



**Comparison of Newcastle and
North Tyneside carers' survey data**
**Understanding carers' experiences during
the pandemic**

About Healthwatch Newcastle

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.

Healthwatch Newcastle is part of Tell Us North CIC (company no. 10394966).

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1. Introduction

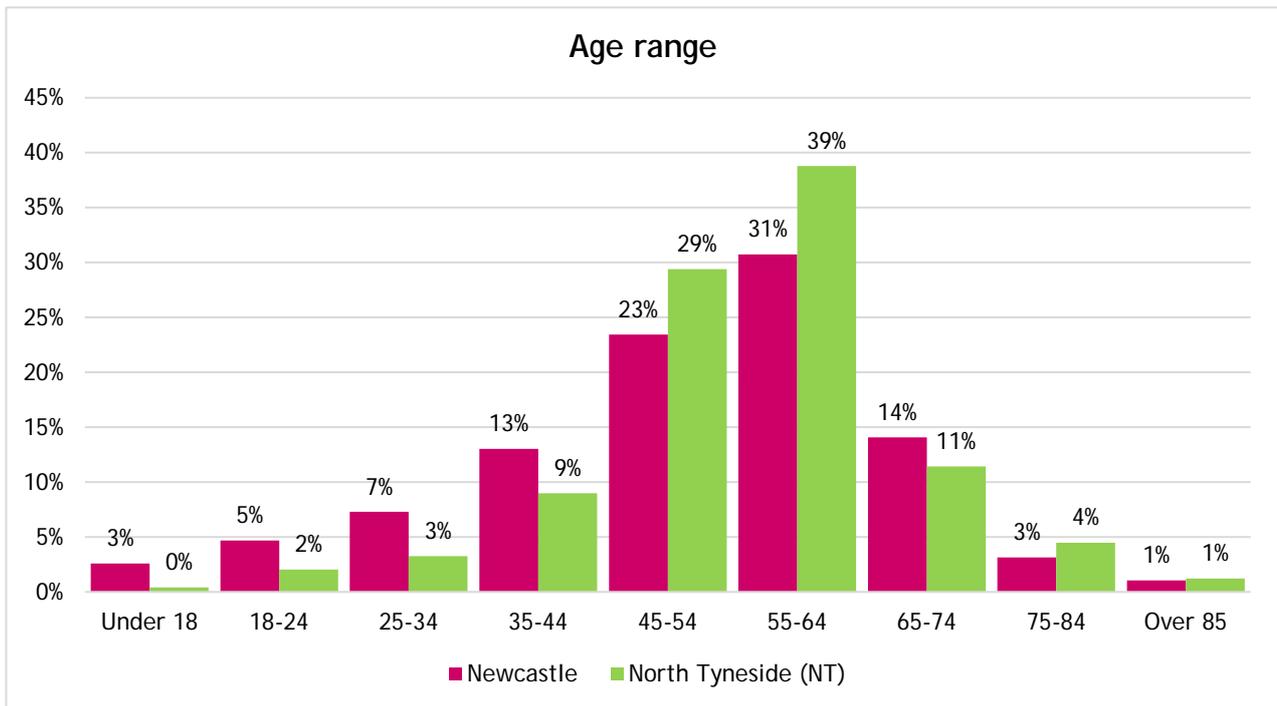
Healthwatch North Tyneside worked in collaboration with North Tyneside Carers' Centre during the summer of 2021 to gather experiences of caring during the COVID-19 pandemic on behalf of the North Tyneside Carers' Partnership Board. An online survey was developed because England was under lockdown restrictions at the time. The survey explored the experience of the person cared for and the challenges around accessing information and support. An additional short survey was included for people who had used North Tyneside Carers' services. The survey was open between 17 May and 23 July 2021 and promoted to carers by all members of the North Tyneside Carers' Partnership Board: 258 responses were gathered.

Newcastle Carers reached out to Healthwatch Newcastle to help reproduce this work to support Newcastle City Council's review of support for carers across the city. The Healthwatch Newcastle survey was open from 22 November 2021 to 23 January 2022, when Plan B restrictions were in place to help control the spread of the Omicron variant. It was promoted to carers in Newcastle through social media platforms and via Healthwatch and Newcastle Carers' networks: 192 responses were gathered.

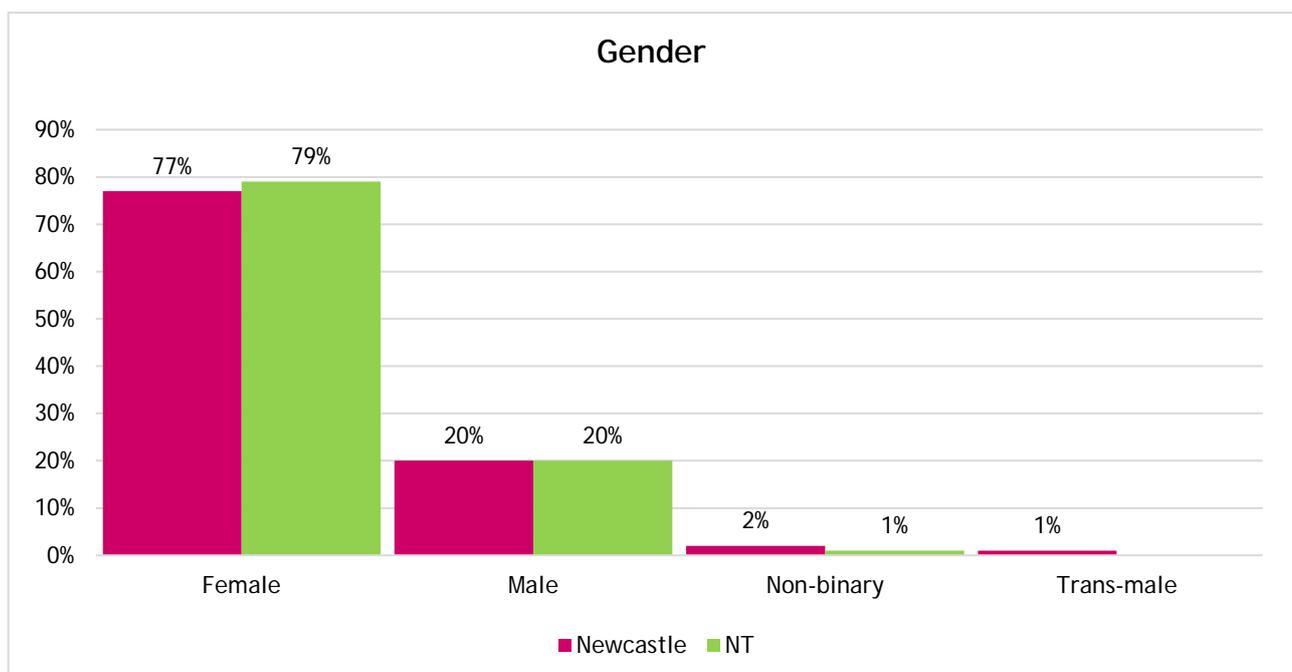
This report compares the findings from the two surveys, looking at the similarities and differences in carers' needs in the two local authority areas. How services were accessed varied according to whether there were restrictions at the time. As a result, the responses reflect the circumstances at the time the surveys were completed.

2. Findings

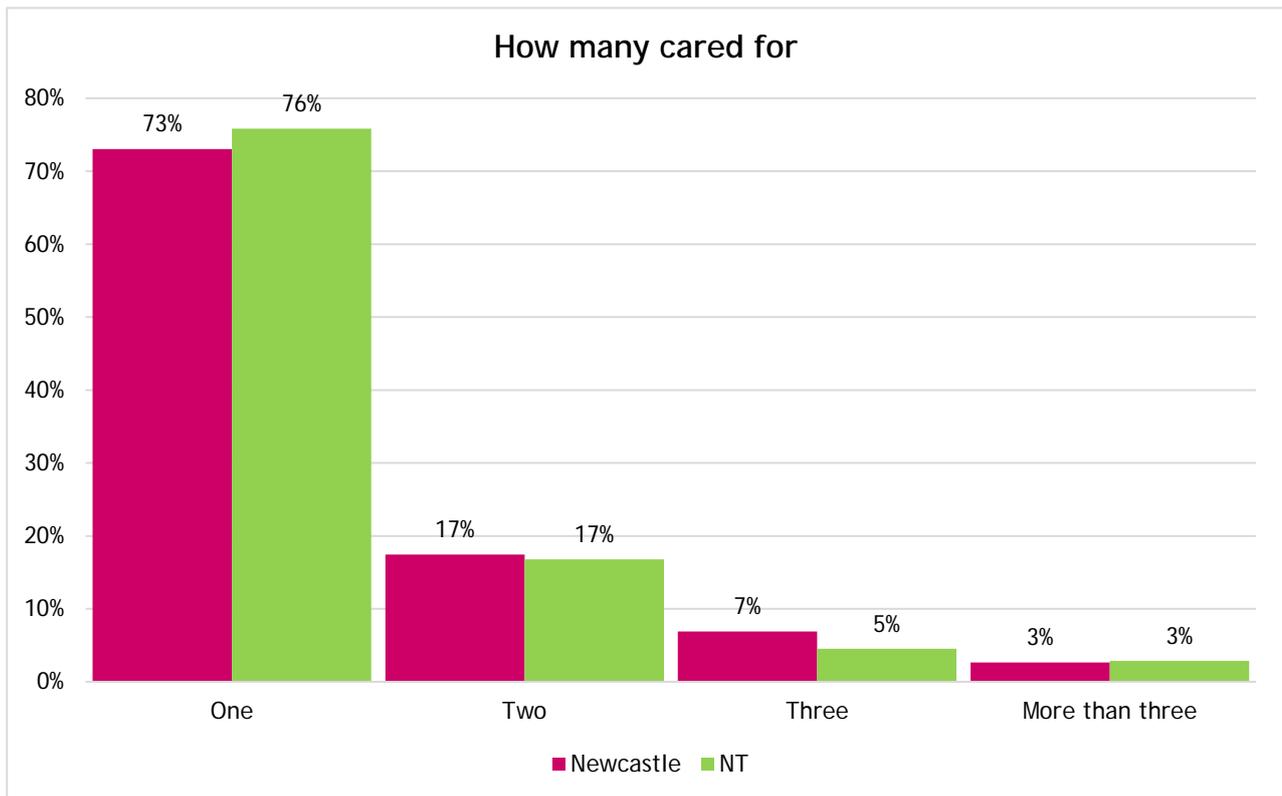
2.1 About carers in Newcastle and North Tyneside



Collectively, carers who responded to this survey in Newcastle and North Tyneside were mostly aged between 45–64 years old. Slightly more views were gathered in Newcastle from people under the age of 34 (15% respondents) and in North Tyneside from 45–64-year-olds (5%), which reflect the different demographics in each geographical area.

