with a learning disability as patients.

Recently published statistics¹ show the target of 75% is being met, despite the COVID-19 pandemic, which necessitated a dramatic change in the way the check was conducted, the mode of delivery changing entirely in some circumstances. Given that these statistics did not match with the feedback we had received, we wanted to explore this further.

Background

NHS guidance² suggests a health check for people with a learning disability should be carried out once a year. The annual health check is designed to identify undetected problems with current medical conditions and detect the development of new ones.

GPs and practice nurses are predominantly cited as being involved in the delivery of the annual health check, however, our research shows it can also involve different clinical professionals, such as nurse practitioners, pharmacists or care assistants.

The check is designed to take a closer look at how a person with a learning disability is doing, check that medication is being taken correctly and when required and talk about staying well. It normally takes between 20 and 30 minutes – sometimes longer – and involves physical checks. It provides an opportunity for the clinician and the patient to have a meaningful two-way conversation, resulting in an assessment of the patient's overall health.

As part of the annual health check, GPs are required to produce a health action plan. The plan contains information about key action points that have been agreed with the patient and sometimes their carer/support worker. It can also contain information such as health promotion advice, including recommendations for appointments to other services such as the dentist. The patient should be given a copy of the plan at the end of the health check.

Since people with a learning disability often find it difficult to understand the implications of certain symptoms they experience with their overall health, making it easier for a person to attend their annual check is vitally important. GP practices can help support patient attendance by making reasonable adjustments. Some examples of common adjustments in practice environments are:

¹ Public Health England, Quality checking health checks for people with learning disabilities
<https://tinyurl.com/54arwp89>

² www.nhs.uk/conditions/learning-disabilities/annual-health-checks

- Providing an easy read format for invitations using a combination of pictures, large print or simpler words to describe the appointment – this creates inclusion, provides understanding and gives control to the patient.
- Having a degree of flexibility, for example, telephone/video call appointments when attending the surgery presents a problem.
- Booking longer appointments and having the patient’s carer/support worker in attendance, creating a holistic environment.
- Having consideration for the time of the appointment, i.e., when the practice is not too busy or out of school hours.

There is a generic process for the annual health check, however, our research was also able to identify some surgeries taking a more holistic person-centred approach to what has generally been a somewhat inflexible process.

What we did

Our study concentrated on people aged 18 years and over with a registered learning disability and their carers/support workers attending GP practices in Newcastle upon Tyne.

1. We invited Skills for People, which supports people with learning disabilities and autism, to work collaboratively with us in a wider consultation.
2. We asked people with a learning disability and their carers/support workers to share their views and experiences of their annual health check through a questionnaire. The questionnaire was developed in collaboration with Skills for People and focussed on three main areas: user experience, continuity of care and accessibility.
3. We spoke to GP practice managers, GPs and people in the local Newcastle Primary Care Network. Our discussions provided an understanding of the problems and achievements in delivering the annual health check at practice level.
4. Lastly, we conducted some statistical analysis using the statutory returns of learning disability annual health checks from practices to the Newcastle and Gateshead Clinical Commissioning Group (CCG).

We analysed the data collected by the CCG at both Primary Care Network and practice levels. This data showed us the numbers of people over 18 years of age on individual practice learning disability registers, who had received an annual review and, in some cases, a formal action plan and outcome.

Early analysis of the statistics showed a low registration of people with a learning disability recorded on practice learning disability registers. We understand however this could be due to several reasons such as:

- Patient choice.
- General diagnosis issues.
- Ability to meet the definition of a learning disability.
- Potential coding errors from Read Code³ (an auditable coding system used to capture a complete picture of a person's medical record: diagnosis, medication, administration) to SNOMED CT⁴ (a structured and consistent electronic code used universally across the NHS).
- Late diagnosis.

Data collection

We used a mixed approach for data collection, based on the questionnaire, and amalgamated the results for data analysis:

1. Skills for People hosted focus group sessions over several weeks. The views of 13 adults with a learning disability were gathered, analysed and included separately in the report as Appendix A.
2. Paper copies of the questionnaires in large font were circulated to several groups supporting adults with a learning disability in Newcastle and Gateshead. Gateshead organisations were included because many of their attendees live in and attend a GP practice in Newcastle. The views of 12 people with a learning disability attending a GP practice in Newcastle and seven carers were gathered.

The views of ten people with a learning disability attending these organisations, with a registered GP out of the scope of the exercise, were collected. Additional views of six carers/support workers were also collected. None of this data is included in this report. Instead, we will pass on this data to other regional Healthwatch organisations. See Appendix C for comments from attendees who were registered with out of area practices.

3. In addition, two further online surveys were created. We promoted this in collaboration with regional partner organisations supporting people with a learning disability and their carers/support workers. The views of three people with a learning disability and five carers were obtained.

What people with a learning disability told us

Understanding about diagnosis, GP learning disability registers and the annual health check itself was high across both people with a learning disability and their carers/support workers.

We received 28 questionnaires (27 of them contained comments) and 27 people said they had a learning disability diagnosis.

³ https://en.wikipedia.org/wiki/Read_code

⁴ www.england.nhs.uk/digitaltechnology/digital-primary-care/snomed-ct

Twenty-two people indicated they were on their GP learning disability register, four people indicated they didn't know and one didn't know what the register was.

Twenty-five people were aware that there was an annual health check for people with a learning disability and only two respondents said they were not aware.

The user experience

In healthcare, user experience is essential for developing lasting, long-term relationships. The comments varied across the questionnaires and in focus group sessions, however, most were positive.

- Twenty respondents told us that they felt listened to during their annual health check although seven suggested this was not the case (one person responded by ticking both 'yes' and 'no').
- Sixteen respondents told us their experience was positive and 11 had negative views. Ten comments out of 13 attendees at Skills for People focus groups had a negative user experience.
- The majority of people (but not everyone) were happy.
- Sixteen out of 27 comments were positive.
- Most of the negative comments were received through the focus group sessions. Possible reasons for this may be that the relaxed atmosphere in the group sessions made it easier for people to share their experiences openly.
- When asked if there was anything they would like to change about the annual health check, 14 respondents said 'no'. One person advised they would like to see change; however, no suggestions were made as to what these could be.

From a continuity of care perspective

Twenty-seven respondents told us they had had an annual health check and one declined to answer.

The responses also showed us that although the timeframe for the check differed, the majority (24) were conducted between six months and two years ago. Only three were conducted more than two years ago.

Twenty-six people also said their annual health check took place at the surgery, with only one conducted by telephone.

Only three respondents told us they were given a health action plan⁵. Although the data suggested not everyone with a learning disability may need one, they are important as they hold all valuable details about an individual's health in one place.

⁵ Mencap, What is a health action plan? <https://tinyurl.com/2s4aefvs>

How accessible was the service?

Although information obtained from respondents highlighted that GPs have adopted a flexible approach to the invitation process, making paper invitations easy to understand is a concern. Responses highlighted that most practices appear to have chosen a variation of paper, telephone invitation, text or to the carer directly.

Only nine of our respondents told us that their invitation was in easy read format.

What carers told us

Twelve carers/support workers completed the carers' questionnaire. Eleven carers/support workers told us the person they cared for had a formal diagnosis of a learning disability. All were clear that there was an annual health check available to the person they cared for.

One individual specifically advised us the person they cared for did not have a formal diagnosis and as a result had never attended their GP practice for an annual health check, although one could have been requested at their surgery.

The user experience

Ten individuals told us booking the appointment was straightforward as the practice gave them an appointment in the invitation.

When asked about the overall experience of the annual health check, ten carers/support workers felt it was positive. Comments related to feeling listened to during the appointment.

When asked if there was anything they would like to change about the annual health check process, four carers/support workers said 'no' and three said 'yes'. Their comments related to a lack of information or advice.

