

Survey of Adult Carers in England (SACE) 2021/22



**Informatics and Insights
March 2022**

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Introduction

This report summarises the findings for Newcastle from the statutory national Survey of Adult Carers in England, which is overseen and collated nationally by NHS Digital. The survey takes place every other year and was due to go ahead in November 2020 but due to the pandemic creating other pressures and changing ways of working, it was postponed nationally for one year and took place in November 2021.

From the official survey guidance:

“Data from the survey is not just intended to be used to monitor performance through national outcome measures but also to be used locally to inform delivery of service and support and to monitor and develop standards.”

“The purpose of the survey will be to provide assured, benchmarked local data on outcomes, to support local services to think about ways of improving outcomes in a very challenging financial climate.”

This report focuses upon the key findings from both the mandatory questions and our own questions from the 2021/22 survey, and how they compare to previous years.

Methodology

Questionnaires were sent to a random sample of carers who were assessed or reviewed (either separately or jointly with the cared-for person) by Newcastle City Council’s Adult Social Care Services in the past 12 months. Our sample was drawn on **30 September 2021**.

We had a population of 1003 adult carers who had been assessed or reviewed by Newcastle City Council Adult Social Care Services in the time period. From this group we sent questionnaires to 951 carers.

Responses and margin of error

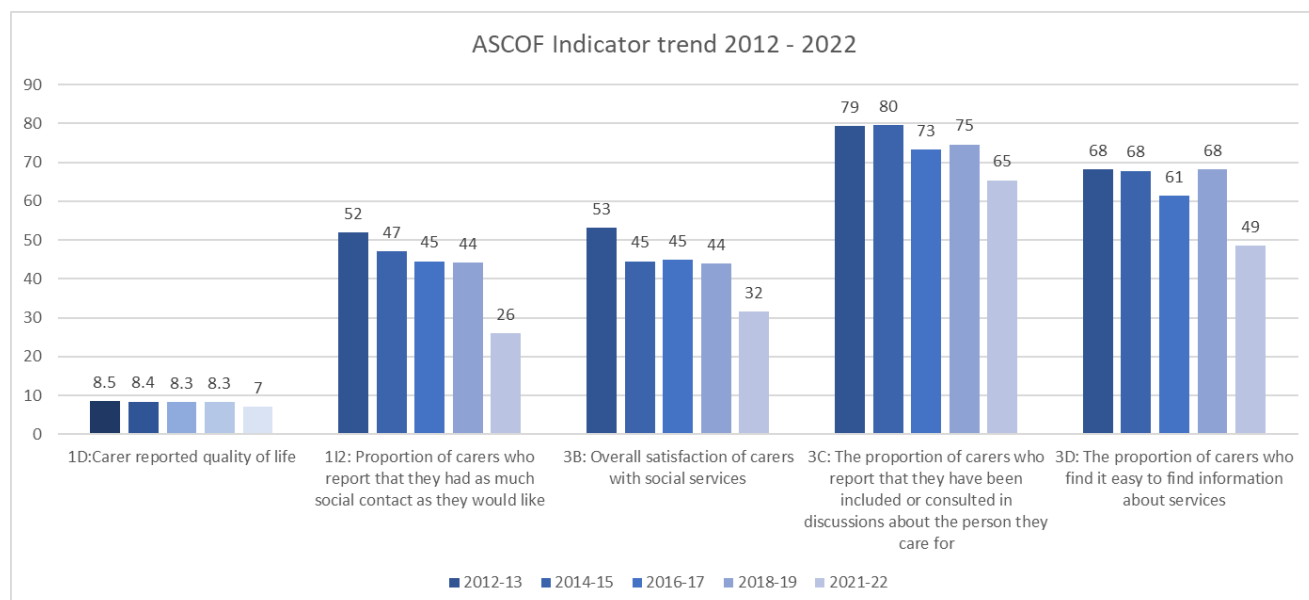
Questionnaires were sent out between 27 October - 1 November 2021. We sent out one reminder on 17 November 2021 and received **371** questionnaires returned out of **951** sent out, giving a response rate of **39%**. This gives a margin of error for the entire survey of **+/-4** percentage points, given that the total number of service users we drew our random sample from was 1003. This is inside the maximum margin of error specified by the NHS Information Centre, which is +/- 5 percentage points.

We can consider that the results from the survey are representative of the entire population of 1003 carers at 18 and over in Newcastle who were assessed or reviewed during the twelve months prior to the date of extracting the sample (30 September 2021), to within +/-4% percentage points either way. As an example of what this means in practice, the percentage of people in the survey who report that they have been included or consulted in discussions about the person they care for is 65.4% - so the “true” figure for the population as a whole lies between 61.4% - 69.4%.

Key findings

ASCOF Measures

In 2021-22 all ASCOF measure outcomes from the Survey of Adult Carer for Newcastle have declined to the lowest level since the first survey took place in 2012-13.



Restrictions during the pandemic resulted in reduced social contact for all with lockdowns being enforced and many services being unavailable. During this time carers had to increase the amount of care they were providing due to both the availability of external support and also due to the increasing needs of the person they care for. Many carers have seen their own health suffer as well. There are comments within the survey regarding difficulty in finding information and advice during the past year suggesting that many have tried to get more support, but the system has been stretched and so has not always been available. Its not always clear what type of information and advice carers are looking for and this could be part of the problem that they themselves are also not clear what they need to know which results in a feeling of being unsatisfied.

1D: Carer reported quality of life

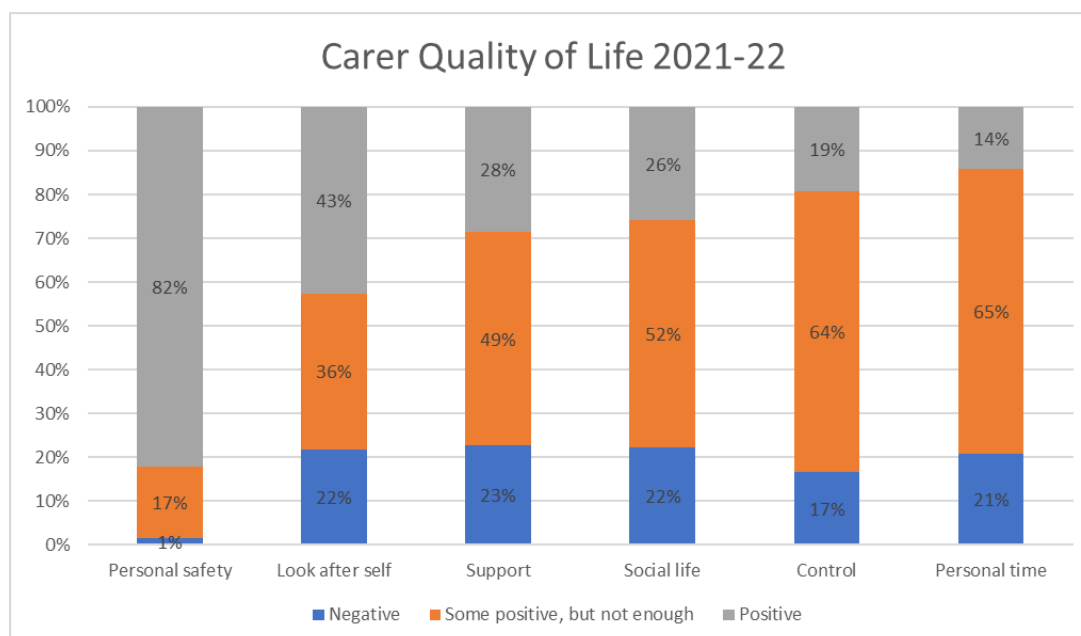
This is a composite measure which combines individual responses to seven questions measuring different outcomes related to overall quality of life: occupation, time and space, control, personal care, safety, social participation and encouragement and support. It is an overarching outcome measure for carers, similar to the equivalent for people who use social care services (1A – social care-related quality of life).