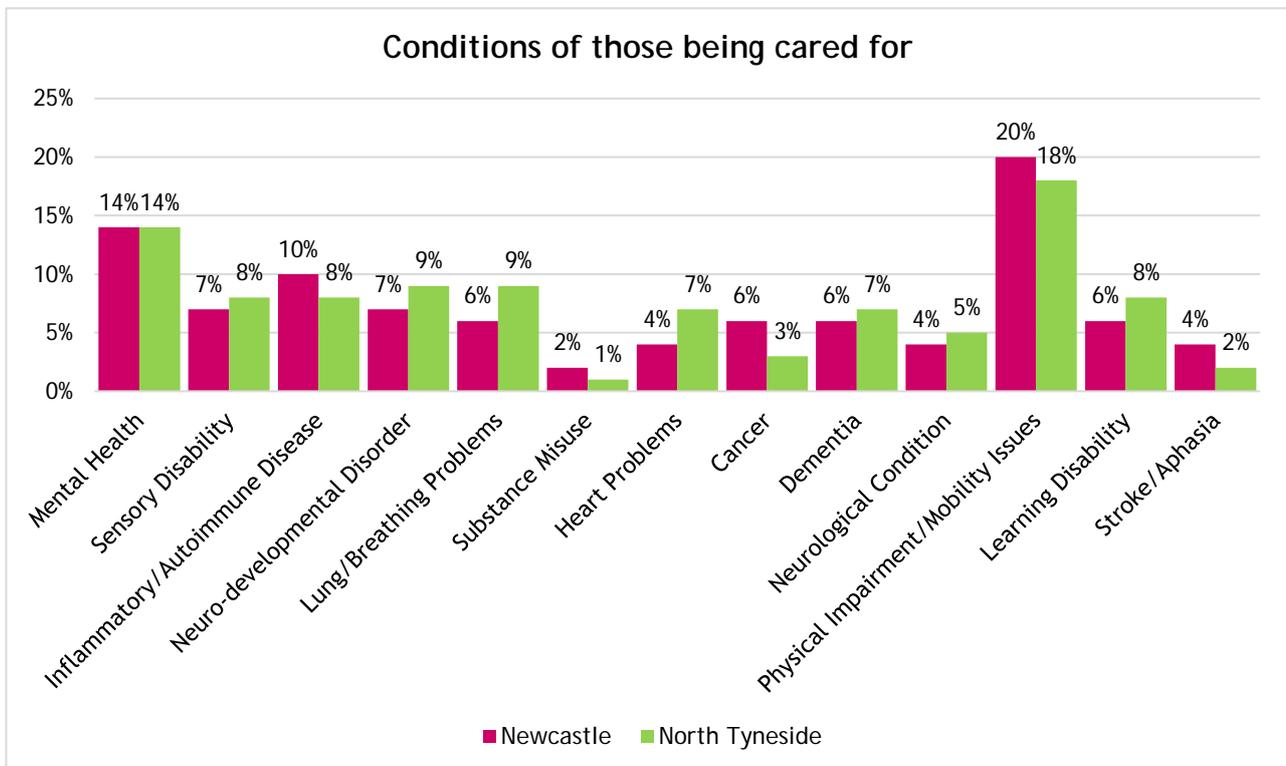


Survey respondents were mostly female, which correlates to national statistics that report that 58% of carers are female.



Most respondents in both Newcastle and North Tyneside provided care to one person (73% and 76% respectively), followed by two (17% and 17%) and then three (7% and 5%).

Who is being cared for?

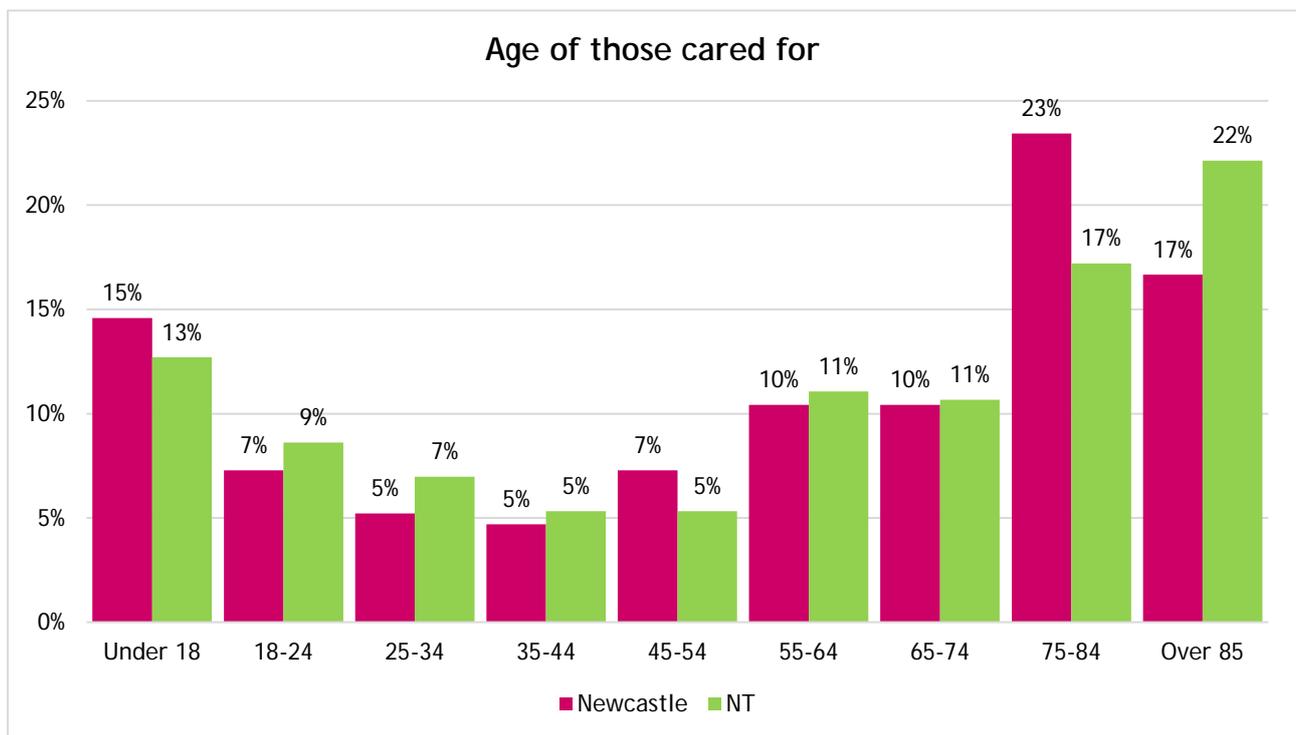


There were no significant differences in the conditions of the people cared for across Newcastle and North Tyneside. The most common condition was physical impairments and

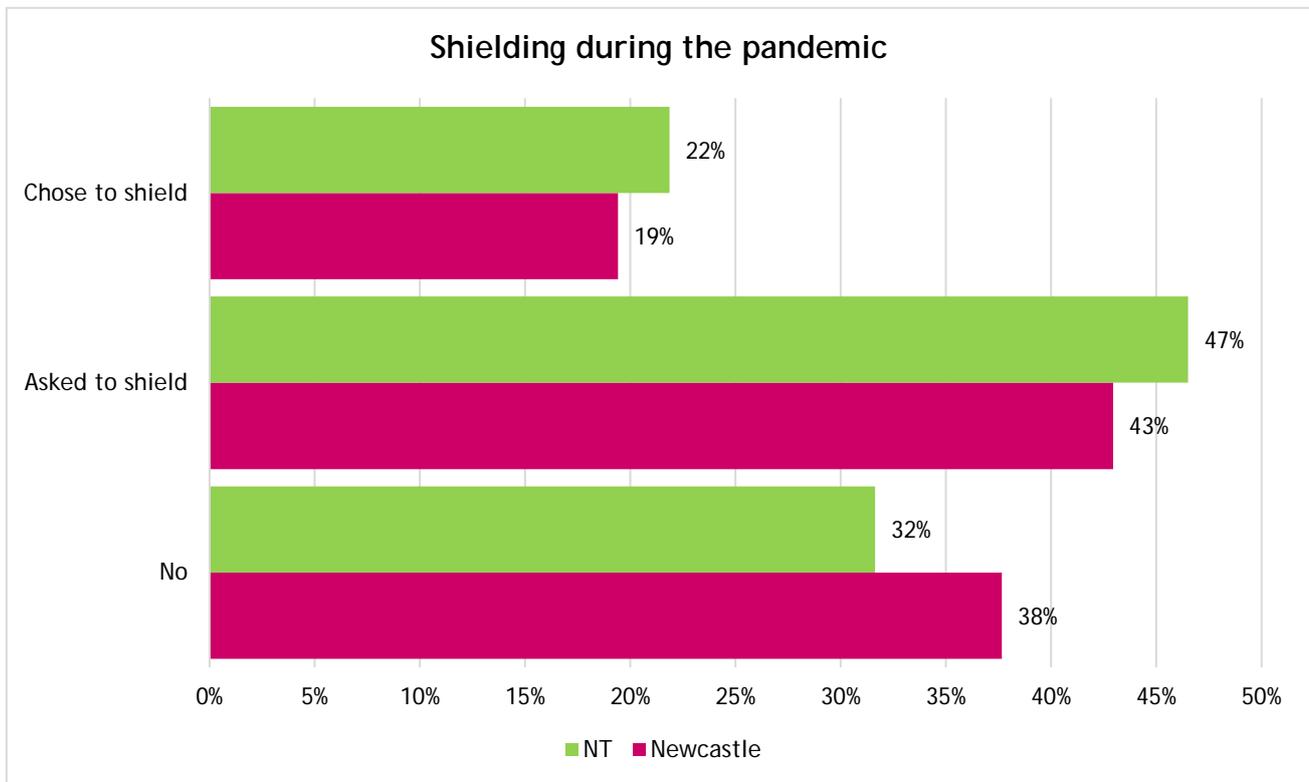
mobility issues (20% in Newcastle and 18% in North Tyneside), followed by mental health conditions (both 14%).

