

Quarterly Report: July-September 2020/21

Introduction

Healthwatch Northumberland is the independent champion for people who use health and social care services. We are a listening organisation working across Northumberland, interested in what people like about services and what can be improved. We act on what people are saying, sharing their views with those who have the power to make change happen. We also help people find the information they need about services in their area and record this as 'signposting'.

People who use health and social care services tell Healthwatch Northumberland about their experiences throughout the year. This report shares a summary of the feedback collected from July to September 2020. During this period we have continued to work in different ways due to the continuation of the Covid-19 pandemic. The next report will cover October – December 2020.

This quarter we received feedback and enquiries from:

- Telephone calls, emails and social media (87¹%)
- Talking to people at online engagement events (7²%)
- Through a third party (7%)

Areas of Focus

We are open to all feedback about health and social care services. Responses to our Annual Survey helped us to identify a specific Areas of Focus which we are prioritising in 2020/21:

1. Mental Health Services, including for children and young people

We have published a report of the feedback about Mental Health Services from our 2020 Annual Survey. The Clinical Commissioning Group has provided a comprehensive response which also addresses issues raised in the forum especially waiting times. You can read the report on our website: <https://healthwatchnorthumberland.co.uk/wp-content/uploads/2020/10/Mental-Health->

¹ All percentages have been rounded up or down to nearest whole number

² Does not include all online engagement event feedback. This has been recorded separately – a summary of findings is shared at the end of this report.

Covid-19 has meant changes have been made to health and social care services. Patients and carers' experiences and signposting requirements are likely to have been different during this time. For this reason we have also chosen to focus on any feedback we receive which is related to covid-19 and these changes.

Aims

The report shows:

- Who Healthwatch Northumberland is hearing from
- What people are saying
 - The general sentiment of comments
- What people are experiencing
 - What is working well?
 - Where there are areas for improvement?

Feedback

Between July and September 2020, we received feedback from 27 individuals from talking to people at online engagement events, telephone calls, emails, our website, surveys, and other sources. We signposted 15 of these people to services³, and provided information or advice to five people. In total we were in contact with 29 people who gave us feedback or were signposted⁴.

This report explores who Healthwatch Northumberland is hearing from across the county, presenting a summary of general respondent demographic information. Demographic information shared includes location, gender, age, and whether the respondent is sharing their own health and social care experience or speaking on behalf of a friend or relative.

We also look at the general sentiment of comments, with specific reference to the service type (e.g. primary care, secondary care, mental health, social care), as well as whether the feedback relates

³ Signposting has not been included in analysis apart from in communication methods of respondents on Page 2, and in the 'signposting' section of the report on Pages 9 and 10

⁴ Excluding those we spoke to through our online engagement events

specifically to quality of care or access to services. Service category, for instance whether the comment refers to a GP surgery or acute care, is also explored alongside the sentiment of feedback. A list of services mentioned in comments has also been shared.

Who is Healthwatch Northumberland hearing from?

Healthwatch Northumberland has collected and anonymised demographic information where consent has been given. The following presents a general summary of who Healthwatch Northumberland is hearing from.

Location:

In total between July and September 2020, we collected feedback from respondents from ten different Northumberland postcode areas⁵, accounting for 56% of all responses this quarter (15 people). A total of 44% of respondents gave no postcode. Below Table 1 shows the number of responses Healthwatch Northumberland received from residents in different Local Area Councils this quarter:

Table 1. Frequency of known responses across Local Area Councils in Northumberland, Q2 2020/21

Local Area Council	Number
Ashington and Blyth	5
Castle Morpeth	3
Cramlington and Bedlington	1
North Northumberland	2
Tynedale	4

There are too few known locations of patients, carers, and families to reliably say where we are hearing from most. It is positive that most of our known responses were from Ashington and Blyth, an area we have heard from less in the past.

Age:

The majority of our respondents did not share their age with us (59%). Of those that did, there were respondents from mainly older age groups (shown below in Table 2).