The table below is the calculation used to produce the 1D indicator score for Newcastle City Council for 2021-22: **7.0**, or **58%** of the maximum possible score. This is lower than the previous survey's score of **8.3 (69%)**.

	No unmet needs	Some unmet needs	No needs met	Total
Occupation (Q7)	48	220	74	342
Control (Q8)	63	221	58	342
Personal Care (Q9)	144	121	77	342
Safety (Q10)	281	57	4	342
Social Participation (Q11)	87	179	76	342
Encouragement and support (Q12)	93	170	79	342
Total	716	968	368	
Score	1432	968	0	
	Numerator	Denominator	1D	
	2400	342	7.0	

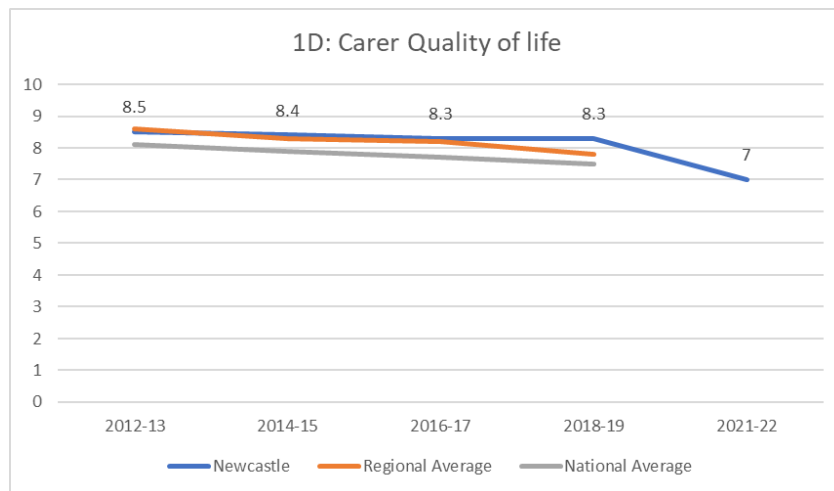
As this is a composite measure; the maximum possible score is 12.0. Respondents had to answer all seven questions to be included in this calculation, and any who did not have been removed from the totals.

The chart below shows the contribution each domain makes to the overall ASCOF score. Most carers were satisfied with how safe they felt, 82% said they had no worries about their personal safety. At the other end of the scale only 14% replied 'I am able to spend my time as I want, doing things I value or enjoy'.



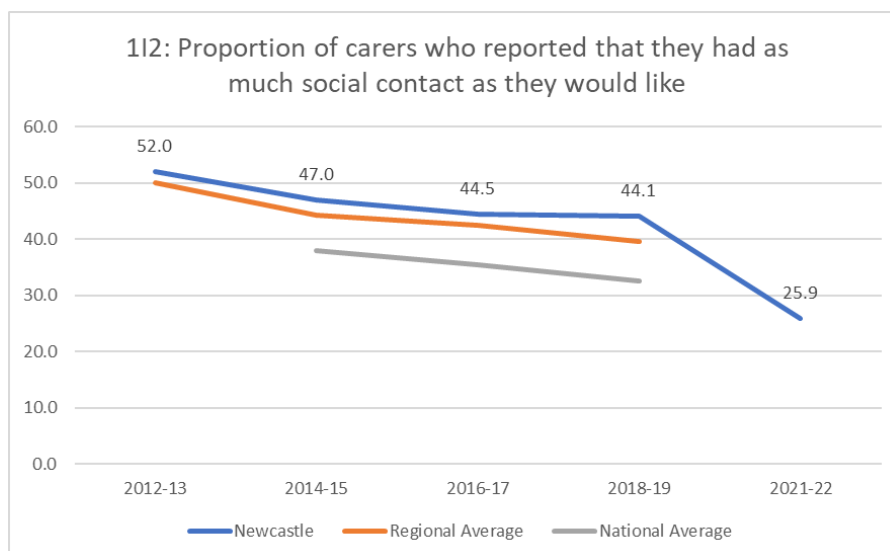
There has been a decline in the carer quality of life measure for Newcastle since the first survey of Carers in 2012/13, but the decline between the most recent surveys has been the biggest. Decline has also been seen in the NE region and nationally

since 2012, we do not have the current year figures to know whether the sharp decline can be seen in these areas too.



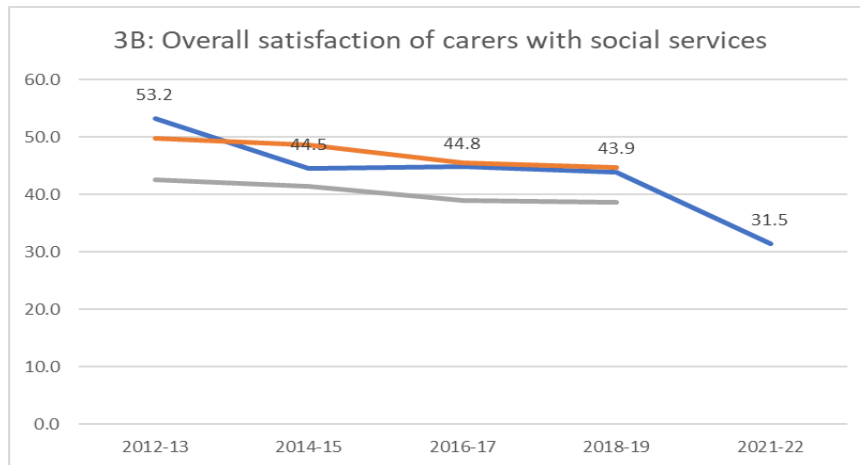
1I2: Proportion of carers who report that they had as much social contact as they would like

When asked “Thinking about how much social contact you’ve had with people you like, which of the following statements best describes your social situation?”, the percentage of carers who replied “I have as much social contact as I want with people I like” was **25.9%**, this is an 18.2% decrease compared to the previous survey.