It must be noted that not all respondents provided demographic data therefore the figures do not exactly correlate with the demographics for all carers in Newcastle and North Tyneside.

It is interesting to see that North Tyneside respondents cared for people mostly aged over 85 (22%), whereas Newcastle had the highest numbers caring for people aged 75–84 (23%). Collectively, Newcastle and North Tyneside had a lot of carers caring for those under 18 (15% and 13%).

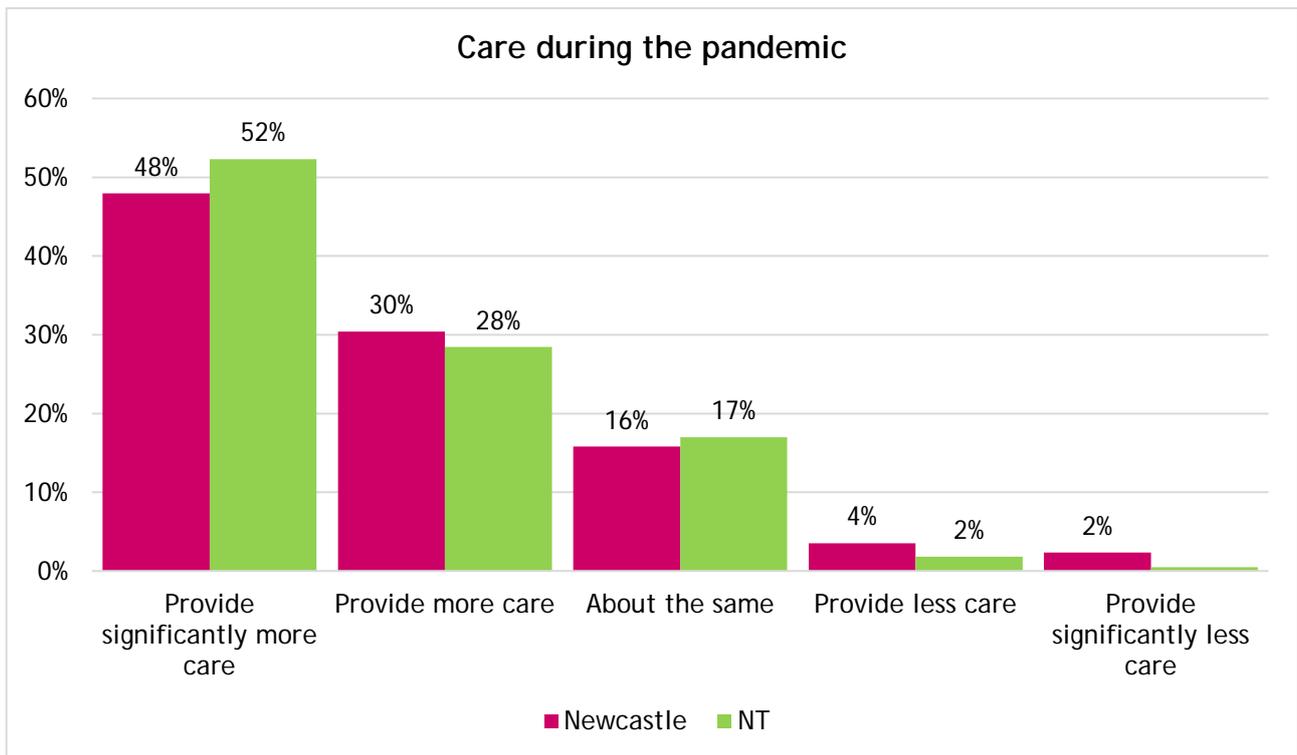


Those cared for varied in shielding requirements during the pandemic. Many people being cared for were asked to shield (47% in North Tyneside and 43% in Newcastle). More carers in Newcastle did not shield (38%) compared with those in North Tyneside (32%).



2.2 Carer experiences

Care during the pandemic

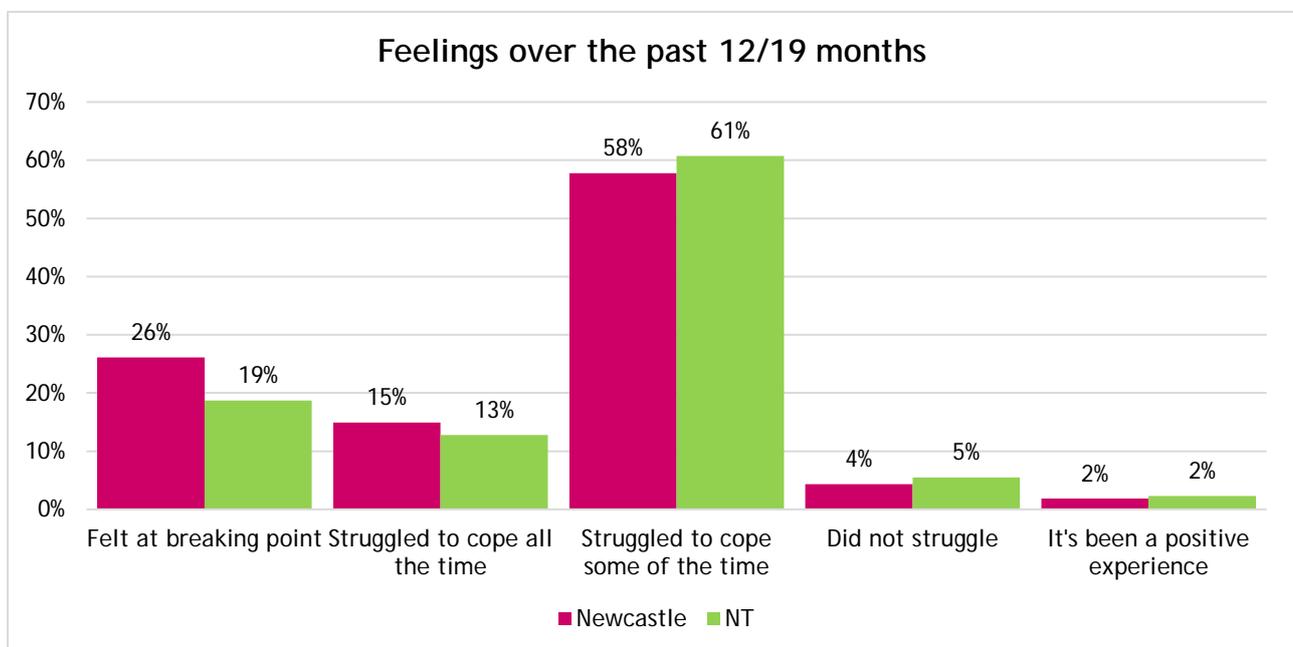


It is unsurprising to see that out of those who responded to this question, carers said they provided significantly more care during the pandemic: 48% in Newcastle and 52% in North Tyneside. Similar numbers of carers across both authorities felt they provided the same care. Comments reveal some gave this answer because they had not previously accessed support services.

Some respondents told us more about their increased care and the following themes emerged.

Newcastle carers	North Tyneside carers
1. Condition deteriorated/got worse (32%) <ul style="list-style-type: none"> • Anxiety and depression • Increase of Dementia deterioration rate 	1. Service closure (32%) <ul style="list-style-type: none"> • Day centres • Schools • Clubs and activities
2. Reduced outside care (28%) <ul style="list-style-type: none"> • Cancelled care due to fear of COVID-19 • Reduced support available to them from council social services, support workers/private care agencies 	2. Condition deteriorated/got worse (30%) <ul style="list-style-type: none"> • Anxiety and depression • Dementia increasing the rate of deterioration • Mobility and physical health
3. Provided more care due to shielding (23% of Newcastle carers and 25% North Tyneside) <ul style="list-style-type: none"> • Shopping • Collecting prescriptions • Technology support for medical appointments • Providing more emotional support due to isolation 	

Carer experiences during the pandemic



Due to the different times when this work was carried out, North Tyneside asked respondents how they felt over the past 12 months and Newcastle asked about the past 19 months. Experiences were very similar and around 60% of carers reported struggling to cope some of the time. Nearly 30% reported they felt at breaking point or struggled to cope all the time during the pandemic. An exceedingly small number found it a positive

experience across both areas. Carers told us more about the reasons for their answer and these themes emerged across both areas.

Mental health (18% of Newcastle carers and 41% North Tyneside)

- The strain of working and caring responsibilities impacting mental health
- Increased anxiety and depression caused by lockdown and isolation
- Breakdowns from struggling to cope
- Emotional rollercoasters

Less support (15% of Newcastle carers and 27% North Tyneside)

- Services closed including day centres, schools, respite and dementia care
- Care workers were too busy
- Reduced support from friends and family due to restrictions