⁵ Postcodes only counted by postcode prefix, the number of postcode prefixes may be greater than 7

Table 2. Number and percentage of responses across age groups in Northumberland, Q2 2020-21

	Number	Percentage
Under 18	0	0%
19-24	0	0%
25-49	2	7%
50-64	3	11%
65-79	3	11%
80+	3	11%
Unknown	16	59%
Total	27	100%

Gender:

Of the people who told us their gender there was a higher proportion of female respondents, accounting for 37% of all responses (10 people). A total of 15% of responses were from males (4 people). Below Figure 1 shows a breakdown of responses by gender:

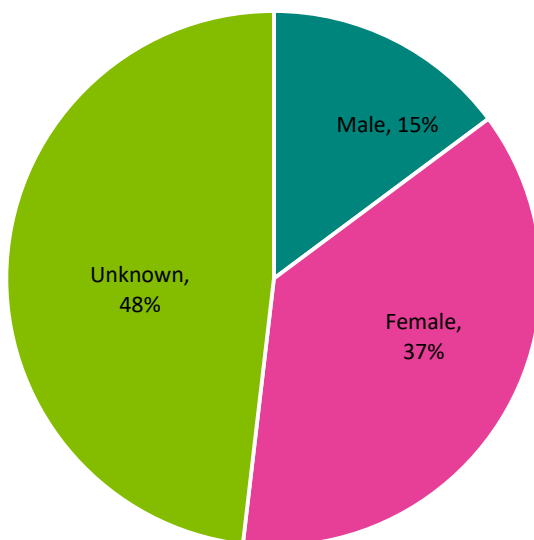


Figure 1. Frequency of responses by gender in Northumberland, Q2 2020/21

Whose experiences are we finding out about?

Most respondents were sharing their own individual experience of health and social care with us. A total of 34% of all respondents gave us feedback about the health and social care experiences of a relative, friend, or someone they care for (10 people).

Below a breakdown of all respondent types, and the number and proportion of responses from these groups is shared in Table 4.

Table 4. Frequency of responses by respondent type, Q2 2020-21

	Number	Percentage
Individual	17	59%
Client relative, friend or carer	10	34%
Advocate	1	3%
Health or social care professional	0	0%
Local Campaigner	1	3%
Other	0	0%
Total	29	100%

What people are saying and experiencing

Of the 27 total responses⁶, respondents told us about 16 individual services/service providers. Many respondents shared their experiences of using more than one service in their comments and many services were mentioned more than once, bringing the total frequency of services mentioned to 28. Please see Appendix 1 and 2 for a list of all the services/service providers mentioned.

The responses were categorised into four sentiments; positive, negative, neutral, and mixed. Most of the comments we received were negative, with 82% of responses reflecting this sentiment (22 sentiments, please see figure 2). This reflects an increase in negative sentiments from last quarter. Some comments we received with a positive or neutral sentiment have been shared in the blue boxes⁷:

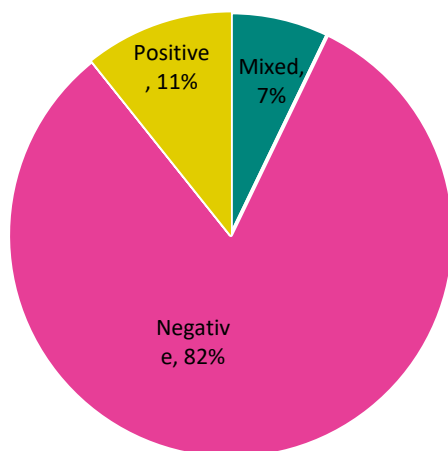


Figure 2. General sentiment of responses

Positive:

Caller wanted to let us know that ward 12 at The Northumbria Specialist Emergency Care Hospital were brilliant caring for a loved one providing good end of life care.

Carer, Northumberland

Caller told us their local flu clinic had excellent pre-communication including the importance of attending on time, was very well-organised, good maintenance of social distancing. Caller was in and out of the building in less than 5 minutes.

Patient, Tynedale

Mixed:

Caller told us that they were discharged from a Physiotherapy appointment without being seen. Caller did find that video appointment worked well though.

Patient, North Northumberland

⁶ Responses related to 'signposting only' have been excluded from this section of the report

⁷ Quotes with negative sentiments are presented later in the report.