From a continuity of care perspective

Most carers told us that the process of being invited for the annual health check was straightforward. Of the 12 respondents:

- Seven said that they/the person they cared for had received a telephone invitation for their annual health check. Three received an invitation by letter (with one carer advising a letter had come directly to them) and one by text.
- Eight carers/support workers advised us that the person they cared for had attended an annual health check in the last year, with four attending between one and two years ago. **It is important to note that we do not know whether the questionnaire responses for people with a learning disability and the carers/support workers are related and so the data may not tally.**
- Ten of the 12 carers advised us the physical check took place in the surgery, with two highlighting appointments such as by telephone or video link.
- Only one respondent told us the person they cared for had been given a health action plan.

When we asked how easy the process of being invited for the annual health check was, three respondents out of the 12 said they would like to see a change. Four were happy with the service and five did not give a response.

Eleven respondents advised us the person they cared for had received an annual health check, with equal numbers advising us the invitation was easy to understand and the instructions were clear.

Ten respondents told us that the practice gave the person they cared for the appointment. All ten appointments were held in the surgery despite the pandemic.

Individual feedback

The feedback below offers the personal perspective of some of the service users who responded to this work. Their comments are in keeping with the aim of the work - a focus on user experience, continuity of care and accessibility. Real names have not been used.

"I phoned the surgery to book my health check and it was easy to do. My doctor is fantastic. I see her every time and she is very helpful. When I was struggling with my depression, and she really helped me. She went over the time and listened to me. She even calls me sometimes to check on how I am doing."
'Sarah'

"The surgery always gives me one date for the appointment, but I have to rearrange because it is never suitable. Sometimes the appointment is with my doctor and sometimes with the nurse as well. My health checks are always crap. The appointment is too short. It usually lasts half an hour. Sometimes they listen to me. It depends on the doctor or nurse. Some of the doctors are interested and some aren't. They don't talk to me at all when my support worker is in the room. They never find any issues because they don't take long enough. They never weigh me. The doctor said they didn't have the scales, so they guessed my weight (wheelchair user). I never get blood tests. I had my last health check over the phone which I was not happy about. I wanted it done in person so it could be done properly."
'Jane'

"I went to the GP myself and asked for an annual health check. I felt rushed so the next people could go in. The doctor didn't explain anything. The doctor kept his head in the computer or his notes and didn't look at me. He didn't really talk to me. The nurse helped a bit to explain some of the information. I was nervous and felt frustrated. Longer appointments would make the health check better so I can express my feelings."
'John'

"I know I have a learning disability. I know I am different to other people, but I don't really know what learning disability means. I received a letter for my appointment. It wasn't in Easy Read. I got help from my support worker, if I didn't have help I would not have been able to understand. I went to my appointment with my support worker. I didn't feel listened to or given the chance to talk. The doctor spoke to my support worker and not me. I didn't really understand what I had to do after my health check."
'Tina'

What discussions with GP surgeries in Newcastle revealed

At the time of the study, GP practices were under enormous pressure. They were dealing with the impact of the COVID-19 pandemic on patients and staff while also meeting increased patient demand. We were mindful of this, recognising contact should be as unintrusive as possible when contacting them for feedback.

Speaking to people in Newcastle's Primary Care Networks and practice managers/GPs, we were able to get a glimpse of how annual health checks have been managed over the past two years, as well as obtain ideas about different ways of working that had local success.

The GPs we spoke to were clear that the annual health check 'has to be real', not just a tick box exercise. Despite pandemic pressures, clinical staff absences and competing health campaigns (including getting members of this vulnerable group to attend) the service continued, albeit differently.

This is what we discovered:

- All practices reached their targets. All patients with a learning disability and on the practice register were invited and attended an annual health check. There were no reported refusals.
- Practices maintained care through a combination of phone calls (in some cases conversations with carers/support workers/advocates), home visits and some surgery appointments. Adjustments such as this clearly highlight the importance of accessibility and continuity of care to some practices.
- Attendance has been flexible and patient-led. "A patient can always ask to come to the practice if they prefer and where practicable, this has been encouraged."
- The light touch approach has, in the main, been very positive. Some practices found it helped in reducing anxiety in patients, building positive relationships for all involved in the health check.
- Patients liked the holistic approach to health care and the focus on the whole person.

- The one hour/hour and a half session allows for mixed needs, with all problems discussed in one place. This approach gives added flexibility in handling other healthcare-related matters such as smear tests or the administration of vaccines.
- Some practices do the 'work up' (bloods, urine testing, etc.) before the patient sees a nurse practitioner or GP. Emphasis is clearly on the 'comfort zone' for the patient, which supports trusting and a positive lasting relationship.

Conclusions and recommendations

Areas of existing good practice

The purpose of this piece of work was to understand how people with a learning disability and their carers/support workers in the Newcastle area experienced the annual health check.

In considering the information gathered from the respondents, we can share some areas of good practice, which will aid in improving the experience for people with a learning disability and their carers/support workers.

Feedback shows that practices are working hard to ensure that they develop lasting and trusting relationships with their patients who have a learning disability. They are doing this:

- Through nonclinical engagements, such as sending a birthday card.
- Ensuring where possible, the patient sees the same clinical member of staff for each review.
- Being technically flexible, while continuing to focus on the needs of the patient.

Through our research, we identified and were impressed with one Primary Care Network sharing ideas and experiences to create lasting good practice and develop robust benchmarking systems.

Areas of concern

Raising awareness and eligibility

To have a recall for an annual health check, people with a learning disability need to be included on the practice learning disability register. This is automatic if they have a learning disability diagnosis code.

Data gleaned from the questionnaires suggested one adult who had a learning disability had never had an annual health check. Although our research identified only one individual in this category, it may indicate that there are other patients not being included on the practice register. This may be due to:

- Misdiagnosis.
- Lack of diagnosis during childhood.
- Lack of recognition of learning disabilities.
- Old/inappropriate clinical code attached to the medical record.

Suggestions for improvement

We would strongly urge that practices increase promotion of the key signs of learning disabilities⁶ in children and adults openly, by:

- Using the NHS England communications toolkit 'Don't miss out'⁷ as a template.
- Displaying posters in the waiting room or video clips where the technology exists.
- Ensuring reference material/leaflets are visible and available on the practice website.

Written communications

The NHS accessible information standard⁸ clearly outlines the benefits of using accessible formats, such as easy read, for communicating information to people with a learning disability. Our responses show this is not being applied universally. Only nine out of 27 respondents with a learning disability received a letter in easy read format.

Easy read incorporates pictures with text, which allows people with a learning disability to understand information more easily. While the methods used by practices to invite their patients for their annual health check varied, the data shows easy read formats are not generally used and could be used more.

The comments below, while highlighting a patient-focused attitude by practice staff, equally highlight that the use of regular formats in written communications may be preventing the patient from having a degree of control when it comes to their health.

Patients told us:

"Staff support me to read the letter."

"Sometimes it's easy to understand and sometimes it's not."

"I got my support worker to help me. If I didn't have help, I wouldn't have been able to understand it."

"The staff read all of my letters for me."

Suggestions for improvement

The NHS accessible information standard means GP practices should contact patients to identify any specific communication and information requirements. Once identified, these should be recorded on an individual's GP record and flagged to alert staff.

In the absence of information to corroborate how widely this has been undertaken for people who have a learning disability and are on the practice learning disability register, we suggest the following:

- A review of the practice learning disability register to identify and update personal communication requirements.

⁶ Improving identification of people with a learning disability: guidance for general practice <https://tinyurl.com/e3wbsta6>

⁷ NHS England communications toolkit: don't miss out <https://tinyurl.com/p6k7kzs3>

⁸ NHS England accessible information standard www.england.nhs.uk/ourwork/accessibleinfo

- Consideration might be given at Primary Care Network level to the development and use of a generic learning disabilities annual review invitation letter/template with pick lists/interchangeable fields.
- Using the CCG-shared information portal for resources already produced in easy read format. This portal includes information such as easy read appointment letters, videos for waiting room screens and general health information leaflets.