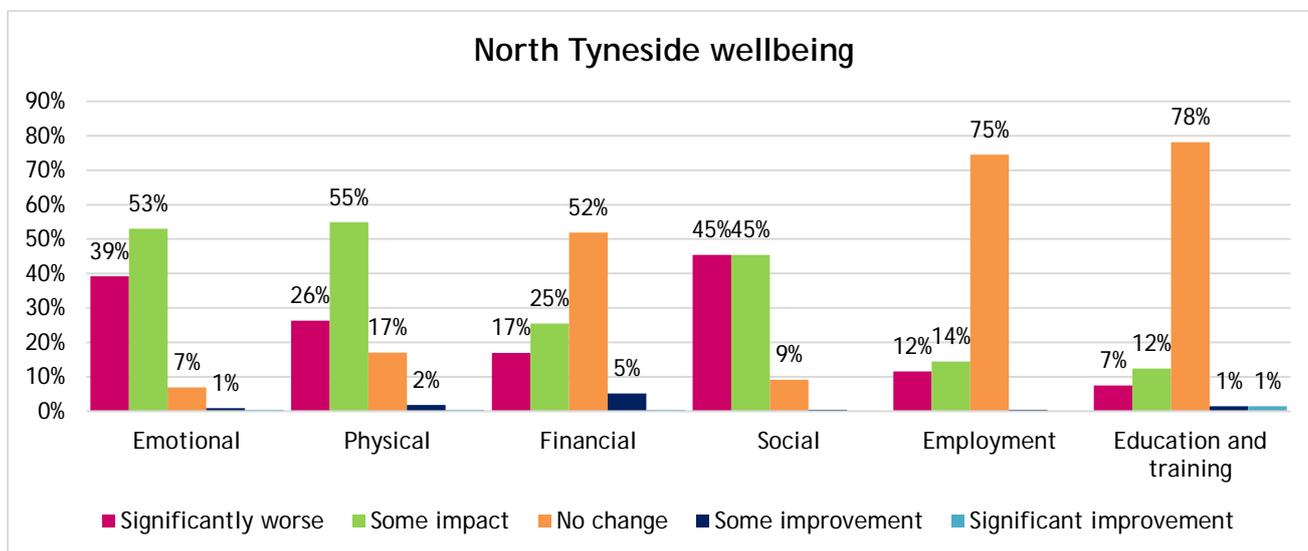
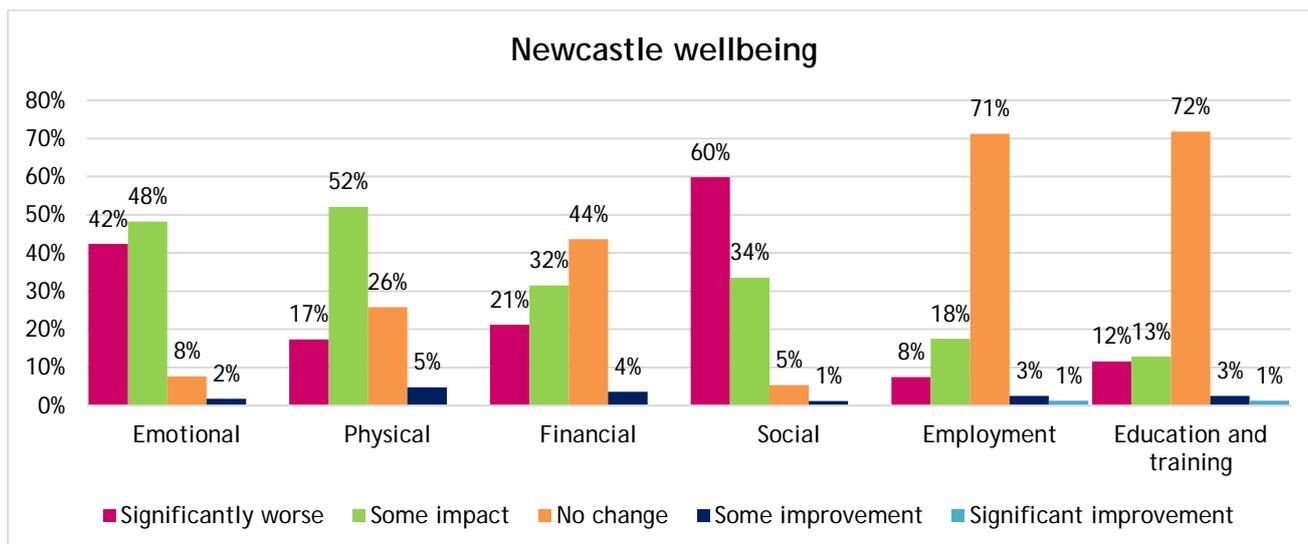
Lack of socialising (9% of Newcastle carers and 11% North Tyneside)

- With family and friends
- Less desire to socialise
- Losing social skills

Working (9% of Newcastle carers and 8% North Tyneside)

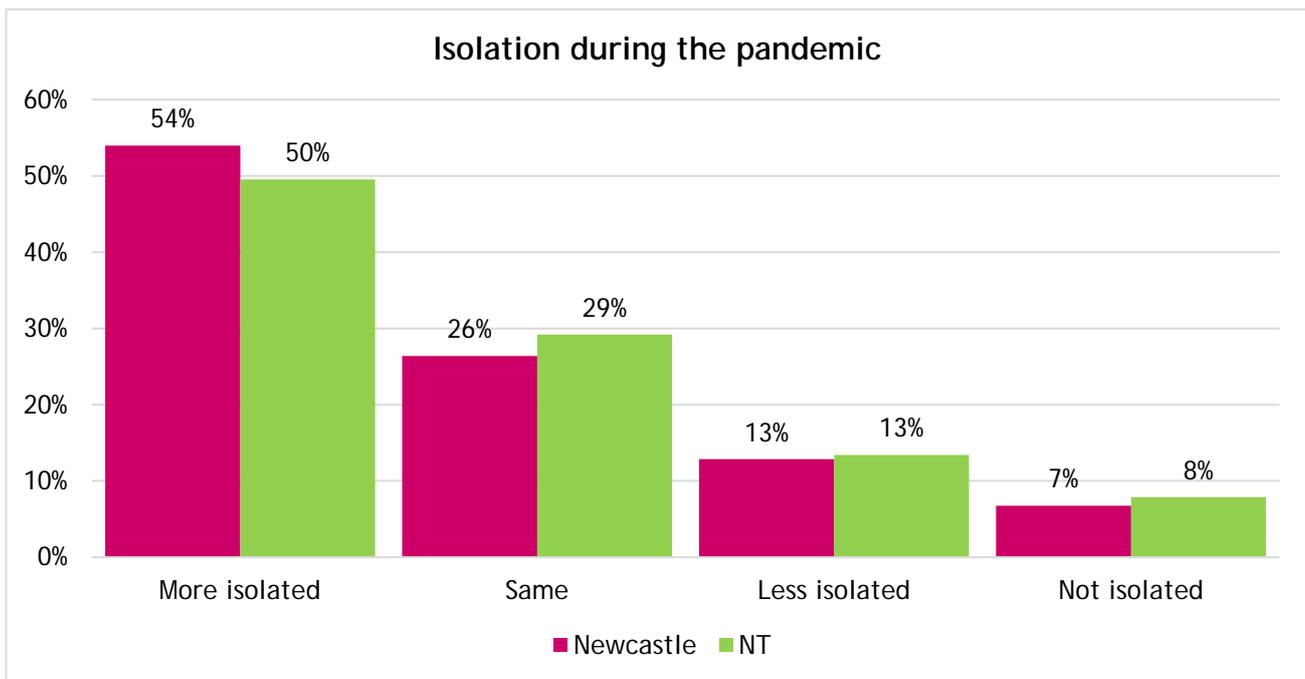
- Working full time while caring and/or home schooling
- Challenges at work

Impact of the pandemic



Across both Newcastle and North Tyneside, social (60% and 45% respectively) and emotional (42% and 39% respectively) wellbeing were reported to be the most negatively impacted by the pandemic. This could also be due to a deterioration in the condition of the person being cared for and the detrimental impact of this. North Tyneside respondents also reported a greater impact on their physical health (26% of carers).

Given an increase in unemployment and furlough schemes during the pandemic, it's good to see that employment, education and training had minimal impact on carers in Newcastle and North Tyneside.



As 62% of carers who responded in Newcastle and 69% in North Tyneside reported they were shielding during the pandemic, it is understandable to see that over 50% of carers felt more isolated.

Around 20% of carers in each area reported feeling less isolated or not at all. This could be due to school and service closure meaning they had company. This could also be the result of people checking in with each other more and having virtual catchups during the pandemic.

Issues during pandemic

We asked carers in Newcastle and North Tyneside what they found most difficult during the pandemic. The following themes emerged.

Newcastle carers	North Tyneside carers
<p>1. Socialising (50%)</p> <ul style="list-style-type: none"> • Constant interaction with people cared for • Attending clubs and activities with others • Missing out on family life • Unable to meet up with friends • Unable to get support from family/friends • Balancing care around social contact 	<p>1. Service access (26%)</p> <ul style="list-style-type: none"> • Services not available to provide support • Day services, swimming pools and therapy activities closed • Doctors and dentists
<p>2. Mental health (23%)</p> <ul style="list-style-type: none"> • Managing own mental health • Mental health decline in the person being cared for • Unknown increasing anxiety 	<p>2. Isolation (25%)</p> <ul style="list-style-type: none"> • Loneliness • Stuck in the house • Feeling cut off
<p>3. GP access (16%)</p> <ul style="list-style-type: none"> • Face-to-face appointments • Waiting lists • Reduced support • Lack of access causing hospital admissions 	<p>3. Socialising (21%)</p> <ul style="list-style-type: none"> • Constant interaction with people cared for • Missing out on family life • Unable to meet up with friends/family
<p>4. Isolation (11%)</p> <ul style="list-style-type: none"> • Due to testing positive for COVID-19 and being unable to care • Feeling cut off from the outside world • Worried about person cared for being isolated 	<p>4. Balance (8%)</p> <ul style="list-style-type: none"> • Balancing family and caring needs • Full-time work and care

Positives to come out of the pandemic

Whilst the majority of carers from Newcastle and North Tyneside said there were no positives, some provided the following positives.

1. More time (20% of Newcastle carers and 33% North Tyneside)

- Quality time with family/friends
- Take up hobbies and new skills
- Caring responsibilities

2. Working from home (15% of Newcastle carers and 12% North Tyneside)

- Flexible working to support caring needs
- Less time to commute
- Reduce financial costs
- New employment

Newcastle carers	North Tyneside carers
<p>3. Family support (6%)</p> <ul style="list-style-type: none"> • Family coming together • Stepping up when needed 	<p>3. Learning (11%)</p> <ul style="list-style-type: none"> • Technology skills • About self and coping strategies • How to play musical instruments
<p>4. Change of perspective</p> <ul style="list-style-type: none"> • Spending time with loved ones and health more important than materialistic things • Living life to the full • What matters in life 	

What helped carers during the pandemic

Respondents told us what helped them during the pandemic. The following coping mechanisms helped carers.