The services/service providers have been categorised into service type, with the five main groups being: primary care, secondary care, mental health, social care, and urgent and emergency care. Below, Figure 3, shows the service type and sentiment of responses:

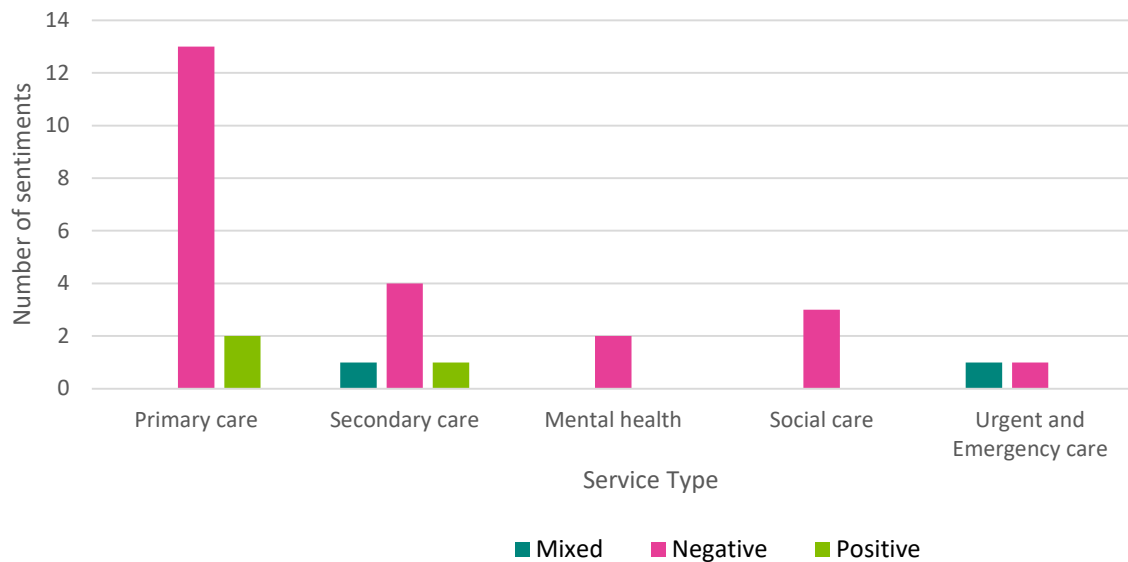


Figure 3. Service Type and Sentiment of responses⁸

Figure 3 shows there is a greater number of negative comments and feedback for all service types. Below Table 5 indicates more comments were about 'primary care' services or service providers (56% of all comments, 15 total comments).

Table 5. Frequency and percentage of responses by Service Type

Service Type	Frequency	Percentage
Primary Care	15	56%
Secondary Care	5	19%
Mental health	2	7%
Social Care	3	11%
Urgent and Emergency care	2	7%

⁸ Where more than one service type and sentiment has been collected per record, it has been presented on the chart. There were more than 47 total sentiments expressed because some people fed back about more than one service.

Covid-19

Between July and September 2020 just over a quarter of comments received were related to the covid-19 pandemic in some way (28%, 13 comments). This is a reduction on last quarter:

Covid-19: what people told us

- *One patient had a cataract operation and their follow up appointments were cancelled due to Covid-19, despite the patient experiencing pain and discomfort since and during the operation. Patient is concerned about quality of treatment and aftercare.*
- *Another patient has a nine month old baby and told us she was concerned about the lack of support from community services during the Covid-19 lockdown, describing the isolation as “unbelievable”.*
- *A family member called us who was concerned about their son being offered a Covid-19 test in Mansfield, Yorkshire by NHS 111 despite them living in central Northumberland.*
- *A family member whose father had died in hospital with Covid-19 told us they were concerned about the lack of PPE used by staff members, cleanliness, and medication used.*
- *A family member told us they had not been able to find a dentist for their elderly mother who had lost their dentures during lockdown because it was not deemed an emergency treatment.*

Most of the negative comments about primary care and secondary care related to access to services (see Figure 4b). Figure 4a shows that more than half of all comments relate to ‘access to services’ (56%, 15 total comments), which is a slightly lower proportion but still generally consistent with previous quarters.

Figure 3 and Table 5 are best considered alongside Figures 4a and 4b (shown below), which show whether comments are related to quality, access, or information and their relevant sentiment.