Patient involvement

Some respondents with a learning disability expressed concerns over feeling excluded and unheard during their annual health check process. All of the comments below suggest to some degree, an exclusion of the person with a learning disability.

When asked whether they had input into their health check some patients told us:

“I didn’t get the chance. The doctor and my support worker talked amongst themselves and not directly to me even though the appointment was about me.”

“The nurse listened to me more than the doctor.”

“It depends on the doctor or the nurse. Some are interested and some are not.”

“Sometimes they don’t listen, and it is hard to understand them.”

“I didn’t have enough time to discuss anything else I wanted to talk about as the conversation was just about my weight. I found this difficult to talk about.”

“The doctor kept looking at his computer and didn’t really talk to me or explain the information clearly.”

Suggestions for improvement

The above comments, although only from a small sample of respondents, do suggest unintentional exclusion.

The General Medical Council has ethical guidance for communicating with patients who have a learning disability⁹. While we appreciate not all clinicians subscribe to this organisation, the guidance underpins the need for clear, patient-centred verbal communication.

In addition, we would like to:

- Reinforce the need for inclusion, by ensuring clinicians talk to the patient and include the carer/support worker only where necessary. For example, when the patient is unable to participate or communicate for themselves.

⁹ www.gmc-uk.org/ethical-guidance/ethical-hub/learning-disabilities

- Suggest Primary Care Networks explore the purchase of tools or software to assist both parties during the consultation, to ensure clarity and understanding. This may not only be beneficial in terms of patient satisfaction but may save time.
- Recommend a clinical training needs analysis with a view to undertaking specialist training in consulting with people who have a learning disability. Mencap¹⁰ research shows that only one in four healthcare professionals have been given training about learning disabilities.

This will:

- Promote confidence across the clinical team in dealing with people who have a learning disability.
- Support in dealing with the multidisciplinary health concerns.
- Improve the management and focus of the conversation.

Use of the health action plan

Although our findings revealed an underuse of the health action plan in the annual health check, this by no means suggests that patients are being denied good quality and appropriate care.

The health action plan is not only a legislative requirement but a valuable and tangible tool for the patient with a learning disability. The document can be used widely in practice and by other healthcare providers in support of the right treatment and care for the patient.

Suggestions for improvement

We suggest:

- The development of a leaflet at Primary Care Network level covering the important aspects of the annual health check in easy read format. This should include information on why a health action plan is important, how it is developed and its uses.
- Consideration of a GP practice or Primary Care Network policy defining the responsibilities for the delivery of key actions included in the plan, for example, medical and non-medical interventions.
- Consideration of the development of a document whose focus is to empower the patient, similar in make up to the baby 'red book' (a personal child health record). This document/folder would outline key priorities, healthcare achievements and goals, a collaborative piece of work between the practice and patients with a learning disability.

¹⁰ Mencap, learning disability and autism training for health and care staff
<https://tinyurl.com/2k834ahc>

Clinical reporting

On analysis, data in learning disability annual reviews collated by Newcastle and Gateshead Clinical Commissioning Group were found to have inconsistencies. These were reported back to the CCG and are being investigated. See Appendix B for further information.

Acknowledgements

This report was made possible thanks to the input and support of people with a learning disability and their carers living in Newcastle upon Tyne and we want to thank everyone who contributed to this work.

We would like to acknowledge Skills for People, which played a key role in providing guidance and support, specifically in helping design the questionnaires and running focus groups to help us gather personal views and experiences of this vital annual check.

Special thanks also to the following organisations for participating in this work and for sharing the questionnaires:

Better Days
Connected Voice
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust
Disability North
The Lawnmowers
Newcastle Carers
Primary Care Networks in Newcastle and GP Practice Managers
The staff at PRS café, MEA House
Skills for People
The Twisting Ducks Theatre Company
Welford Centre

Appendices

Appendix A – Skills for People consultation findings

We invited people from Skills for People social and speaking up groups to share their views of annual health checks over several meetings in December, online and in person. Some attendees said they had never had an annual health check. Others said they had not had a health check in a long time so could not remember a lot of information to be able to take part in the survey.

Thirteen people responded and took part in the focus groups. Here is what they shared about their experiences of annual health checks.

Questions	Number of people	Comments
Q1. Do you have a diagnosis of a learning disability?	All 13 people answered yes	Some people said they know that they have a learning disability but did not really know what the term means.
Q2. Who made the diagnosis?	A clinical psychologist - 4 people A GP - 1 person School - 2 people Don't know/couldn't remember - 5 people Other (Skills for People) - 1 person	
Q3. Are you on your GP Learning Disabilities register?	12 people said yes 1 person was not sure	
Q4. Are you aware there is an annual health check for people with learning disabilities?	All 13 people said yes.	
Q5. Have you ever had an annual health check?	All answered yes: In the last year - 6 people 1-2 years ago - 5 people Over 2 years ago - 2 people	
Q6. How were you invited for your health check?	Phone - 3 people Text - 3 people Letter - 5 people Via your carer or support worker - 1 person	Other - "I went to my GP and requested to have an annual health check."

	Other - 1 person	
Q7. If you received a paper invitation, was it in easy read?	No - 6 people Yes - 3 people Don't know - 1 Other (did not get a letter) - 3 people	
Q8. Was the invitation easy to understand?	6 people - said yes 6 people - said no 1 person - said sometimes it is and sometimes isn't	Comments were: The text message was easy to understand. The letter was not easy read and I got help from my support worker. The letter was easy to understand. It wasn't easy to understand. I had to get help from a friend. I got my support worker to help me. If I didn't have help, I wouldn't have been able to understand it. Sometimes yes, sometimes no.
Q9. How easy was it to book your health check?	8 people said the practice gave them an appointment 3 people found it easy to book an appointment 2 people found it difficult	Comments were: It was easy to book, I just rang the practice to get an appointment. I had to book it myself, but it wasn't difficult. I was given a date, but I had to rearrange it as it wasn't suitable. The date was not flexible, and the GPs assume that people with learning disabilities do not have things to do or jobs, etc.
Q10. Where did your health check take place?	In the surgery - face to face - 12 people By phone - 1 person	Comments: I had my health check over the phone, and I was not happy about that. I wanted it done in person so it could be done properly.
Q11. Please tell us all the people involved in your health check?	GP only - 1 person Nurse only - 3 people GP and nurse - 7 people GP and support worker - 2 people	
Q12. How long did the appointment take?	6 people - Under half an hour 3 people - Between half an hour and an hour 4 people - Between one and two hours	

<p>Q13. Did you feel people listened to you during your health check?</p>	<p>6 people - answered yes 7 people - answered no.</p>	<p>Comments were: The nurse listened to me more than the doctor. It depends on the doctor or the nurse. Some are interested and some are not. Sometimes they don't listen, and it is hard to understand them. I don't feel listened to. I just feel fobbed off, have been given different medication and none of them work. I have anxiety and depression and feel the doctors and nurses just fob me off and just give me medication which doesn't really work. I didn't get the chance. The doctor and my support worker talked amongst themselves and not directly to me even though the appointment was about me. They listened to me I didn't have a lot to say. They were fantastic, I didn't have any issues and they were very helpful.</p>
<p>Q14. Did you have enough time to discuss any worries you had?</p>	<p>3 people answered yes 10 people answered no</p>	<p>The common theme amongst people that said no was that they felt the appointments were in and out and felt rushed so that the next people could go in. They also felt the list of questions were done too quickly. People did not feel listened to. One person commented: I didn't have enough time to discuss anything else I wanted to talk about as the conversation was just about my weight. I found this difficult to talk about.</p>
<p>Q15. Did your health check find any new health issues or any changes that were needed to your current care?</p>	<p>2 people - had changes to physical health care 5 people - had changes to current medication. 6 people - answered no</p>	<p>The people that had changes to their medication, stated that they had issues with their anxiety and depression medication not working so their dosage was increased. One person commented: "I didn't have long enough in the appointment."</p>