1. **Exercise (13% of Newcastle carers and 17% North Tyneside)**
 - Running
 - YouTube exercise videos
 - Yoga/Pilates
 - Walking

2. **Online contact (8% of Newcastle carers and 9% North Tyneside)**
 - Zoom quiz nights with family and friends
 - Social media
 - Neighbour WhatsApp groups
 - Online social groups
 - Medical appointments

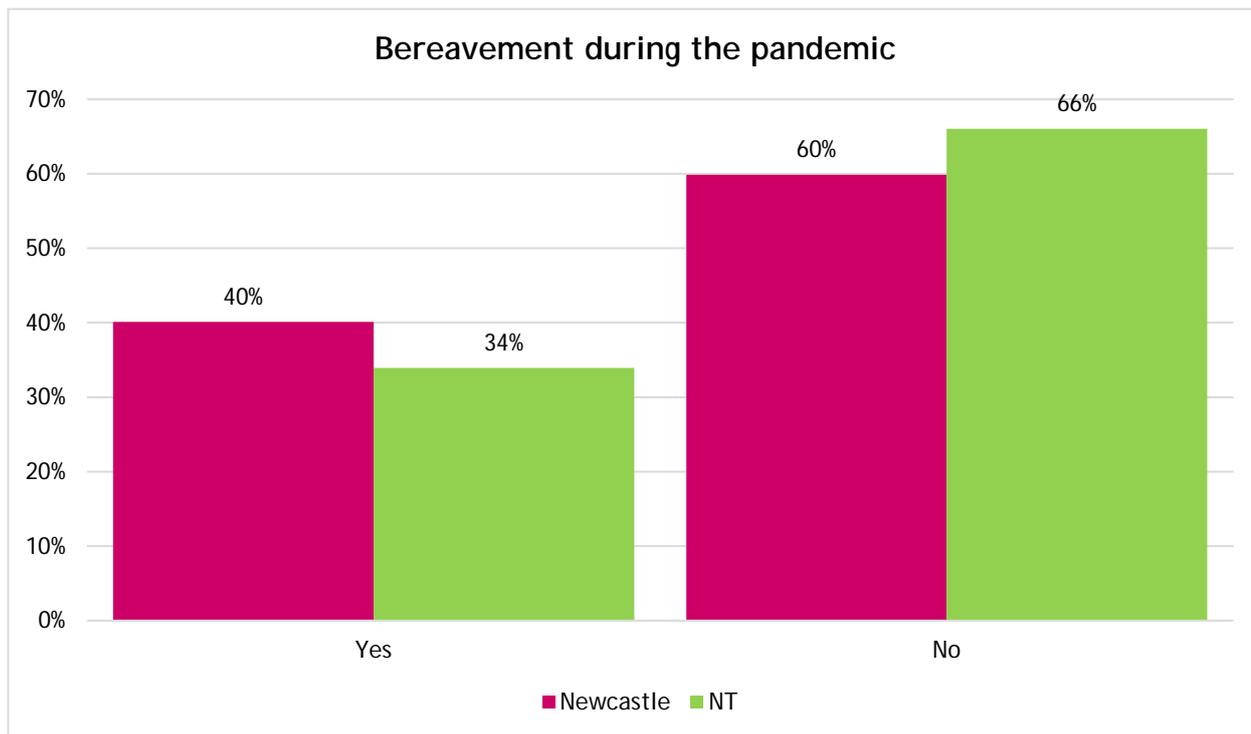
Newcastle carers	North Tyneside carers
3. Medical help (6%) <ul style="list-style-type: none">• Occupational therapists• Counsellors• Early intervention psychosis team• District nurses	3. Carers' centre (8%) <ul style="list-style-type: none">• Support telephone calls• Carer meetings on Microsoft Teams• Virtual training and activities

Biggest fear coming out of lockdown

We asked what people's biggest fear was coming out of lockdown. The following top themes emerged.

Newcastle carers	North Tyneside carers
<p>1. COVID-19 spreading (16%)</p> <ul style="list-style-type: none"> • Passing virus to vulnerable people • Cared for person catching COVID-19 • People not following rules/guidelines 	<p>1. Another lockdown (29%)</p> <ul style="list-style-type: none"> • Pandemic not ending • New variants causing lockdown
<p>2. Another lockdown (15%)</p> <ul style="list-style-type: none"> • Ever coming out of the pandemic • Living in fear of lockdowns 	<p>2. COVID-19 spreading (26%)</p> <ul style="list-style-type: none"> • People not following rules/guidelines • Losing friends/family to COVID-19
<p>3. Support available (13%)</p> <ul style="list-style-type: none"> • Limited support for carers • Difficult to access services • Reduced NHS service provision 	<p>3. Normality (14%)</p> <ul style="list-style-type: none"> • Unable to be the 'same' person since the pandemic • Having to make choices
<p>4. Normality (10%)</p> <ul style="list-style-type: none"> • Getting used to the new 'normal' • Return of normality too quickly 	<p>4. Work (7%)</p> <ul style="list-style-type: none"> • Going back to an office • Juggling work and caring responsibilities

Bereavement during the pandemic

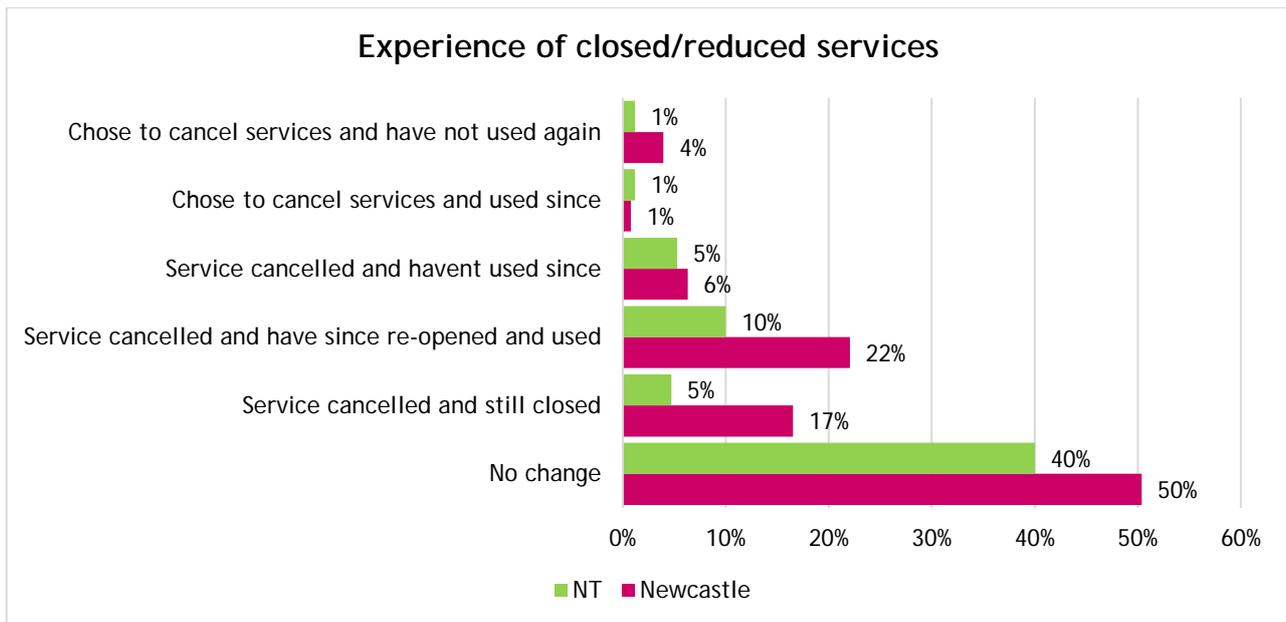


Most respondents did not experience bereavement during the pandemic (60% Newcastle, 66% North Tyneside). Of those who did, we asked what support carers had received: 61% of Newcastle respondents and 53% of North Tyneside respondents did not receive any support with their bereavement. Three respondents in North Tyneside (6%) stated they received bereavement support from North Tyneside Carers and another three were provided with support from work, school and care workers.

Although most bereaved respondents did not receive professional bereavement support services, 31% of them in Newcastle and 26% in North Tyneside did receive support from friends and family. This provides evidence that professional bereavement support across both local authorities needs to improve.

2.3 Experiences of the person cared for

Reduced/closed services

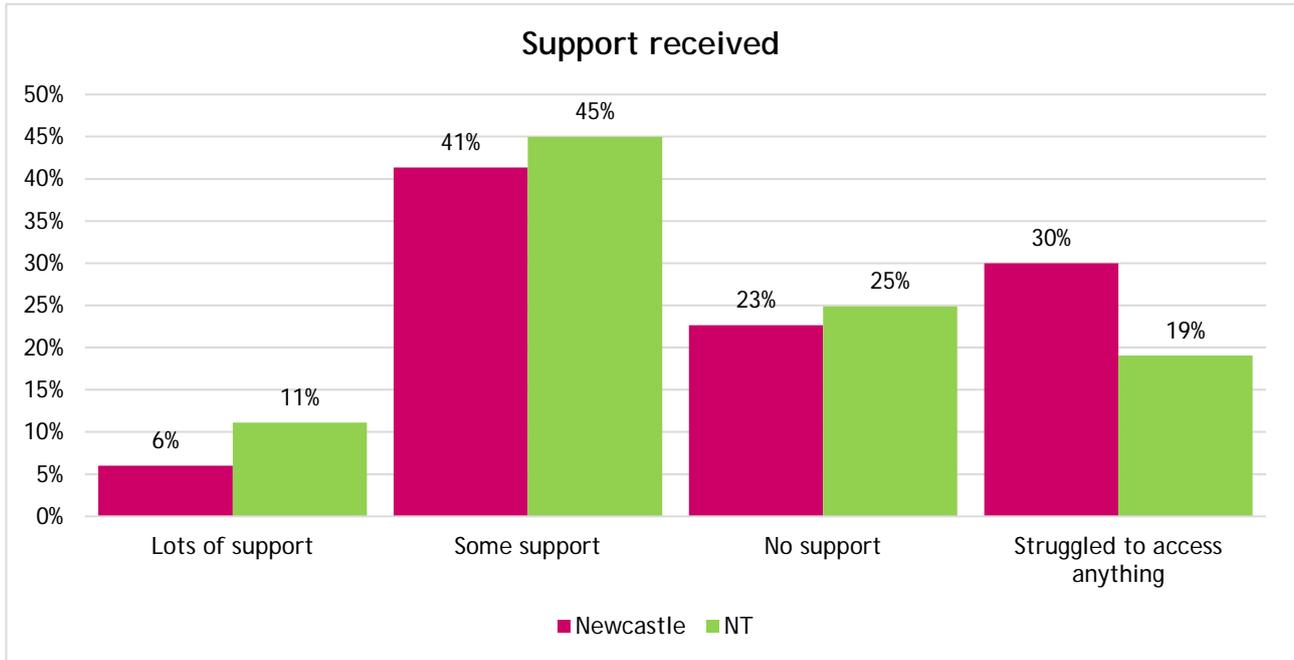


Out of those who responded, it is good to see that 50% of people cared for in Newcastle and 40% in North Tyneside experienced no change in services during the pandemic. However, many carers across Newcastle and North Tyneside commented that this was due to not previously using or being able to access services before the pandemic. Services reported to be cancelled or still closed included face-to-face social groups, cafes, sporting activities and overnight respite care.