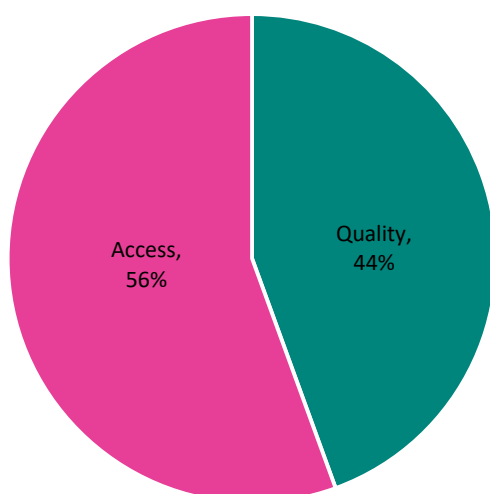


Figure 4a. Proportion of responses related to Quality of Care and Access to Services

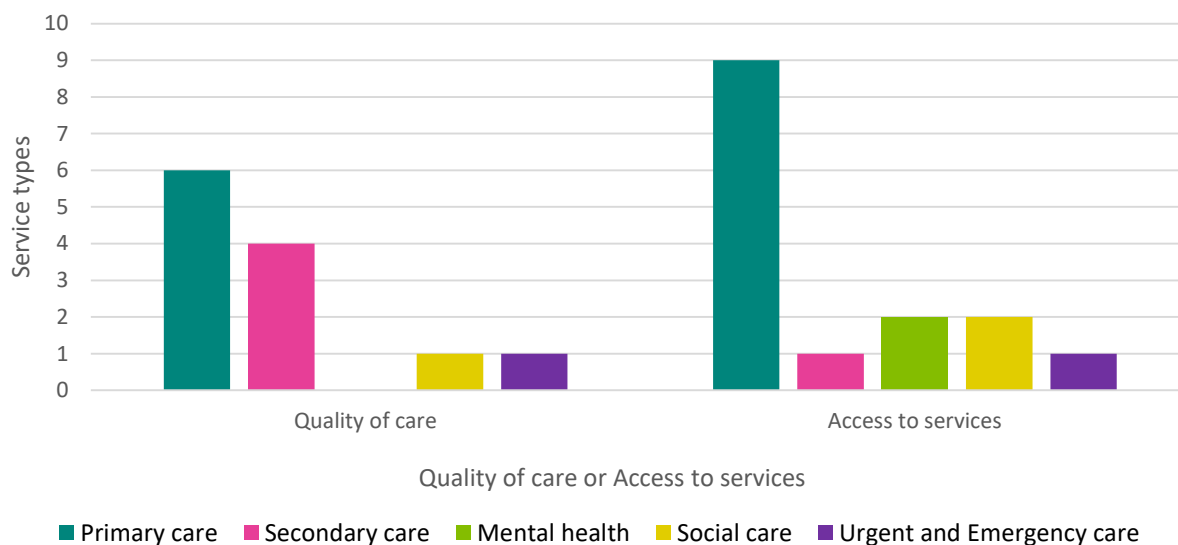


Figure 4b. Frequency of responses related to Quality of care and Access to services

Signposting

In total we signposted or gave information to 17 people who contacted us with an enquiry. Some people were signposted to more than one service. Below Table 6 shows the services Healthwatch Northumberland signposted people to this quarter:

Table 6. List of services Healthwatch Northumberland signposted people to, Q2 2020/21

Service Name	Service Type	Number of times signposted to	Signposted to in Apr-Jun 20-21?
Choices 4 Growth	Voluntary Sector	1	No
ICAN	Voluntary Sector	3	Yes
Independent Complaints Advocacy	Voluntary Sector	1	No
JMAPS	Health	1	No
NHS 111	Health	1	No
North of Tyne PALS	Health	2	Yes
Northumbria Healthcare NHS Trust	Health	2	Yes
Onecall	County Council	1	Yes
Talking Matters Northumberland	Mental Health	1	Yes
Link Workers	Health	1	No
Tyneside and Northumberland Mind	Voluntary Sector	1	No
CQC	Regulatory body	1	No
Cygnus Support	Mental Health	1	No
Health Trainers	Health	1	No
Northumberland Clinical Commissioning Group	CCG	1	Yes

Table 6 shows people were signposted to a range of service types this quarter. In previous quarters most of our signposting has been to voluntary sector organisations.