<p>Q16. Did you understand what you had to do after your health check?</p>	<p>8 people - answered no 3 people - answered yes 2 people - said they didn't know</p>	<p>Comments were: The doctor and/or nurse did not explain what was happening. The doctor kept looking at his computer and didn't really talk to me or explain the information clearly. The doctor doesn't talk to me at all if I have my support worker with me in the room. I had my support worker to help me understand otherwise I would not have been able to understand.</p>
<p>Q17. Please tell us if any of the options below apply following your health check?</p>	<p>Change to the management of an existing problem - 5 people No further action - 8 people</p>	<p>Most people said they had never been given a health action plan and didn't know what it was.</p>
<p>Q18. How did you find the annual health check overall?</p>	<p>3 people - said it was positive 3 people - said it was negative 7 people - said it was just ok</p>	<p>Positive comments were: I was given the right medication. The nurse helped to explain to me what was happening which made it easier. Getting seen quicker and not having to wait later than usual. I had issues in the past with having to wait a long time at appointments, but this rarely happens now. The staff were friendly and approachable. I see the same doctor all the time which makes it better. The doctor went over the time, so I had enough time to discuss my concerns and they listened to me. At the time I had depression and she really helped me a lot and even called me to check on how I was doing. Other comments: It was just ok because I was nervous. It was ok but I found the conversation about my weight difficult as the doctor kept talking about it.</p>

<p>Q19. Is there anything you found difficult or would like to change about your health check?</p>		<p>Some people said no. Others said yes, and gave the following comments:</p> <p>For doctors and nurses to understand learning disabilities more. A learning disability nurse to be in the appointments with me during the health check. For staff to be more patient and understanding. To be given a guidebook with pictures which you can write your thoughts in if you struggle to explain everything to the doctors during the appointment. Explain the health checks and what happens during the checks clearly. Make it easier to get appointments and be more flexible. Knowing that the doctor or nurse will listen to me, talk to me, and be kind. Provide easy read letters. Be friendly and look at me and not just the computer. Have the Annual Health Checks face to face so they can be done properly. Train all the staff at the practices on how to work with people with Learning Disabilities and address negative attitudes from staff. Have longer appointments so I can express my feelings and worries. Speak to me directly and not my support worker. Staff at the GP who listen to me and are interested in me.</p>
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Additional feedback

Collated from consultations on other projects looking at health services in South Tees.

Annual health checks

Not always done every year.

Sometimes rushed.

Not supported afterwards.

Not weighed due to being in a wheelchair.

Nothing different.

Questionnaire too long.

Just left to get on with things after the Annual Health Check.

People's GP experiences

Maria (not a real name):

"My GP said I needed an operation. He only spoke to my carer.

Because I'm disabled, they think I can't speak. I can speak, I just need time.

I told them it was about me, but they didn't listen. They still talked to my carer.

It happens a lot to me at the GP.

When the nurse came in, she was different. She sat next to me, she looked at me and told me what would happen next.

The nurse made it easy to understand. I was confused about what the doctor said but the nurse said it in a better way.

The nurse let me ask questions and that helped me feel less scared. I wanted to know if it would hurt, and she told me how they would make sure it didn't hurt.

It is horrible to be scared of what is happening."

Barry (not a real name):

"When I was ill earlier this year, I had a lot of doctor's appointments.

I had a lot of tests and different medicine. The GP explained what they were looking at.

I felt like the doctor listened to me and after I had been in hospital, they helped me with how to stay healthy. They talked to me about what foods would help and how much to drink.

I felt like they talked to me like an adult and that made it easier to talk about things.

One thing that makes it difficult is when I must wait a long time for my appointment. At my last appointment I had to wait over an hour, it should have started at 10 o'clock but I waited until after 11 o'clock.

Sitting and waiting made me feel frustrated and upset and more worried.

It is not easy to talk to the GP when you are feeling bad."

Health action plan

We are not really sure what this is. Most people in our group don't think they have got one.

What does good feel like?

Get appointments faster.

Appointments run on time.

Be able to book and attend appointments myself - that means everyone at the GP surgery needs to help me. Receptionists, practice manager, doctors and nurses.

It's about me not anyone else who comes to the appointment to support me.

Everyone gets an annual health check.

See the same person when I come to the GP surgery, so I have a good relationship with them. This is really important if I have to come a few times about the same thing.

Things that help us to not be nervous when going to the GP:

- Having someone with me.
- Staff at the GP who listen to me and are interested in me.
- I know who I am going to see.
- Knowing that the doctor or nurse will be kind, listen to me, talk to me, and help me feel safe.

GP training suggestions:

Doctors and nurses need to take the time to talk to the patient and not carers or family.

If they don't talk to the patient, they could get the wrong information.

Help people speak for themselves, don't let others speak for them:

Use simple signs like a thumbs up or thumbs down so people can say how they feel or answer a question.

Have pictures ready to use so that people can show you where the problem is.

Give people time to talk and ask questions.
Explain who is in the room and what is going to be happening.
Use a clear voice, give clear information, and use easy read.
Remember, a disability doesn't tell you about the person.

Time is important:

People communicate in different ways

People with a learning disability might need longer appointments so that they have time to talk.

It is the doctor or nurse's responsibility to make sure people are heard and that they understand what is happening.

Less Jargon:

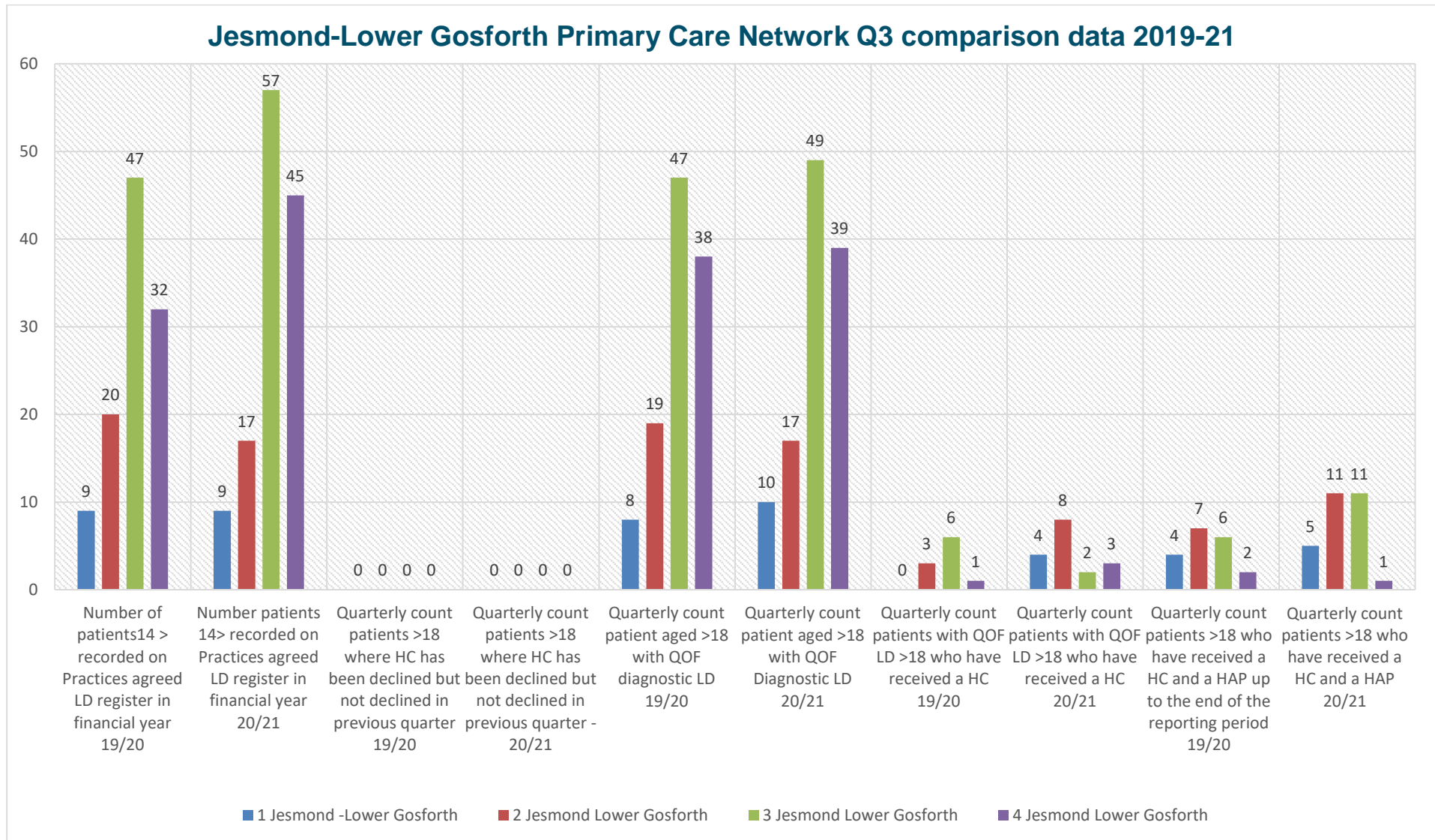
We (and our family/carers) are not doctors. Doctors and nurses need to make sure that the patient gets all of the information they need.