Despite Newcastle respondents reporting the least changes to their service experience, 17% experienced more service cancellations during the pandemic than North Tyneside carers.

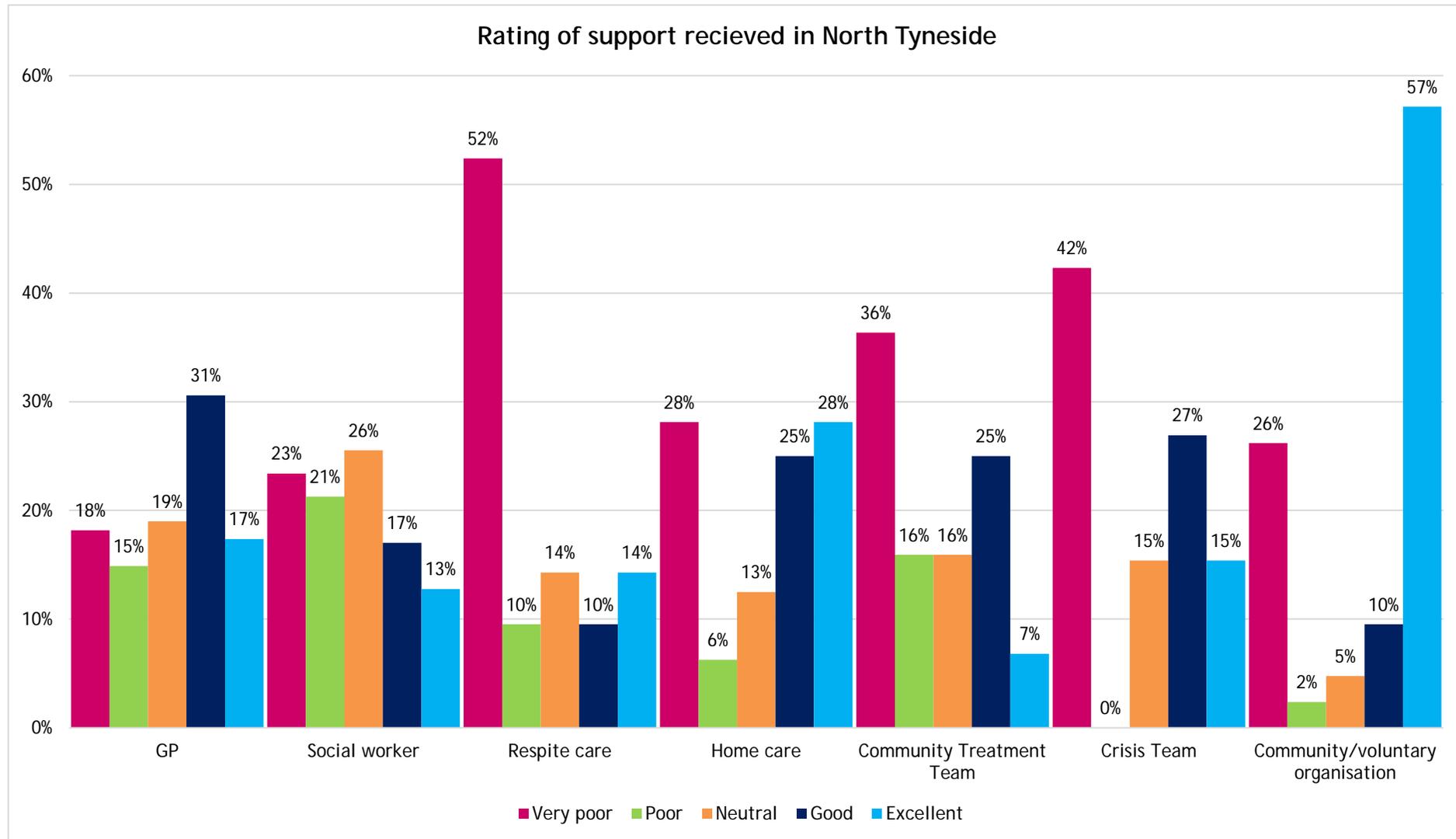
Numerous comments were also made by Newcastle carers regarding service access before the pandemic. New service users also found it almost impossible to access services because of the pandemic, examples included housing services and care support. No comments of this nature were made by North Tyneside carers.

Support received

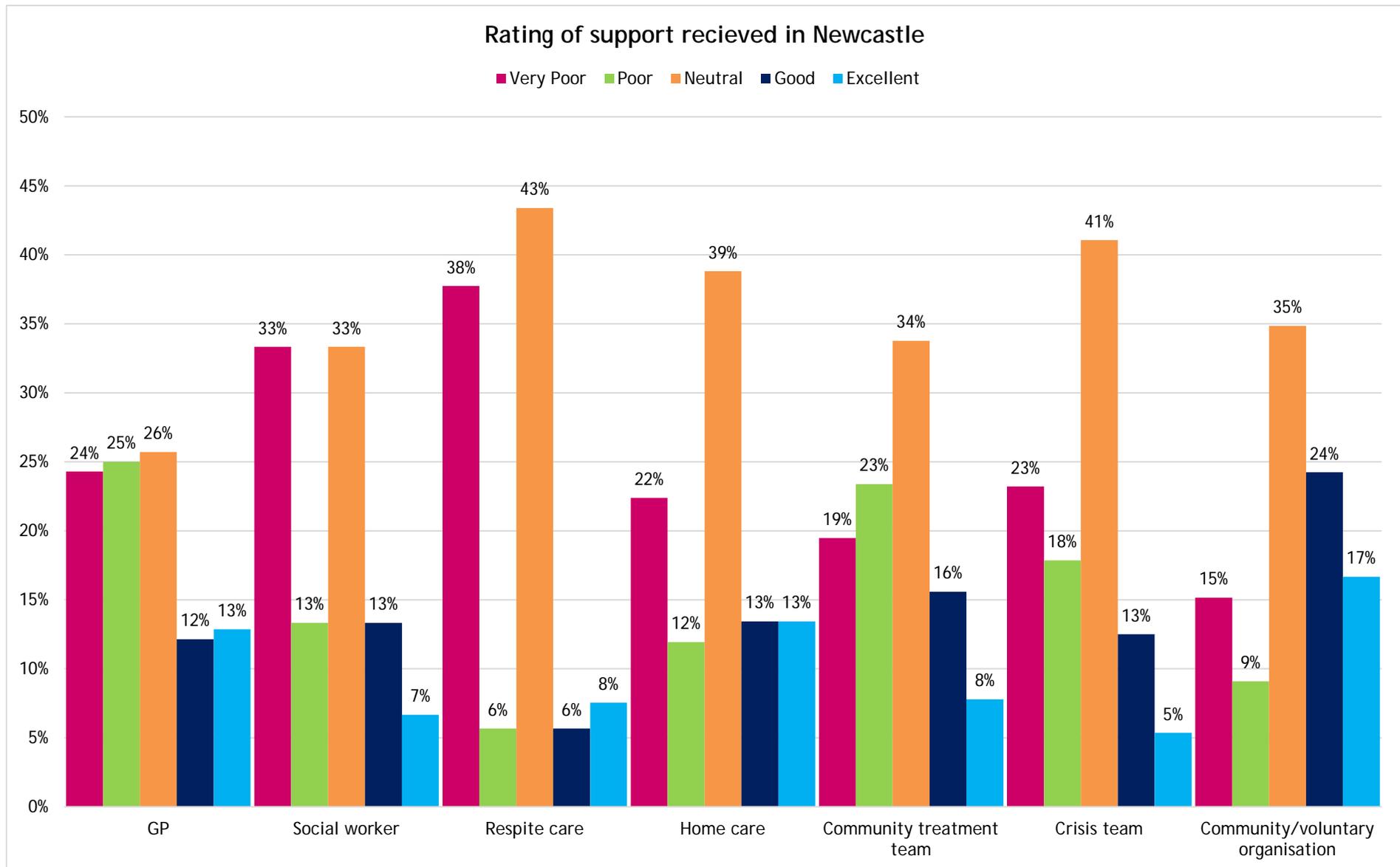


Carers were asked if the person they cared for received the support they needed during the pandemic. Most received some support during the pandemic – 41% of carers in Newcastle and 45% in North Tyneside. However, it is concerning to see that 53% of respondents in Newcastle and 44% in North Tyneside struggled to access or receive support from services.

Carers were also asked to rate the support their cared for person received during the pandemic. It is excellent to see that community and voluntary (VCS) organisations had the highest support rating, with 67% in North Tyneside and 41% in Newcastle. Newcastle and North Tyneside carers both reported that VCS organisations were responsive and moved their support online.



Home care received the second-highest support rating for both North Tyneside and Newcastle – 53% of North Tyneside carers and 26% in Newcastle. This was followed by GP support (48% in North Tyneside and 25% in Newcastle).