Online forums

As part of our engagement work Healthwatch Northumberland have been running online forums so that we can continue to find out about people's experiences of health and social care without speaking with people face to face. Between July and September we ran seven forums with themes of discussion including: mental health services, GP surgery closure, cancer services, the experience of carers, and children and young people's services. We did not set a theme for one of the online forums we conducted (please see Appendix 3 for the list of forums). These forums were another opportunity to gather intelligence about what people across Northumberland have been experiencing, and a summary of the notes we collected through these forums has been included below.

Mental health services

Patients and mental health organisations told us:

- There can be a 6-8 week wait for contact from Talking Matters after self-referring.
- People have already got to a certain stage by the time they see a GP then the wait for Talking Matters is far too long. Many people come to use voluntary sector services because they can't access statutory mental health services. The wait puts people off seeking help. Counselling is not always needed, sometimes it's just about building a sense of purpose e.g. employment.
- It is an incredible service but there can be a wait of one year for Talking Matters, where the patient may only receive a couple of phone calls before accessing service. People call voluntary services near crisis point because they can't get statutory support unless they are in crisis.
- Many patients are too unwell for primary care but not poorly enough for secondary, leaving a gap in the middle. Many regular clients are coping quite well during the pandemic, they no longer feel 'different' as the world is in the same place.
- 95% of patients from the trailblazers program are seen within four weeks and CNTW is also following this standard. The service is working in three new areas in Northumberland and

also in schools. Also looking to broaden reach with new mental health support in Ashington and Bedlington. The service also works with parents and carers, linking with Early Help Locality Practitioners, and alongside Cygnus offering preventative wellbeing and awareness sessions.

- Suicide ideation, domestic abuse, female anxiety, male anxiety, attempted suicide, children with suicide ideation referrals have all increased during this time. More referrals for adults than children recently, where usually there are more referrals for children. Some clients were put on the Talking Matters list and heard nothing back so reached out to us.
- Many children are still not in school so staff are not reporting as much as usual.
- Many of the older people we work with are not getting out so mental health is a worry.
- Someone asked “How many organisations are relying on funding and from where?”. Someone responded “If people want to find out where the money went to why don't they go to the Local Area Council meetings which are run by NCC”

Laburnum surgery closure

Laburnum Surgery, based in Ashington closed on 27th July. Healthwatch Northumberland organised an online forum so that patients and carers could communicate any issues about this closure directly with Northumberland CCG. The session was run as a question and answer forum. Where we received feedback from patients, carers, and families about this service outside of the online forum, this was also shared with Northumberland CCG.

Patient representative: Do Laburnum patients get a choice of new practice or are they just allocated one?

CCG: Patient choice will be respected. However, given the tight six-week timeline and the current situation with Covid-19 the safest option was to automatically register all patients with another practice close to their home. However, they can still choose to register with a different practice after Laburnum has closed.

Patient representative: As Laburnum is part of a network of practices do patients only get a choice of the other practices in that network?

CCG: This is not relative to the networks of practices. Patients can register with any practice if they live within the boundary.

Patient representative: Will there be an effect on Seaton Park Medical Group, for example if all 2,400 patients went to Seaton Park would it make it difficult to get an appointment?

CCG: More resources are being provided e.g. more GP and nurse time, drug and alcohol support, mental health support. There will be open communication on a regular basis and if any practices feel they can't take any more patients then a temporary hold can be put on new registrations.

Patient representative: Even now without the extra patients it is hard to get an appointment, sometimes you can wait up to three weeks.

CCG: please bring up this issue separately with the practice.

Northumberland CCG asked if anyone had any feedback about communications around the surgery closure. Patients responses are below:

- ***One patient representative told us “there’s been a good job done sending out information but patients who don’t speak English are worried about what it says. Could’ve identified people who speak other languages and translated.”***
- ***Another patient told us their community is concerned about being allocated a GP or being able to choose but this question has been answered. Many asylum seekers have language barriers so there is confusion. Many patients have a good relationship with a specific GP at Laburnum.***
- ***Some patients prefer to see a GP from a BAME background who understands their culture. Would it be possible to consider this when allocating patients to GPs?***
- ***A patient representative told us “the main anxiety for patients is being allocated a new practice and being worried about what will happen next. Patients are comfortable with their current GP, and are unsure what will happen when they change practice.”***

Northumberland CCG recognised from this discussion that there is an issue with engaging with

a specific community in Ashington, and want to work towards finding out the most popular languages of service users and providing translated communications with the support of community groups saying “it’s about removing barriers to healthcare.”