Family/carers should not be expected to explain things to the patient.

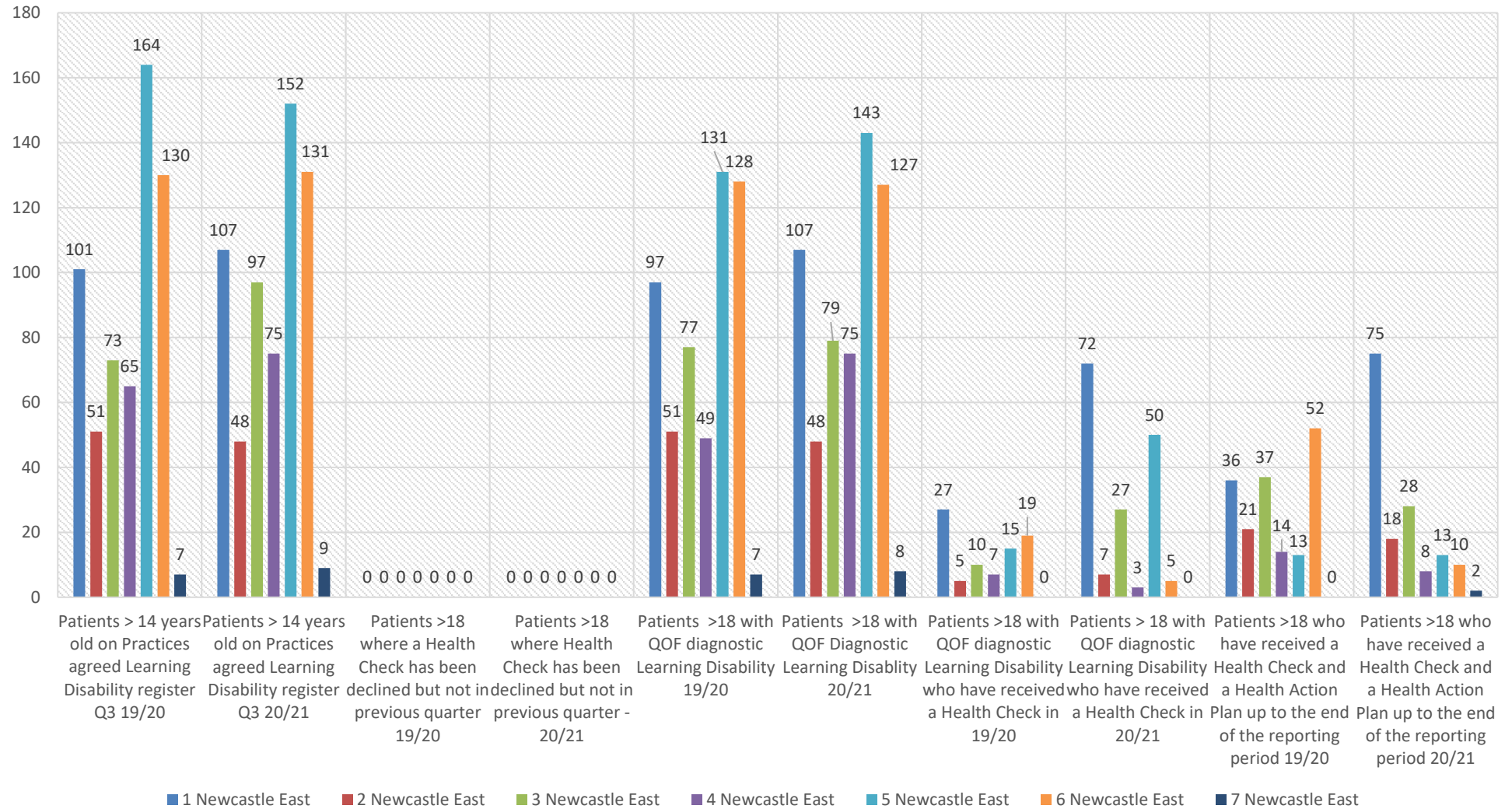
Write things down (next appointment, medication instructions) or send text reminders to help people manage their health - ask what people need.

If people don't understand, they can't be in charge of their own health.