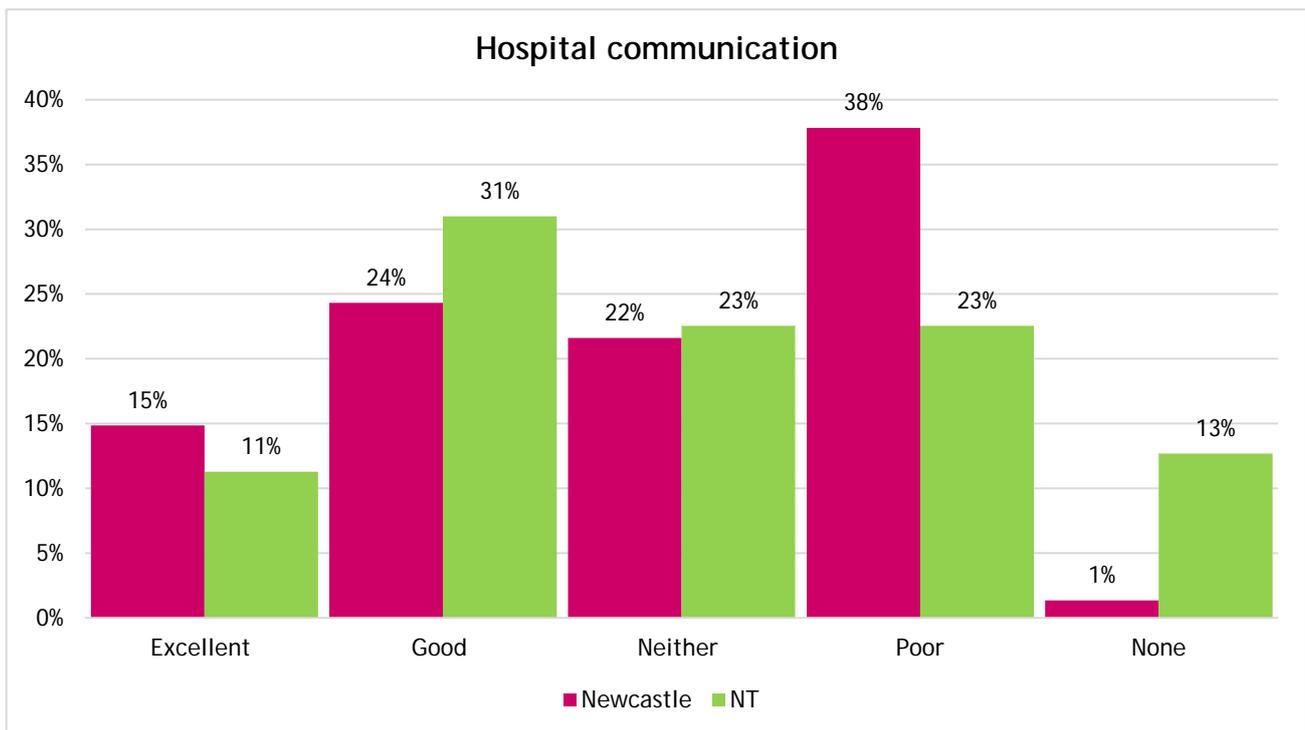


Respite care received the lowest support rating across both areas – 52% of carers from North Tyneside and 38% in Newcastle. The mental health crisis team in North Tyneside was rated second lowest with 42% of carers, whereas in Newcastle this was social workers with 33%. However, it must be acknowledged how overworked and under pressure social care was and still is.

Across both data sets, GPs were understandably the most accessed service, providing support to over 93% of carers in Newcastle and 40% of carers in North Tyneside. On average, GPs services received the lowest support ratings from 49% of respondents in Newcastle but this was one of the highest-rated services in North Tyneside (48% of carers).

Newcastle carers gave the most neutral ratings for social care support: respite care (43%), crisis team (41%) and home care (39%) rated the highest. As previously mentioned, many reported that respite care had stopped, which explains the neutral rating as they wouldn't have received support. In North Tyneside, social workers (26%) and GPs (19%) were rated as neutral. It should also be noted that many respondents stated they didn't receive support because they managed and relied on themselves to provide support to the person they cared for.

Hospital communication



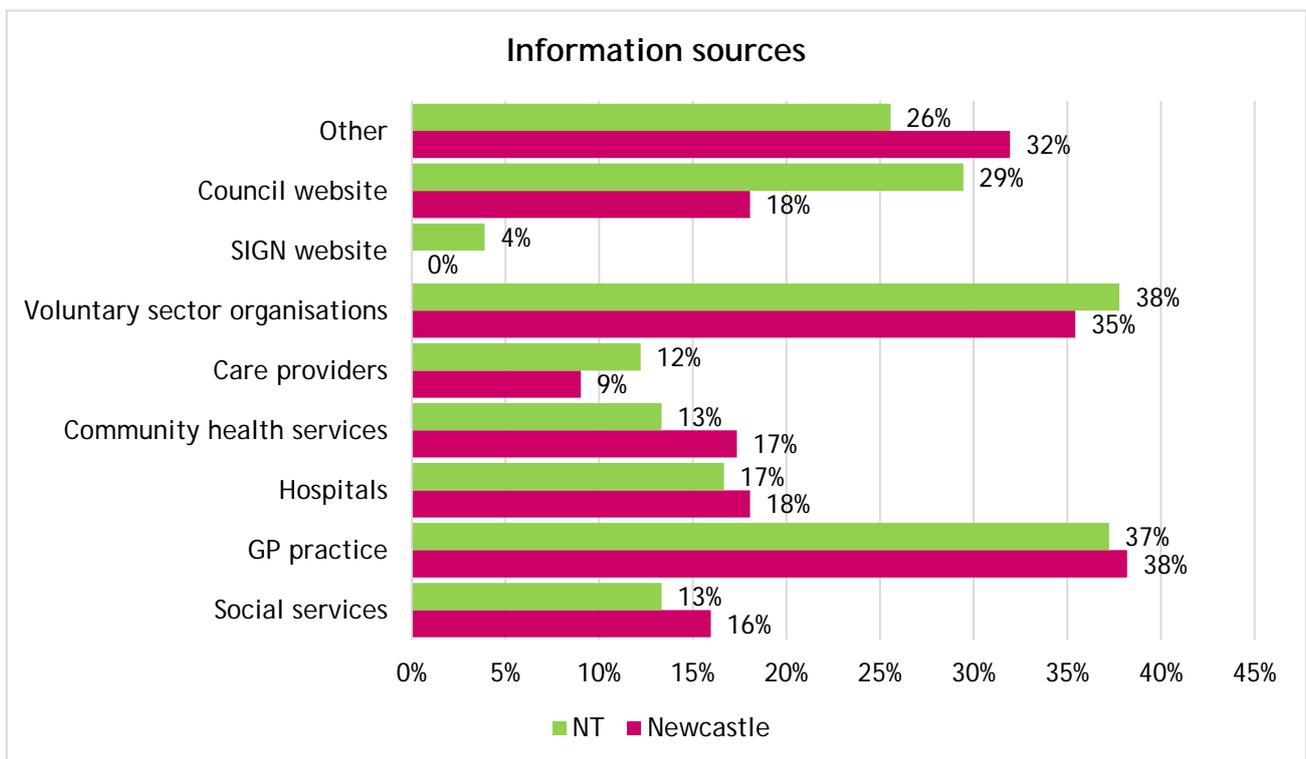
When asked about communication from the hospital during the admission of the person they cared for, it is interesting to see that 38% of Newcastle carers significantly experienced poor communication whereas 31% of North Tyneside experienced effective communication. This may be due to different hospitals being accessed. However, on average, 39% of carers in Newcastle and 42% in North Tyneside did receive good or excellent communication. It must also be noted that 13 carers in North Tyneside had more experience of no communication than Newcastle carers with only 1%.

When asked for further detail of their experiences, Newcastle carers reported a lack of communication between hospital and multi-agency professionals from GP practices and care homes causing confusion. Whereas North Tyneside carers reported that communication depended on who was on shift and their attitude.

Hospital discharge was also mentioned: a Newcastle carer said that safe discharge communication would have prevented re-admissions and in North Tyneside a cared-for person was discharged too quickly. However, once hospital visits were allowed, many carers in Newcastle and North Tyneside reported they received sufficient communication.

2.4 Information and support

Information for carers

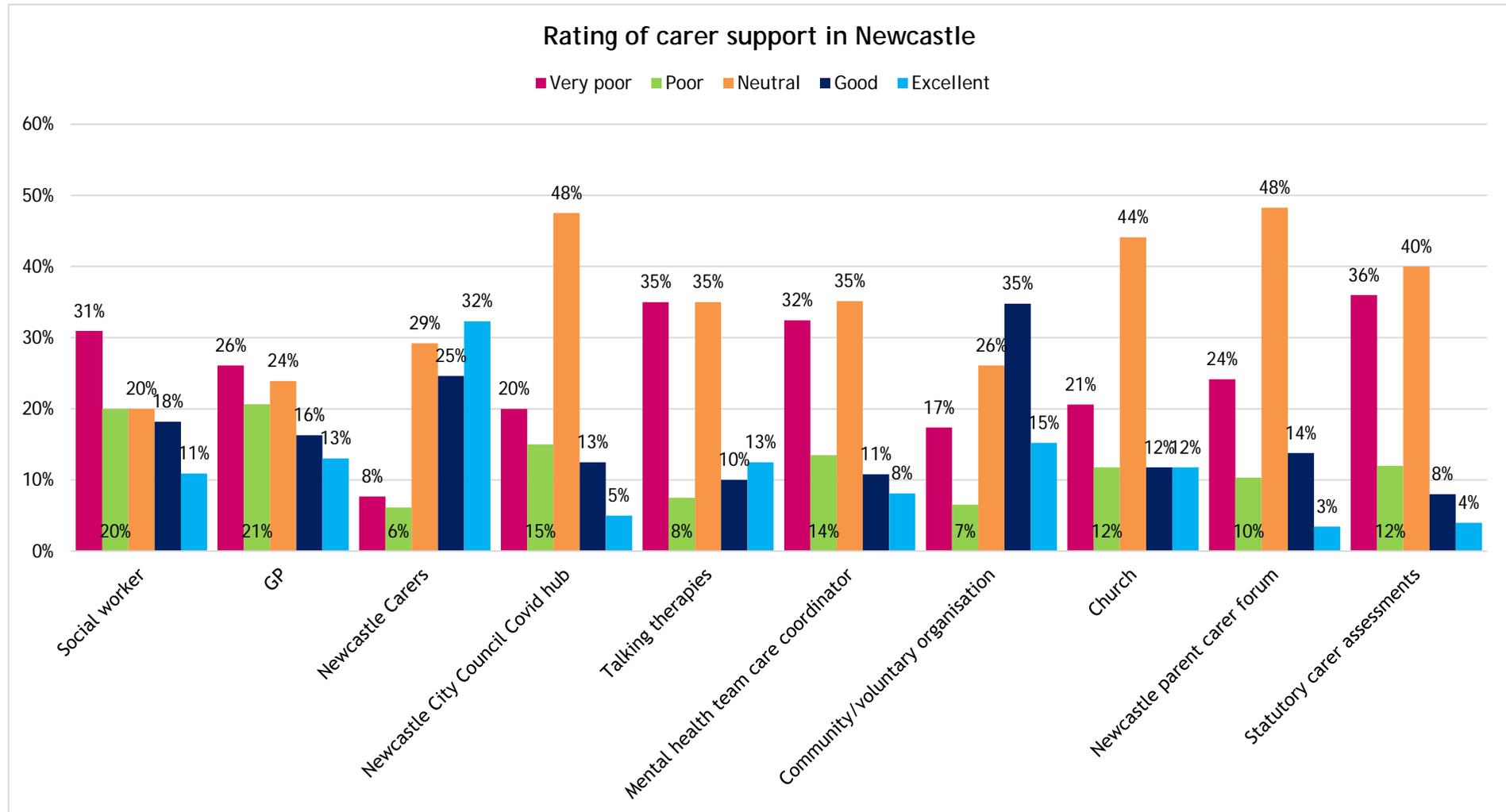


This question asked respondents where they got health and care service information from. The top three information sources across Newcastle and North Tyneside were VCS organisations (38% in North Tyneside and 35% in Newcastle) and GP practices (37% in North Tyneside and 38% in Newcastle). It could be said these were the services that carers accessed and trusted the most.