A patient’s family member told us that their parents had been with Laburnum for 70+ years. “They haven’t got internet so can they call someone to discuss? How can my mother change practice without having to leave the house? She’s gone from being able to get an appointment on the day to a three week wait.”

CCG: they can call the number on the letter and speak to the CCG or Healthwatch. If the patient wants to change practice they can ring the one she wants to register with and they will support her over the phone.

The Clinical Commissioning group is contacting all patients affected by the Laburnum Surgery closure. Patients will be asked how they feel the change was handled and how they are settling into their new practice. Healthwatch Northumberland will be involved with this process.

General online forum

- People are frightened to come out of the house after shielding, particularly the elderly.
- Lack of meetings during lockdown risk duplicating support, rather than supporting holistically. Issues are getting more complex and need to be dealt with efficiently.
- Where work is duplicated - most people glad to hear from you but some found it difficult to be reminded of their vulnerability.
- Rural isolation is an issue, people aren’t always aware of certain services.
- Some patients in Central Northumberland waited 4-5 weeks for shielding letter or support or didn’t receive anything.
- NCC bridged the gap. Complicated process to register for shielding help, especially without computer access – nationwide issue. Look at what needs improving for second wave.
- Social Prescribers sent shielding lists for GPs and contacted patients – checking welfare and signposting.
- If there’s a second wave there is a stronger process in place locally.

- People will need advice e.g. after redundancy. Many clients receiving phone advice have been more proactive but there are still tech barriers and haven't seen some of the clients they would usually see.
- People who are new to leaving the house may need help with social distancing- more understanding and support needed
- Some patients concerned about going into hospital after shielding, staff not wearing masks and huge anxieties about going back to appointments again.
- Lots of patients with stress and anxiety feeling there is no help in Northumberland - anxieties heightened by lockdown. There is so much information it can be confusing.
- More integration between services will make work more efficient

Carer's forum

- Receiving lots of referrals for carers – mental health needs of carers increasing as care needs have increased. Lots of uncertainty and worries e.g. worries about people coming into the home when the person they care for is shielding.
- The definition of 'carer' is becoming more blurred. The difference between 'care workers' and 'unpaid carers' needs to be clearly defined. Carers Week is supposed to celebrate unpaid carers but care workers jumped on the band wagon. Some miscommunication.
- Carers are frightened they will be 'blacklisted' and not get services if they complain to a GP too much but Carers Northumberland can feed back on their behalf.
- Many unpaid carers do it because they want to, carrying guilt and seeing it as their duty – don't see themselves as carers. Some of the work they do is skilled work. Leads to mental health issues and self-esteem drops. Many carers are under the radar including children.
- An issue with booking appointments at Guidepost and Seaton Park. Can take 2 hours to get online then no appointments left.
- GP appointments texts help to remind patients, so fewer missed appointment - but doesn't work for people without a mobile phone. Could be sent to carer who takes them to appts.
- Two carers who didn't want to attend the forum in person gave feedback:
 1. The first carer was having problems with GP availability, the phone not being answered or being hung up on, not answering the door to the practice. For those who don't use online services, the phone is the only way of getting in contact so this is a problem. Also worried about cancelled routine blood tests.

2. The second carer had a phone call from physio during lockdown. Three weeks later they rang again to discharge the patient without ever seeing him. Carer also found a District Nurse had walked into the house and started taking her husband's blood pressure without her knowing. Has found video appointments have worked well.

Laburnum surgery closure, partially non-digital

We ran a forum where the video was streamed at a local YMCA and translators were available to hear back from patients, carers and families about the closure of the Laburnum surgery. We had no attendees and but it was positive to attempt a method of partially non-digital engagement.