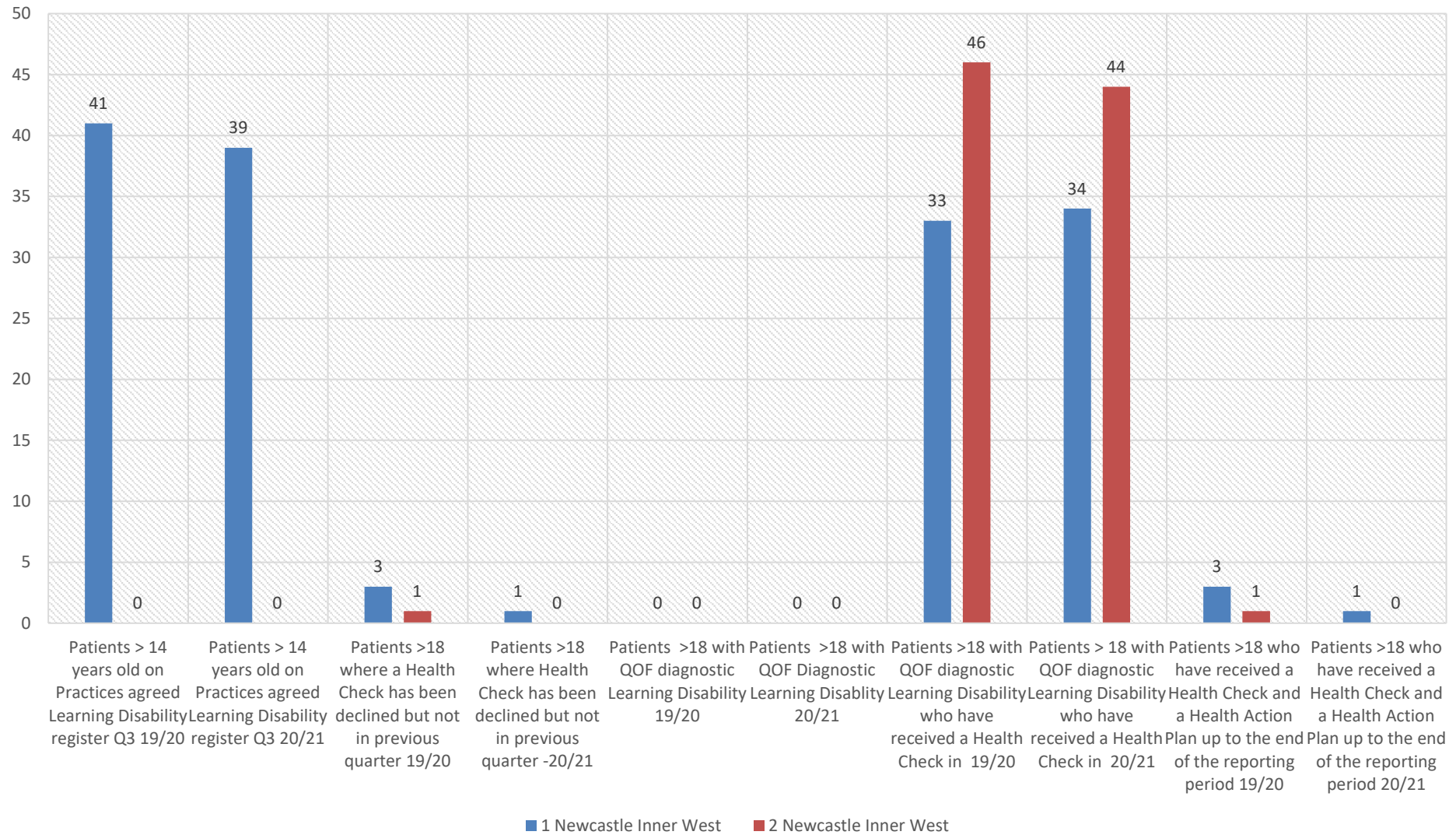
Appendix B - learning disability annual review statutory returns



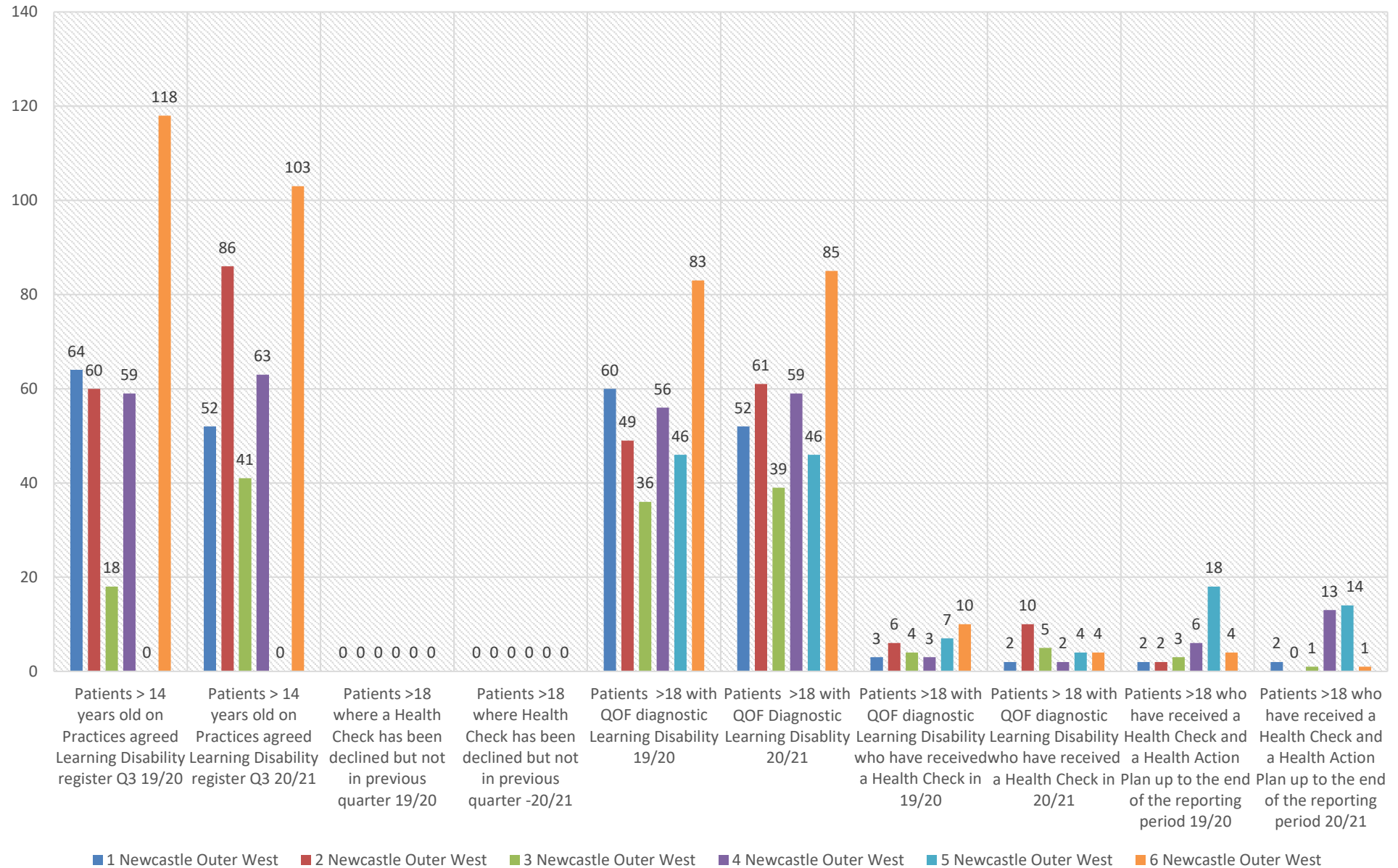
Newcastle East Primary Care Network Q3 comparison data 2019-21