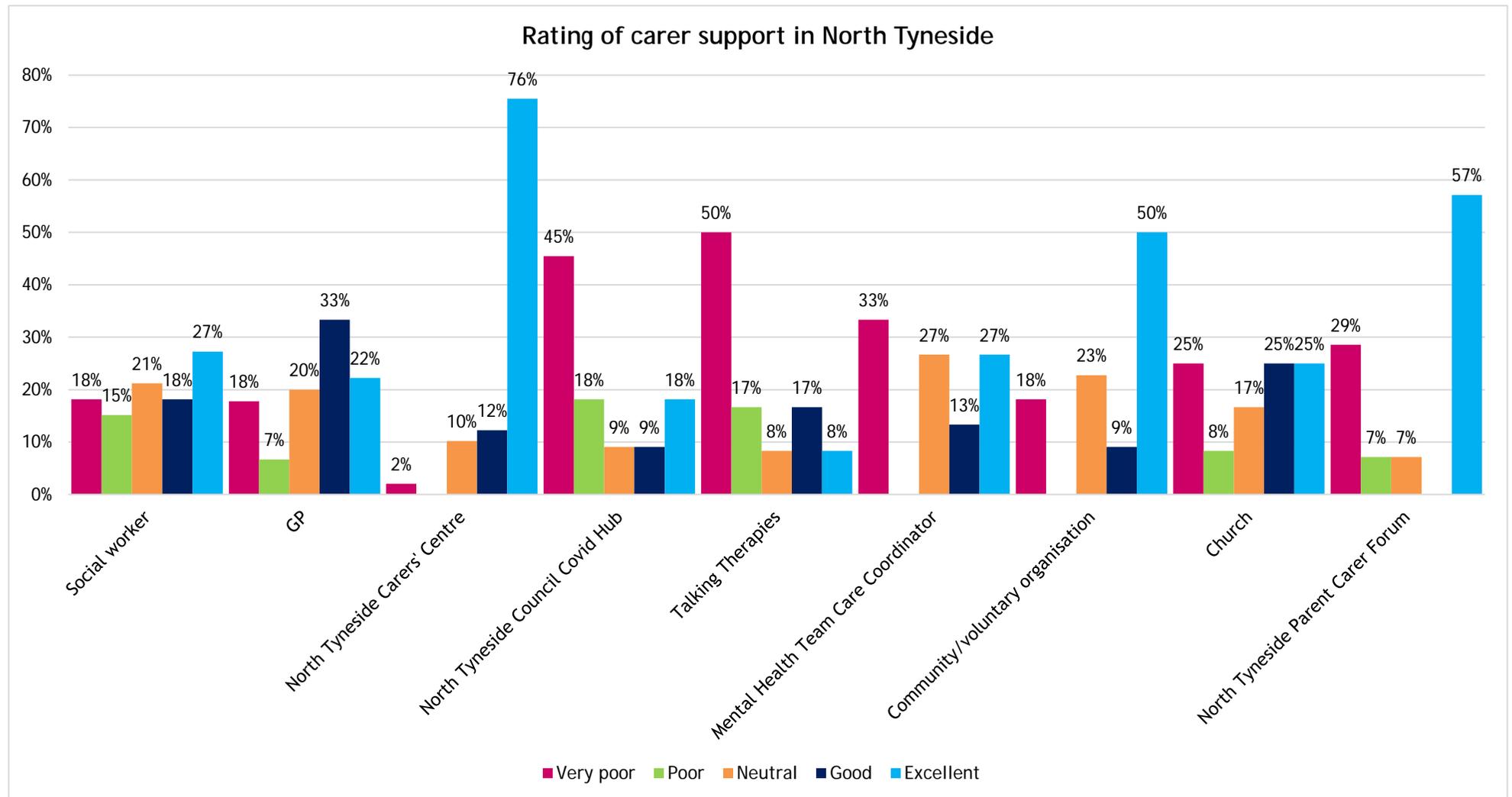
North Tyneside Council website came next for 29% of North Tyneside carers, whereas only 18% used Newcastle City Council’s website. Instead, 32% of Newcastle respondents used other sources, with many using internet search engines, Information Now, Facebook and contacts such as family and colleagues. Information Now is Newcastle City Council’s information website for residents so this may be why usage of their main website is lower than in North Tyneside; 26% of North Tyneside also used these other resources.

Support for carers

We asked carers to rate the support they received for themselves during the pandemic. Overall, carers in North Tyneside gave a higher percentage of positive ratings than in Newcastle. It is excellent to see that both Newcastle and North Tyneside carers' centres have the highest rating of support – 32% of carers in Newcastle and 76% in North Tyneside.



Community and voluntary organisations follow – 15% of carers rated their support as excellent in Newcastle. However, in North Tyneside it was the parent carer forum with 57%, which only received a 3% excellent rating in Newcastle.



In North Tyneside, talking therapies and the North Tyneside Council COVID-19 hub received the lowest ratings from carers (50% and 45% respectively). In Newcastle, 35% of respondents also rated talking therapies as very poor. Despite this, 23% of Newcastle carers and 25% of North Tyneside carers said support was excellent or good which may demonstrate that great support is provided once it can be accessed.

It should also be noted that many carers stated they did not receive any support because they had not accessed it.

Improving carer support

Respondents outlined improvements for carer support, with the following themes emerging.

1. More accessible (27% of Newcastle carers and 51% North Tyneside)

Similarities	Newcastle only	North Tyneside only
<ul style="list-style-type: none"> • Single point of contact • GP access • Home/face-to-face appointments • Remain open • More support groups • More services to access in the local area 	<ul style="list-style-type: none"> • Dental access • More support groups for men 	<ul style="list-style-type: none"> • More communication from hospitals and adult social care • More support services for people with autism and young carers

2. Awareness (13% of Newcastle carers and 12% of North Tyneside carers)

Similarities	Newcastle only	North Tyneside only
<ul style="list-style-type: none"> • More advertising of available services 	<ul style="list-style-type: none"> • Main providers making aware during initial conversations 	<ul style="list-style-type: none"> • Use schools to make aware

3. Check-ins (7% Newcastle carers and 11% North Tyneside)

- More communication to check carers are OK
- Update on how things are
- Not relying on carers to reach out

3. Conclusion

3.1 Carer experiences during the pandemic

Carers had to provide significantly more care during the pandemic across both North Tyneside and Newcastle. The main reasons were deteriorating medical conditions and more care being required due to shielding. Newcastle carers reported greater reductions in externally provided care, whereas North Tyneside reported more service closures. Most Newcastle and North Tyneside respondents reported they struggled to cope some of the time, with many reporting this was due to their mental health and less support being available. Again, carers' social and emotional wellbeing was reported to be most significantly impacted by the pandemic across both local authority areas, with most feeling people more isolated.

Newcastle carers reported they found a lack of socialising the most difficult, whereas for North Tyneside carers this was accessing services. A positive outcome of the pandemic was more time for caring responsibilities, family/friends and hobbies. This was followed by the positive impact of working from home, including flexibility and reduced costs. Similarly, carers from both areas reported exercise as the best coping mechanism during the pandemic, followed by online contact. Across Newcastle and North Tyneside, carers' biggest fears coming out of lockdown were COVID-19 spreading and another lockdown.

It is unfortunate to see that across both local authorities many carers did not receive professional bereavement support and relied on family and friends. This suggests improvements are needed around the offer and availability of bereavement support.

3.2 Experiences of the person who is cared for

It is good to see that most of those cared for experienced no change in services during the pandemic. However, some Newcastle and North Tyneside carers reported this was due to difficulty accessing services before the pandemic. This also coincides with both cohorts of carers reporting that they received little support or struggled to access anything. It is excellent to note that community and voluntary sector organisations (VCS) across Newcastle and North Tyneside received the highest support rating.

Respite care across both areas received the lowest support rating, with many reports of services being closed. A difference in response should be noted for GP services: Newcastle respondents rated Newcastle GPs as providing the worst support, whereas North Tyneside GPs were rated as one of the best forms of support. In terms of hospital communication, carers in Newcastle reported poorer communication whereas North Tyneside's carers received good communication. This may be due to different hospitals being accessed.

3.3 Information and advice

Many carers received their health and care service information from VCS organisations and GP practices in both local authority areas. More carers in North Tyneside used their council's website for information than those in Newcastle. Both Newcastle Carers and North Tyneside Carers' Centre received the highest support rating for carers. Talking

therapies received a poor rating of support for carers across both areas, followed by the North Tyneside Council COVID-19 hub for North Tyneside carers and statutory care assessments for Newcastle carers. Improvements suggested by carers across both areas included services being more accessible and increasing awareness of the services they offer.

It must finally be noted that different services operated differently at different points during the pandemic. It is surprising to see how similar the results were given the different times the work was conducted.

4. Acknowledgements

We would like to acknowledge and say thanks to the following organisations for their contribution and support to complete this piece of work.

- Connected Voice
- Friends Action North East
- Healthwatch North Tyneside
- Information Now
- MEA House community
- NAS Tyne and Wear
- Newcastle Carers
- Newcastle City Council
- NHS Newcastle Gateshead Clinical Commissioning Group
- Newcastle Vision Support
- North Tyneside Carers' Centre
- North Tyneside Carers' Partnership Board
- Throckley Primary Care

Contact details



Healthwatch Newcastle
MEA House, Ellison Place
Newcastle upon Tyne, NE1 8XS



0191 338 5720



07551 052 751



info@healthwatchnewcastle.org.uk



www.healthwatchnewcastle.org.uk



@HWNewcastle



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