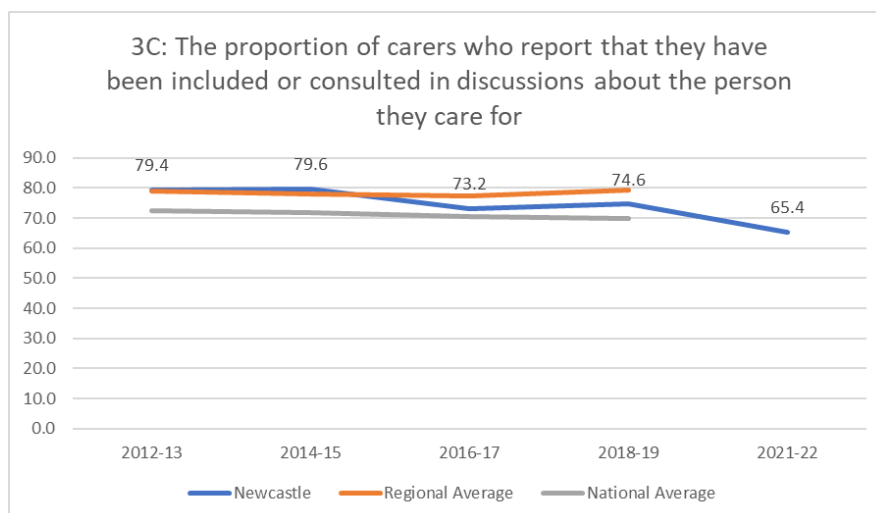
3B: Overall satisfaction of carers with social services

When asked “Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from social services in the last 12 months?”, a quarter of carers were extremely or very satisfied: **25.9%**. This is lower than in previous years and a drop of 12.5% from the previous survey. There has also been a decline over time in the NE region and nationally.



3C: The proportion of carers who report that they have been included or consulted in discussions about the person they care for

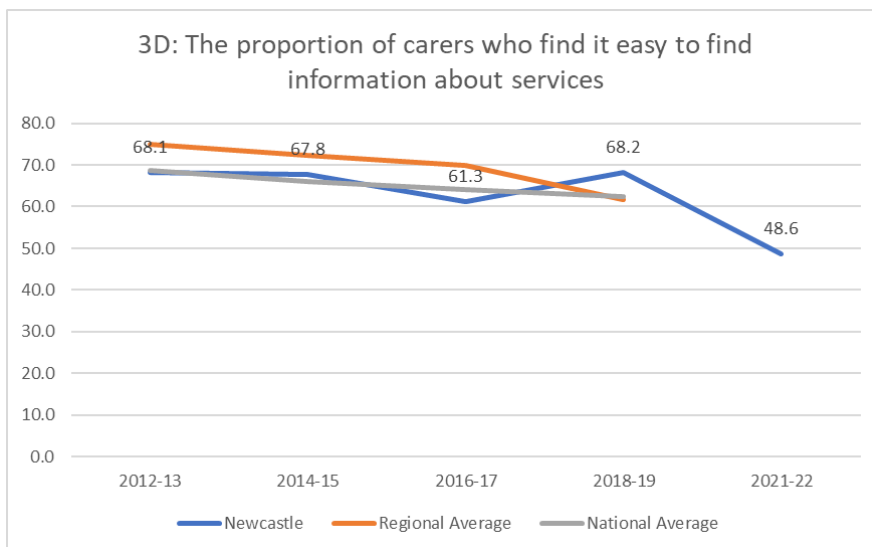
When asked “In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?”, **65.4%** of carers said that they always or usually felt included or consulted. This is the lowest response level we have had since the survey of carers began.



3D2: The proportion of carers who find it easy to find information about services

When asked “In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?”, the percentage of people finding it very or quite easy was **48.6%**, which is lowest figure we have for this measure over the history of the survey. There has been a decline in the NE region and national averages for this measure since the survey began. The survey of carers carried out by Health Watch also highlighted communication as an issue. Investigation into how messages are passed on within teams and service areas is needed to better understand the issues that have been raised.

Note that this percentage is calculated using the total number of **people who had tried** to find advice or information in the last 12 months, excluding people who had **not** tried to do this.



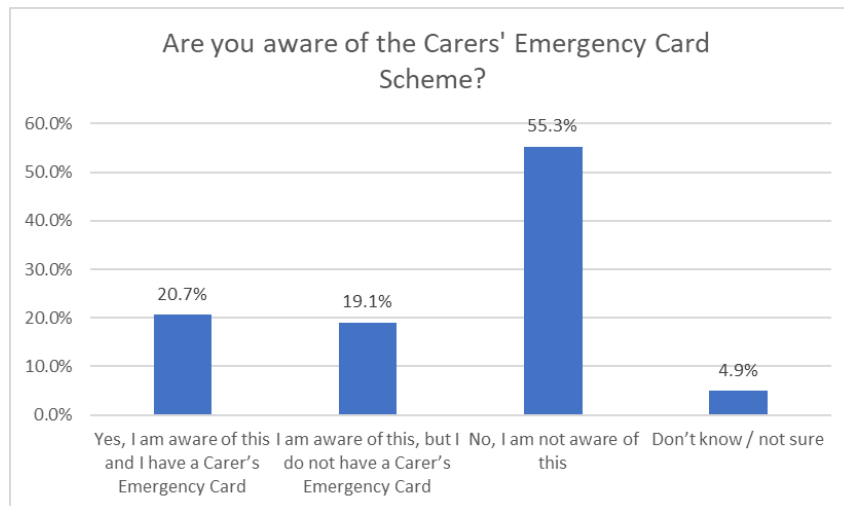
Questions added by Newcastle ASC

We added three additional questions to the survey:

Q6b. Are you aware of the British Red Cross Carers' Emergency Card Scheme?

This is a scheme run by Newcastle City Council and the British Red Cross where carers can register their details and can ring the Red Cross in an emergency and ask them to call up an emergency plan which helps assist the cared-for person.

The majority of carers (55.3%) responded to say they are not aware of the scheme. In 2018-19, 59% of carers responded to say they were not aware of the scheme so although more than half are still not aware it does show there has been an increase in awareness since the last survey.