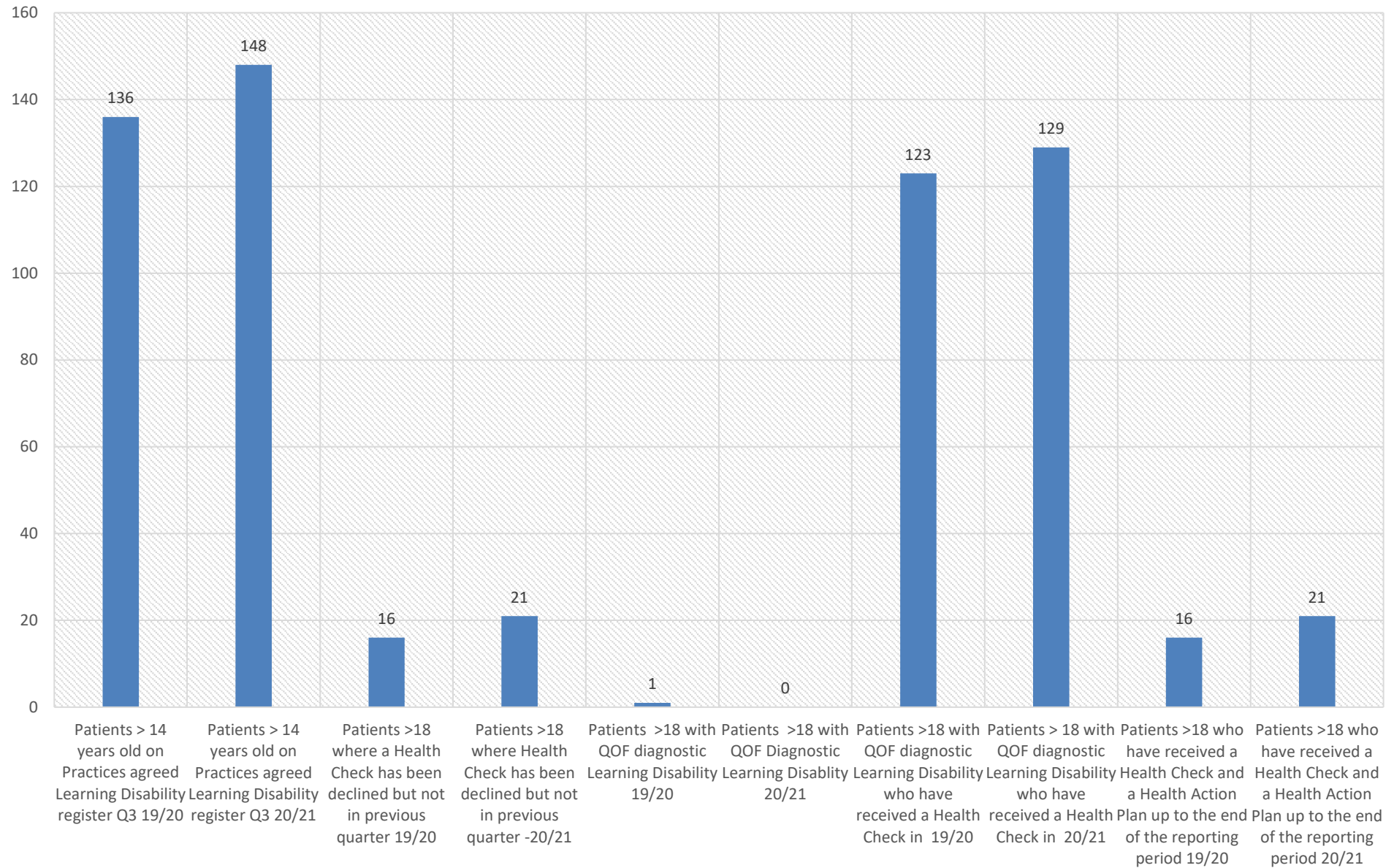
Newcastle Inner West PCN Q3 comparison data 2019-21



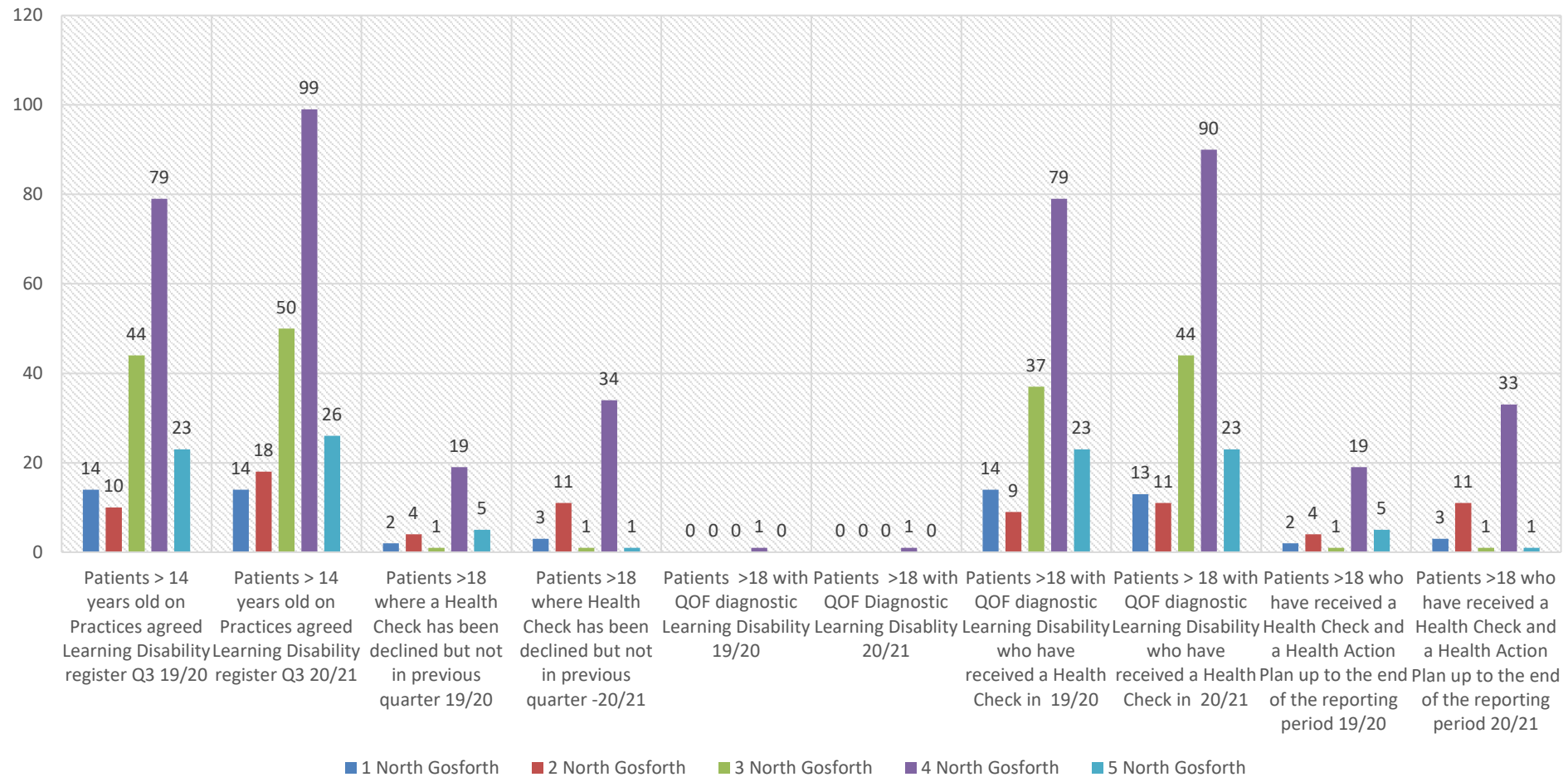
Newcastle Outer West PCN Q3 comparison data 2019-21