Cancer services

Patients and voluntary services told us:

- Transport has been an issue – couldn't get treatment in Hexham and had to go to Bedlington. For example, Daft as a Brush will only go to Newcastle Hospitals not Hexham Hospital. But Tynedale Hospice at Home drivers can help in Hexham. Daft as a Brush will collect patients from Hexham and take to Newcastle. Some people think they won't come to Hexham at all. Some confusion here.
- Patients not telling GP about symptoms or not coming into hospital because they are worried about catching coronavirus or don't want to put extra pressure on NHS.
- Limited information in Chinese, even on Macmillan website. Language and culture barrier for those whose first language is not English. Some services are working on this.
- Lack of signposting for wigs for the African Caribbean community.
- Arts and crafts sessions at Living Well With Cancer are open to patients and their families to take their minds off treatment.
- Children with a parent or grandparent with cancer may be quiet or challenging at school. Art therapy or one-to-one therapy can help. There is amazing support for patients but often the impact on children is forgotten. Children think cancer means they are going to lose a parent/grandparent.
- At first some appointments were deferred but lots of measures in place now including handwashing, social distancing, masks, temperature checks and swabs in some high-risk

areas. Transport has been difficult; it is starting up again now but social distancing is hard. Some treatments were delivered so the patient didn't have to come and pick up.

Children and young people's services

A parent told us that they continuously met with new professionals for their son, and had to re-tell his story at each appointment. They told us they would find it easier to see the same person consistently, and felt uncomfortable having to discuss their son's problems in front of him. The parent told us that once the patient stops taking medication they are discharged from CYPS with no further support. They also told us that the time before diagnosis is even more difficult and it takes a long time, asking whether GPs could refer to supporting voluntary organisations while waiting for a diagnosis? The parent told us "parents need to talk to other parents who understand".

Another parent told us their daughter was in CYPS service three times and was told nothing could be done unless their school pointed out behaviour issues.

People from local voluntary organisations told us:

- We need to know what autism services are available so we can refer on
- Parents don't always know who their CYPS support worker is and they feel lost
- Situation can deteriorate while waiting for organisations to communicate - lots of red tape
- It can be difficult if the family lives far away and has to travel
- Issues include timings of appointments, care of siblings during appointment, location and language barriers over the phone
- Families can't access funding while waiting for assessments
- The services might be there but families might not know about them

This report has been produced by:

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If you would like any further information, or have any feedback or questions about this report, please get in touch using the following contact details:

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Appendix

Appendix 1. List of services mentioned in feedback and comments

Service name	Frequency
Alnwick Medical Group	1
Aspire Health and Care	1
Burn Brae Medical Centre	1
CNTW	1
Felton Surgery	5
Greystoke Surgery	1
JMAPS	1
Lintonville Medical Practice	1
Newcastle Freeman hospital	1
NHS 111	1
Northumberland County Council	1
Northumbria Healthcare NHS Trust	5
Northumbria Specialist Emergency Care Hospital	1
Prudhoe Medical Group	1
Royal Victoria Infirmary	1
Seaton Park Medical Group	1
The Rothbury Practice	1
Unknown GP	2
Unknown service	1

Appendix 2. Service category and sentiment⁹

Service Category	Mixed	Negative	Positive	Total
Acute services with overnight beds	0	1	0	1
Care at Home	0	2	0	2
Community Mental Health Team (CMHT)	0	1	0	1
Dentistry	0	0	1	1
Diabetic Medicine	0	1	0	1
End of Life Care	0	0	1	1
GP practice	1	12	1	14
Health Visitor	0	1	0	1
Ophthalmology	0	1	0	1
Outpatients	0	1	0	1
Physiotherapy	0	1	0	1
Psychiatry/Mental Health (Hospital Services)	0	1	0	1
Other	1	1	0	2
Total	2	23	3	28

Appendix 3. List of online forums Q2 2020/21

1. Mental health services - 1st July
2. Laburnum surgery closure - 3rd July
3. General online forum - 8th July
4. Carer's forum in partnership with Carer's Northumberland - 15th July
5. Laburnum surgery closure, partially non-digital - 21st July
6. Cancer services - 12th August
7. Children and young people's services - 9th September

⁹ Where more than one service type and sentiment has been collected per record, it has been presented in the table