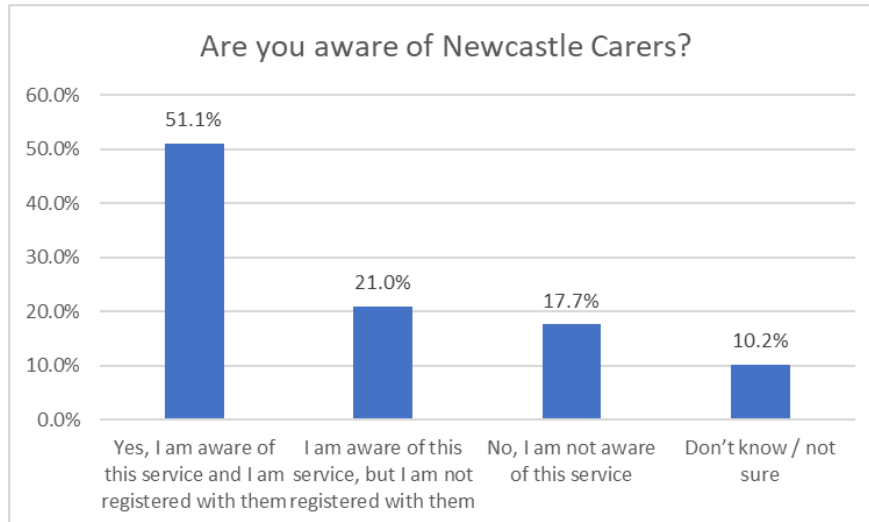


4 people did not provide a response to this question.

A new one year contract starts in April 2022. A key change to the scheme will be no volunteer support, so calls where there is no emergency contact listed will be passed to CHSCD or EDT for assessment and emergency support to be provided.

Q6c. Are you aware of Newcastle Carers?

Newcastle Carers are commissioned by Newcastle City Council and the Newcastle Gateshead CCG to provide support to carers in the city. The majority of carers (51.1%) responded to say they are aware of Newcastle Carers and are registered with them.

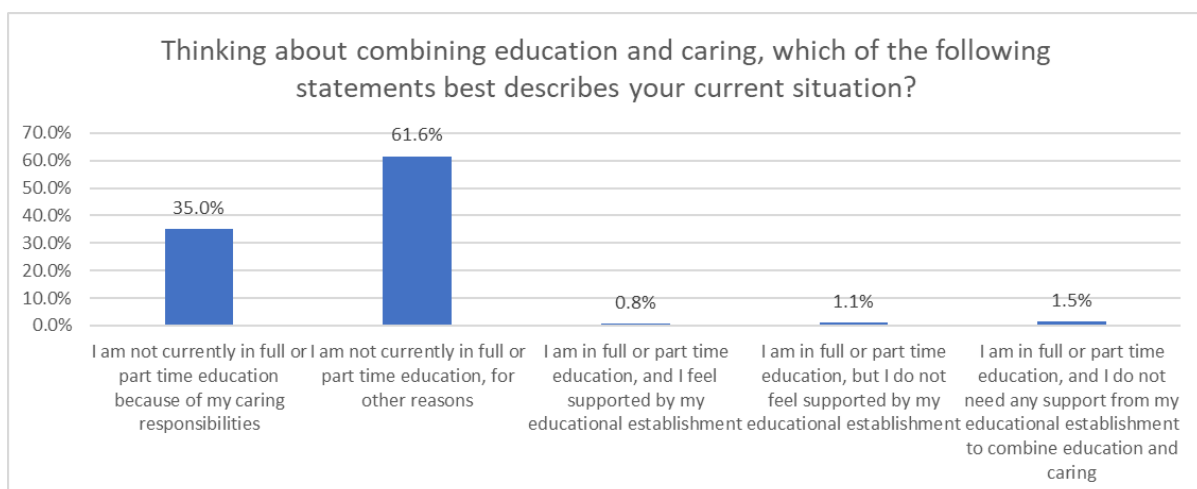


9 people did not provide a response to this question.

A tender exercise is being undertaken in 2022 for a new carers support contract.

Q20b. Thinking about combining education and caring, which of the following statements best describes your current situation?

Only 3.4% of carers responded to say that they were in full or part time education. The majority of carers responded to say that they were not in full time education (96.6%).



108 people did not provide a response to this question.

Questions about the Coronavirus pandemic

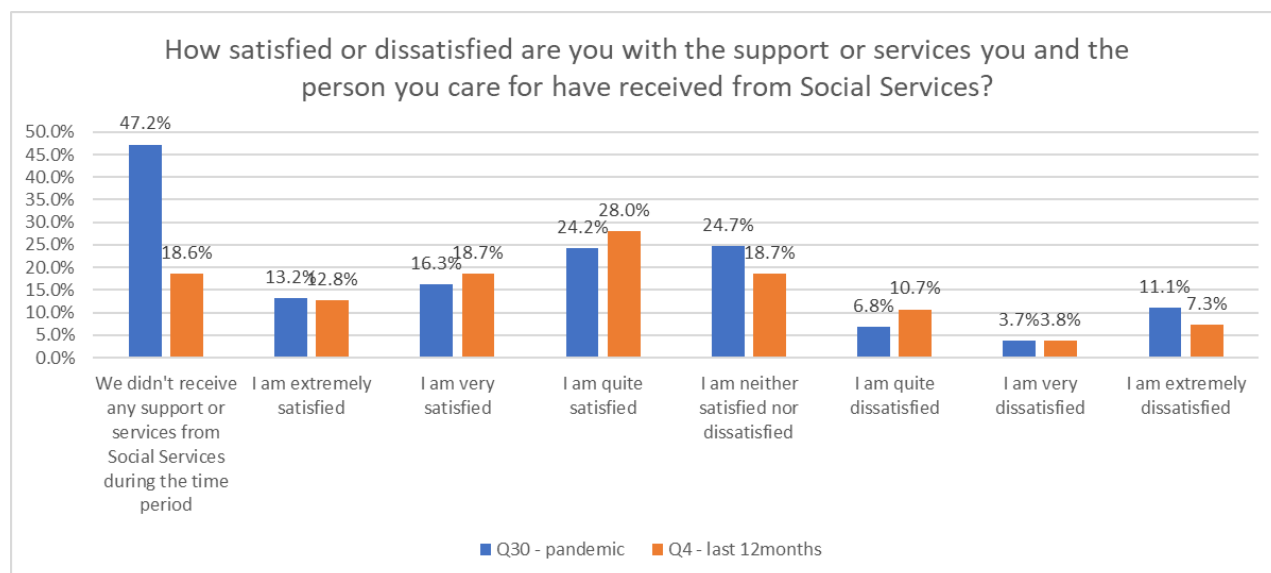
Four additional questions have been included in the survey this year to ask carers about their experiences during the coronavirus pandemic. These questions match with existing questions about experience over the last 12 months and so can be compared.

Q30. *Thinking about your experiences during the Coronavirus (COVID-19) pandemic, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services?*

Q4. *Overall, how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?*

47.2% of carers who responded reported that they didn't receive any support or services from social services during the pandemic, compared to 18.6% in the last 12 months. Its unclear whether this is because the carer did not request any support or services, or whether it was because they were not contacted and made an offer of support.