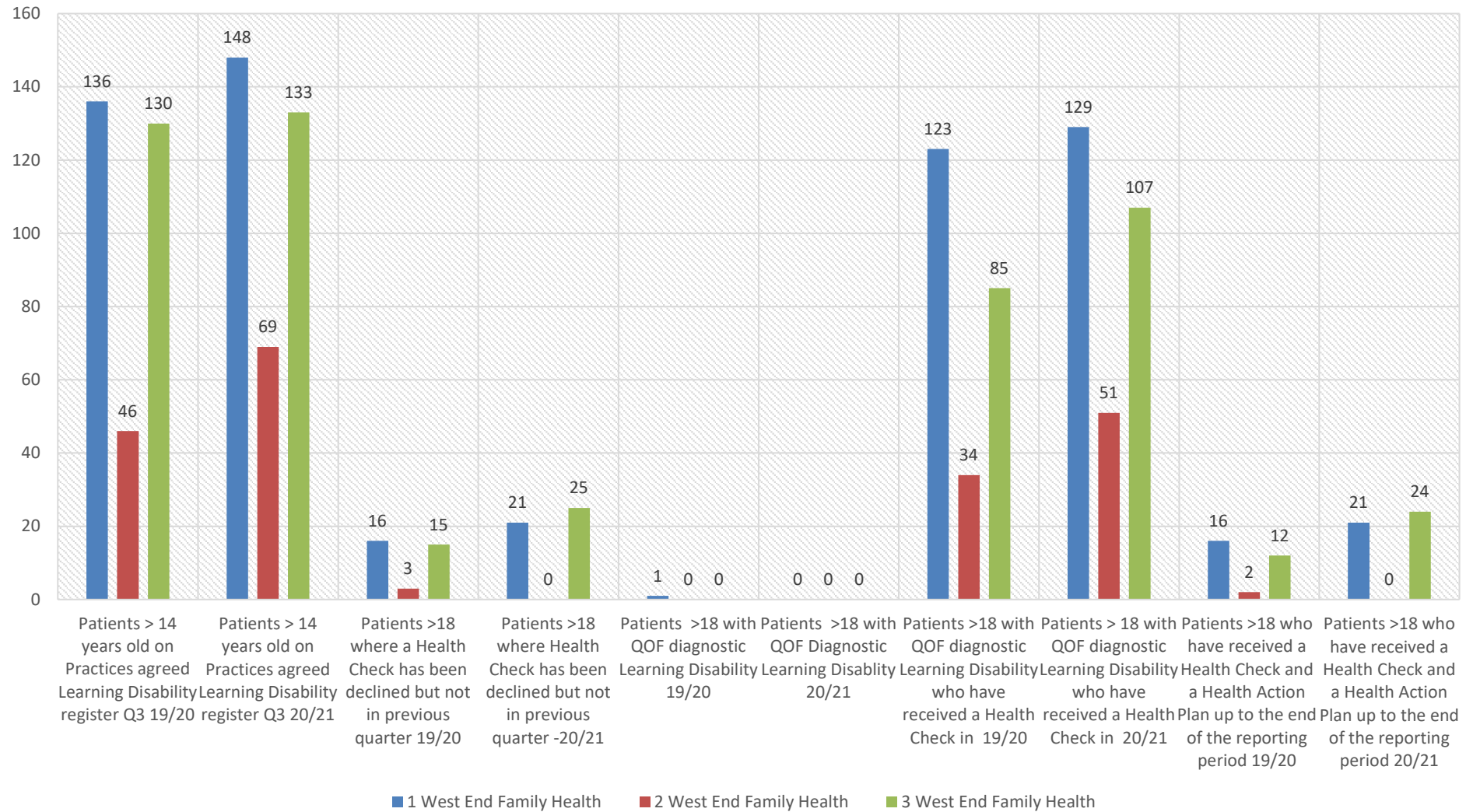
Newcastle Central Health PCN Q3 comparison data 2019-21



North Gosforth PCN Q3 comparison data 2019-21



West End Family Health PCN Q3 comparison data 2019-21



Appendix C - out of area responses

From people with a learning disability

Question	Response	Additional comments
Do you have a diagnosis of a learning disability?	10 people with a learning Disability answered 'yes'	
Who made the diagnosis?	Clinical Psychologist-0 GP-5 Hospital-4 Self-Diagnosis-0 Don't Know-1 Other-0	
Are you on the GP learning disability register?	Yes-9 No-1	
Are you aware there is an annual health check for people with Learning Disabilities?	Yes-10 No-0	
If yes, when did you have the health check	In the past year-8 1-2 years ago-1 Over 2 years ago-0	One person failed to answer
How were you invited for your health check?	Letter-3 Phone call-4 Text-2 Via Carer-1 Other-1	One person answered via carer and other with an additional comment of 'by questionnaire'
If you received a paper invitation, was it in easy read?	Yes-6 No-2 Don't Know-1	One person failed to answer. Other comments: Never in easy read, last year the health check was completed on paper because of COVID-19

Was the invitation easy to understand?	Yes-8 No-0	Two people failed to answer. Other comments: Letter is easy to read it explains the date and time of the appointment and the Dr who will carry out the checks and the surgery it is at.
How easy was it to book your health check?	GP Practice gave the appointment-7 Easy to book-4 Difficult to book-0	One person answered both GP practice gave the appointment and easy to book Other comments: Through my mum, she tells me when she's booked it.
Who was involved in your health check?	Nurse-6 GP-8 Physiotherapist-0 Pharmacist-0 Care Assistant-0 Other-0	Other comments: Support worker
How long did your appointment take?	Under half an hour-7 Between half an hour/hour-3 Between one and two hours- More than two hours-	Other comments: Quick and easy
Did you feel people listened to you during your health check?	Yes-9 No-1	Other comments: Yes, the nurse is a friend of my sister No, they didn't tell me how much I weighed.
Did you have enough time to discuss any worries you had?	Yes-9 No-1	Other comment: The GP had no time, all for themselves.
Did your health check find any new issues?	Yes-Other physical health-0 Yes-Mental health-1	Other comment:

	Yes-Current medication-2 Yes-Other-2 No-5	Talked to me about fluids and not as much fizzy stuff.
Did you understand what to do after your health check?	Yes-8 No-1 Don't Know-1	Other comment: No follow up advice was given.
Did any of these options apply after your health check?	Care regarding new problem-0 Change to the management of existing problem-2 I was given a health action plan-1 Other-1 No further action-6	Other comment: My tablets were changed.
How did you find your annual health check overall?	Positive-9 Negative-1	
Is there anything you found difficult or would like to change about the health check?	No-9 Yes-1	Other comments: They did not pay much attention to me. I got worried they did not have more time for me.

Out of area responses from carers/support workers

Question	Response	Additional comments
Are you completing this in your capacity as a...	Carer-2 Relation-5 Friend-0 Charity employee/volunteer-0 Health/social care professional-0 Other-0	1 person answered both carer and relation.
Does the person you look after/support have a formal diagnosis of a learning disability?	Yes-6 No-0	

Are you aware that people with a registered learning disability can have an annual health check?	Yes-6 No-0	
Has the person you care for/support been offered an annual health check by their GP?	In the past year-3 1-2 years ago-2 Over 2 years ago-1 Never-0 Don't know-0	
Has the person you care for/support attended an annual health check?	Yes-6 No-0	
How was the person you care for invited for their health check?	By letter-4 By phone call-4 By text- Direct to person or you as carer- Other-	2 people commented: By phone call to me and letter to patient.
Was the invitation easy to understand?	Yes-6 No-0	
Were the instructions clear?	Yes-6 No-0	
How easy was it to book the health check appointment?	Practice gave the appointment-5 Easy to book-1 Difficult to book-0	
Where did the health check take place?	At home-0 In the surgery-6 By video/web link-0 By phone-0	Comments: I requested a face to face appointment which was not a problem but could have had a phone call.
Who was involved in the health check?	Nurse-2 GP-5 Physiotherapist- Pharmacist- Care Assistant-1 Other	Two people answered both a nurse and a GP.
How long did the appointment take?	Under half an hour-3 Between half an hour and hour-3	Comment:

	Between one and two hours- More than two hours-	My son has seen the same GP each time. This is very useful as don't have to go over old ground which is very time consuming when attending appointments where the practitioner is not constant.
Were you actively involved during the health check?	Yes-6 No-	Comment: The GP actively seeks the views of my son first and foremost, he does not include me at his expense.
Was there enough time to discuss any concerns you had?	Yes-5 No-0	One person said, "Not applicable".
Did the person you care for have enough time to discuss any concerns they had?	Yes-6 No-0	
Did the health check find any new issues?	Yes-Other physical health-0 Yes-Mental health-0 Yes-current medication-0 No-6 Other-0	Comment: But did find health issues from appointment three years ago from blood test.
What were the next steps following on from the health check?	Care regarding new problem- Change to management of existing problem- Given a health action plan-1 Other-1 No further action-4	Comment: My son was given the contact name and number of someone in response of a request for advice.
How was your overall experience of the health check process?	Positive-6 Negative-0	Comments: I have attended AHC for several years now, excellent for re in forcing advice re lifestyle, gives parents' support. Good to have concerns checked and monitored.
Is there anything you would like to change about the health check process?	No -6 Yes-0	

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