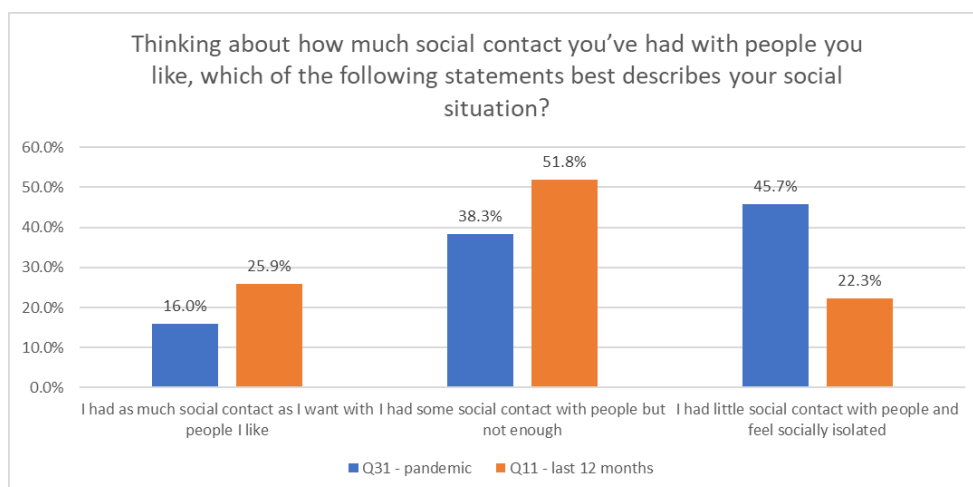
Of those who had received services during the period, satisfaction in the last 12 months was higher than in the pandemic period, 59.5% compared to 53.7%. Dissatisfaction levels during the two periods were very similar, 21.7% dissatisfied to some extent in the last 12 months compared to 21.6% during the pandemic period.



Q31. Thinking about how much social contact you've had with people you like during the Coronavirus (COVID-19) pandemic, which of the following statements best describes your social situation during this time?

Q11. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?

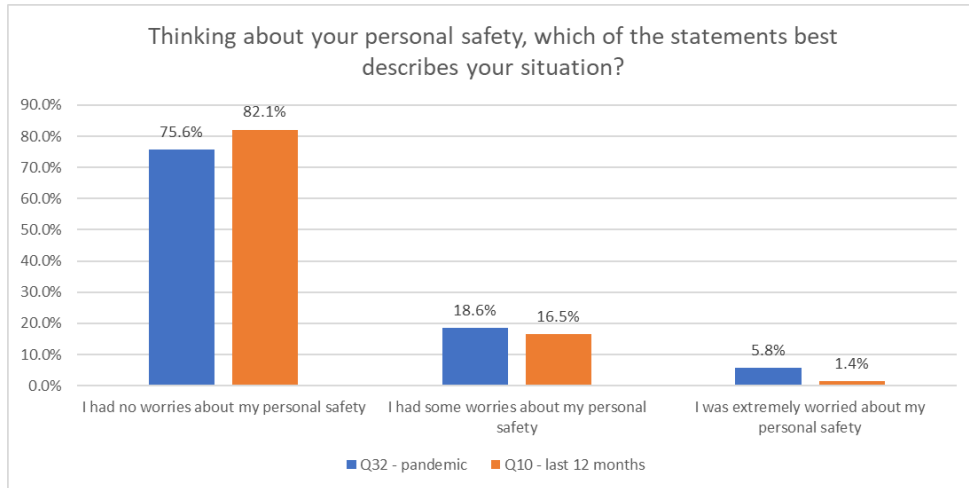
Fewer carers during the pandemic period had had as much social contact as they would like, 16% compared to 25.9% during the last 12 months. 45.7% of carers reported that they had little social contact and felt socially isolated during the pandemic. This reflects a national reported feeling of isolation during the pandemic period of the past two year.



Q32. Thinking about your personal safety during the Coronavirus (COVID-19) pandemic, which of the statements best describes how you felt during this time? By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.

Q10. Thinking about your personal safety, which of the statements best describes your present situation?

There was slightly more worry about personal safety during the pandemic with 24.4% having some or extreme worries about their personal safety compared to 17.9% in the last 12 months. Although the question asked respondents to think about their personal safety in terms of 'from fear of abuse, being attacked or other physical harm', it could be that some carers felt unsafe due to the risk of catching coronavirus and so responded as feeling unsafe.

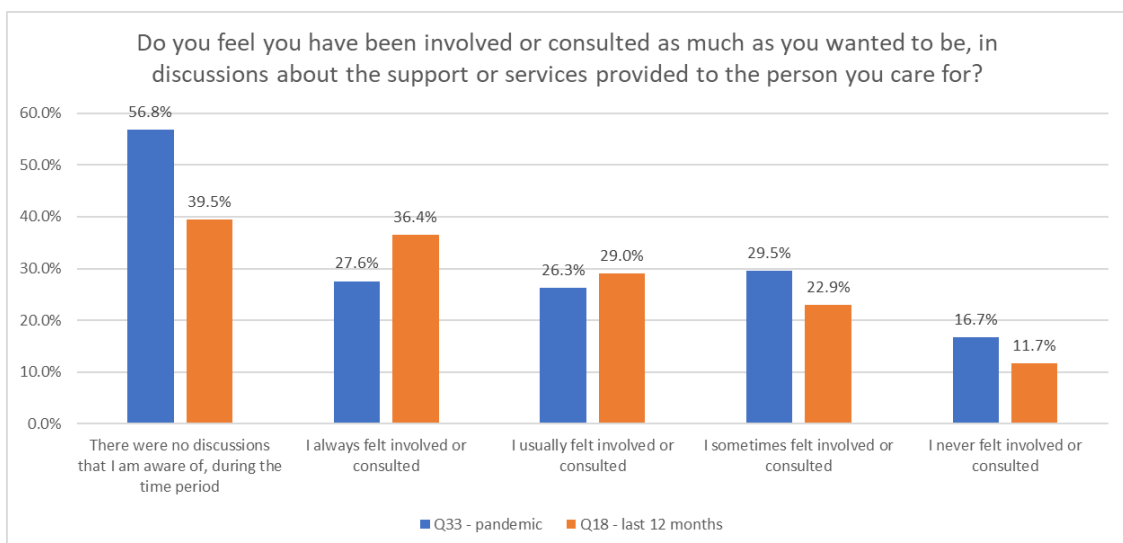


Q33. Thinking about your experiences during the Coronavirus (COVID-19) pandemic, did you feel you were involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Q18. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

56.8% of carers who responded reported that there were no discussions about the support or services providing to the person they care for during the pandemic, compared to 39.5% in the last 12 months. The question did not ask for clarification over whether this was due to no discussion being needed.

Of those who had been involved in discussions, more felt they had not been involved or consulted during the pandemic, 16.7% compared to 11.7% during the last 12 months.



Qualitative feedback

Feedback was requested from respondents in the form of written comments for four questions.

Q5a. Has the person you care for used any of the support or services listed below in the last 12 months? - If other, please tell us about it

Answers for Q5 were mainly factual giving details of other support or services that the cared for person had received or used. This included:

- Different types of equipment e.g. stairlift, raised arm chair, raised toilet seat,
- Health service professional visits
- Assisted living
- Search and Chain Reaction
- Independent care providing companies
- Maggie's Centre
- Ouseburn Farm
- Smile Through Sport

Overall, there were 328 comments made across Q16, Q17 and Q31 which covered a wide range of topics. More negative comments were made than positive ones, many people feeling they had not received enough support or that support they had received had been taken away. Comments of carers feeling 'physically and mentally exhausted' by extra responsibilities during the pandemic resulting from day services and respite not being available.

I accept all the help I am offered to provide care but day services and RESPITE are essential to keep people caring for people. By now I feel the day centres should be back to normal service. The extra care needed at home is taking its toll on most carers.

*Q16. In the last 12 months, have you found it **easy or difficult** to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services.*

Some comments made were about the type of support, services and benefits which had been researched, rather than answering how easy or difficult it had been to find information.

Of those that were made regarding how difficult finding information had been, many comments were about difficulty in contacting social workers and NCC:

Can't get through to social workers, don't know who is our current social worker. Very difficult to contact direct payments via telephone.

Difficulty finding correct charges for services from NCC - especially care - bills often wrong and many would miss this and overpay. Very hard to find out if I qualify as a carer.

I am 69 years old and have had difficulties understanding how to manage the cost of my mothers care. The Local Authority is contributing but I have asked questions which have been ignored or the staff don't know the answers. I keep getting legal forms to complete which I don't fully understand.

No continuity in social care direct. Spoke to a different person each time. Sometimes conflicting advice given, sometimes just rude and impatient.

There is no one stop share where someone can tell you clearly all you need to know when you need to know it. Financial assessments are not transparent and difficult to understand

Of those comments made about how easy finding information had been, many were about family and friends providing support:

If I need help, I have a very kind and helpful neighbour

My daughter and son have done this as I am deaf and cannot hear on the phone.

Carers of Newcastle helped me obtain info, tel nos, website etc they were fantastic

I have not tried to find information, as my husband's ex colleague comes every so often, stays a couple hours to chat with him, and let me go out to give me that break and meet friend for coffee or lunch.

*Q17. In the last 12 months, **how helpful** has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.*

The majority of comments made about how helpful the information and advice received has been have been positive, but again there were several comments saying that carers felt their questions had not been answered.

Advice when received was fine. The main issue was due to people working from home it was more difficult to connect with the right person. Messages were taken but had to be passed on, so things took longer to deal with.

I have to say what has happened isn't anybody's fault, but if it had been dealt with faster we wouldn't be where we are today.

Age UK information on care and support choices was very good. I tried to find information online but the question was specific to our situation so I phoned the Age UK helpline and spoke to someone who answered my question and followed up with an email. Prevention is always better than cure.

I receive a lot of information from St Oswalds Hospice. They can always point me in the right direction. The last SW I had was very helpful.

Newcastle carers have always been helpful over the years. Financial advice/information on any Care Act or assessment over the years.

The system is complex; I am assertive, have some awareness of social care and health systems, but even I struggle to access support or help which is necessary to ensure the person I care for is cared for. With the slant of all service to access via IT or websites the elderly are further disadvantaged and marginalised in particular as this is not part of their world. Without me the person I care for would perhaps not still be alive.

Q31. Please use the space provided below to describe any other experiences you would like to tell us about, or to write any other comments you would like to make

The majority of comments made for this question were negative covering topics of health, home care, information, NCC services and funding.

There was recognition within some comments of the difficulties of the pandemic and reduced budgets in providing support services.

Caring for my wife for such a long time is a way of life. It has its ups and downs but the general experience for me has been positive and enjoyable. A bit of back pain and tiredness which i can deal with. We work as a team everyday

My wife and I are very grateful for the help and support that the council pay for. We would not be able to have time together without it.

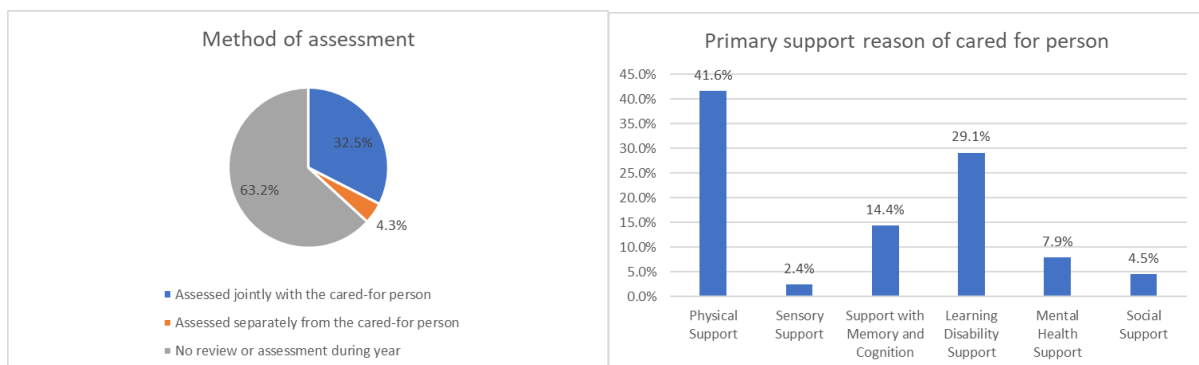
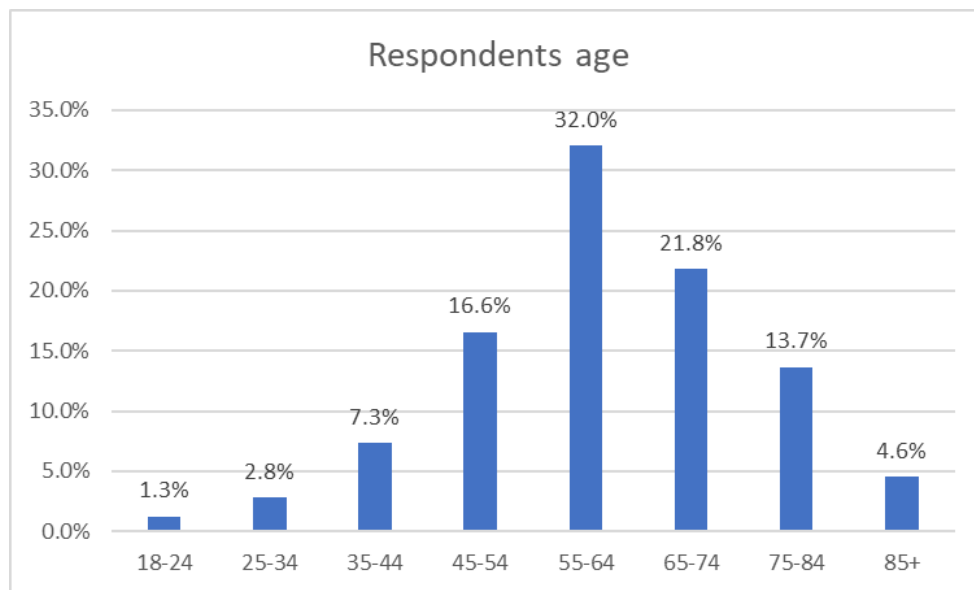
Overall I am very happy that this survey is being conducted. There are a lot of people out there that need more help. I would like to thanks everyone for the help that I receive.

Thank goodness for CVS services, Appreciate my 5 weeks involvement - Recognise S.C stretched and feel that services reflects the pressures. - Wishing more support for hidden disabilities

About the respondents

Most respondents:

- Were female (72.8%)
- Were from a white ethnic background (80%, 12.1% did not declare their ethnic group)
- Described their religious beliefs as Christian (70.3%)
- Were aged 55-64 (32%) or were aged 65 or older (40%)
- Had not had an assessment or review during the year (63.2%)
- Caring for someone with a primary support reason of Physical Support (41.6%)



Those who had not been reviewed or assessed during the year would not be able to access their next carers direct payment.

Action planning

Work so far...

Carers working group: Initial meeting 23/3/2022

- To consider the outcomes from the survey, putting narrative around why we have been perceived in this way
- Discussions have included:
 - o Communication issues
 - o Change to approach eg named social worker, carers direct payments
 - o Pressures on the system eg impact of covid, staff sickness and vacancies, market failure
 - o Backlog of reviews
 - o Changes to financial assessment
 - o Access to digital information

Review of direct payments

- Review carried out and change of process agreed and to be implemented which will mean that DP's to carers can be reissued without the need for a full review if there has been no change and the payment has been used appropriately

Telephone access and messages

- All staff now have access to the Avaya system and so can receive phone calls to their work number

Text local

- Use of the system to send general messages out to carers with information

Information leaflet

- Sent out via post to service users and carers giving information on services and how to get support

Work to be carried out...

Conversations with carers leads across the region

- To understand where other authorities have seen improvements if these have been due to a change in their offer

Contingency planning

- If we were to experience another 'lockdown' how would we respond knowing what we know now

Scoping exercise – complaints

- Understand how many complaints have been received from carers and what the issues have been

Appendix 1: Questions asked

1. How old is the person you care for? _____years
2. Does the person you care for have any of the following....?
 - Dementia
 - A physical disability
 - Sight or hearing loss
 - A mental health problem
 - Problems connected to aging
 - A learning disability or difficulty
 - Long-standing illness
 - Terminal illness
 - Alcohol or drug dependency
3. Where does the person you care for usually live?
4. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Newcastle City Council in the last 12 months?
5. Has the person you care for used any of the support or services listed below in the last 12 months?
They may be provided by different organisations, such as a voluntary organisation, a private agency or Newcastle City Council.

Section 2: About your needs and experiences of support

6. Have you used any of the support or services listed below, to help you as a carer over the last 12 months?
They may be provided by different organisations, such as a voluntary organisation, a private agency or Newcastle City Council. Please do not include any unpaid help from family and friends.
- 6b. Are you aware of the British Red Cross Carers' Emergency Card Scheme?
- 6c. Are you aware of Newcastle Carers?

Section 3: The impact of caring and your quality of life

7. Which of the following statements best describes how you spend your time?
When you are thinking about what you do with your time, please include anything you value or enjoy, including formal employment, voluntary or unpaid work, caring for others and leisure activities.
8. Which of the following statements best describes how much control you have over your daily life?
9. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your

present situation?

10. Thinking about your personal safety, which of the statements best describes your present situation?
By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.
11. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?
12. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?
13. Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation? Please exclude the person you spend most time helping.
14. In the last 12 months, has your health been affected by your caring role in any of the ways listed below?
15. In the last 12 months, has caring caused you any financial difficulties?

Section 4: Information and advice quality

16. In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Newcastle City Council.
17. In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Newcastle City Council.

If you would like to tell us more about this, please do so here. We would be especially interested in hearing about whether the information helped you understand:

- how the system operates,
- the care and support choices available to you and the person you care for, how to access support, and
- how to get access to independent financial advice.

Section 5: Arrangement of support and services in the last 12 months

18. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Section 6: About yourself

19. In addition to your caring role, please tell us which of the following also applies

to you? (employment status)

20. Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation?
- 20b. Thinking about combining education and caring, which of the following statements best describes your current situation?
21. About how long have you been looking after or helping the person you care for?
22. About how long do you spend each week looking after or helping the person you care for?
23. Over the last 12 months, what kinds of things did you usually do for the person you care for?
24. Do you have any of the following? (health conditions)
25. How many children aged 18 or under do you have parental responsibility for?
26. Did someone help you to complete this questionnaire?

Section 7: The Pandemic

27. Thinking about your experiences during the Coronavirus (COVID-19) pandemic, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services?
28. Thinking about how much social contact you had with people you like during the Coronavirus (COVID-19) pandemic, which of the following statements best describes your social situation during this time?
29. Thinking about your personal safety during the Coronavirus (COVID-19) pandemic, which of the statements best describes how you felt during this time?
By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm. We do not mean feeling safe from fear of contracting coronavirus.
30. Thinking about your experiences during the Coronavirus (COVID-19) pandemic, did you feel you were involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Section 8: Comments

Please use the space provided below to describe any other experiences you would like to tell us about, or to write any other comments you would like to make

32. We may be asking some people to take part in follow-up research for this study in the next year or so.
Would you be happy to be invited to take part in more research?

Appendix 2: Regional comparison – provisional data

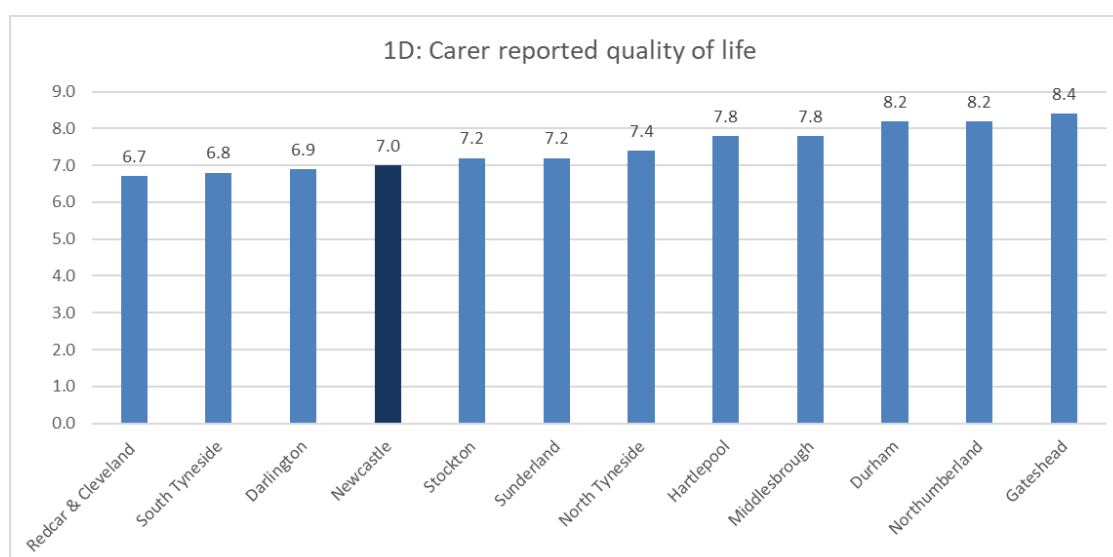
Provisional data from the survey has been shared within the 12 North East regional authorities under the agreement it is for performance management use only and should not be shared widely or published. National data will be published in October 2022.

The Survey of Adult Carers produces 5 of the ASCOF measures. Newcastle has experienced a decline in all 5 measures in 2021-22 compared to the previous survey. Three other North East authorities have also declined across all 5 measures and four authorities have declined on 4 out of 5 measures. Overall Newcastle is ranked 11th out of the 12 regional authorities.

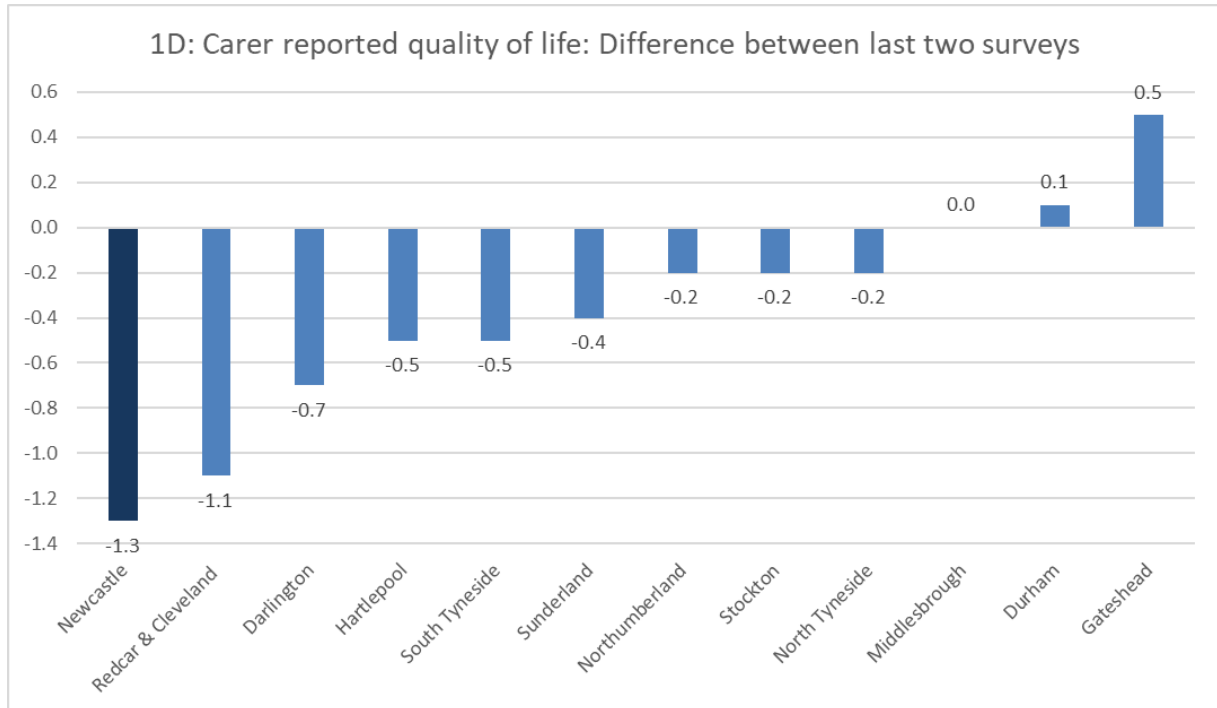
NE Regional Authority	Overall Rank Position
Hartlepool	1
Northumberland	2
Gateshead	3
Durham	4
Middlesbrough	5
South Tyneside	6
Stockton	6
Redcar & Cleveland	8
North Tyneside	9
Sunderland	10
Newcastle	11
Darlington	12

The graphs below show the position of Newcastle within the region for 2021-22 results and also the difference in the outcome between the two most recent surveys across the region.

1D: Carer reported quality of life 2021-22

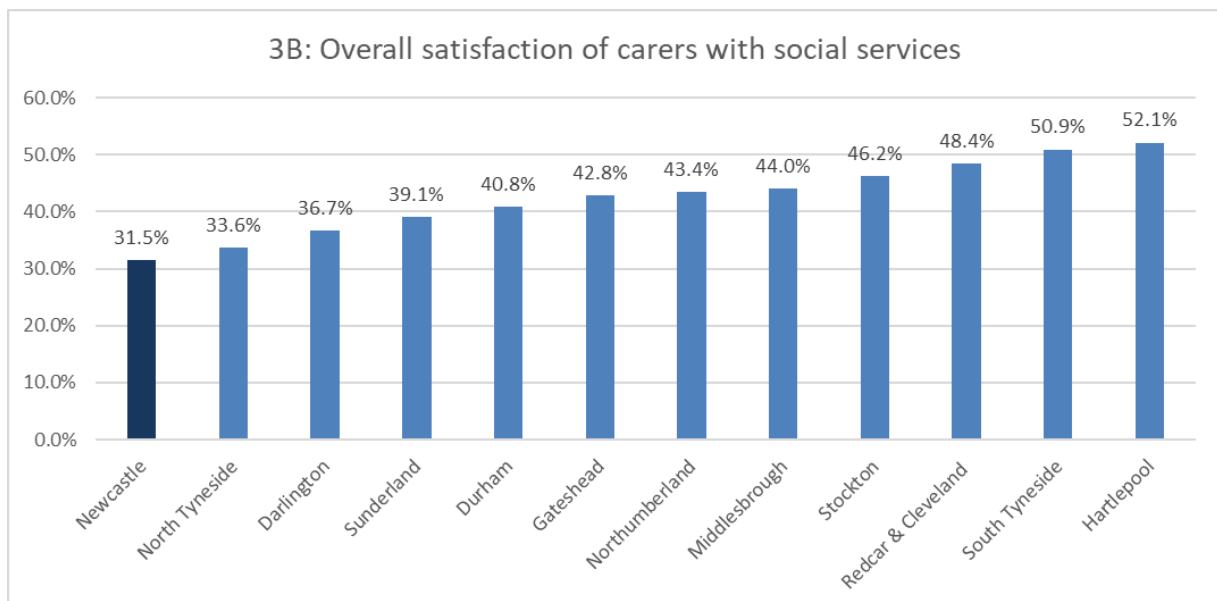


Newcastle: 7.0
 Rank position: 9th
 Regional average: 7.5
 Regional spread: 6.7 – 8.4



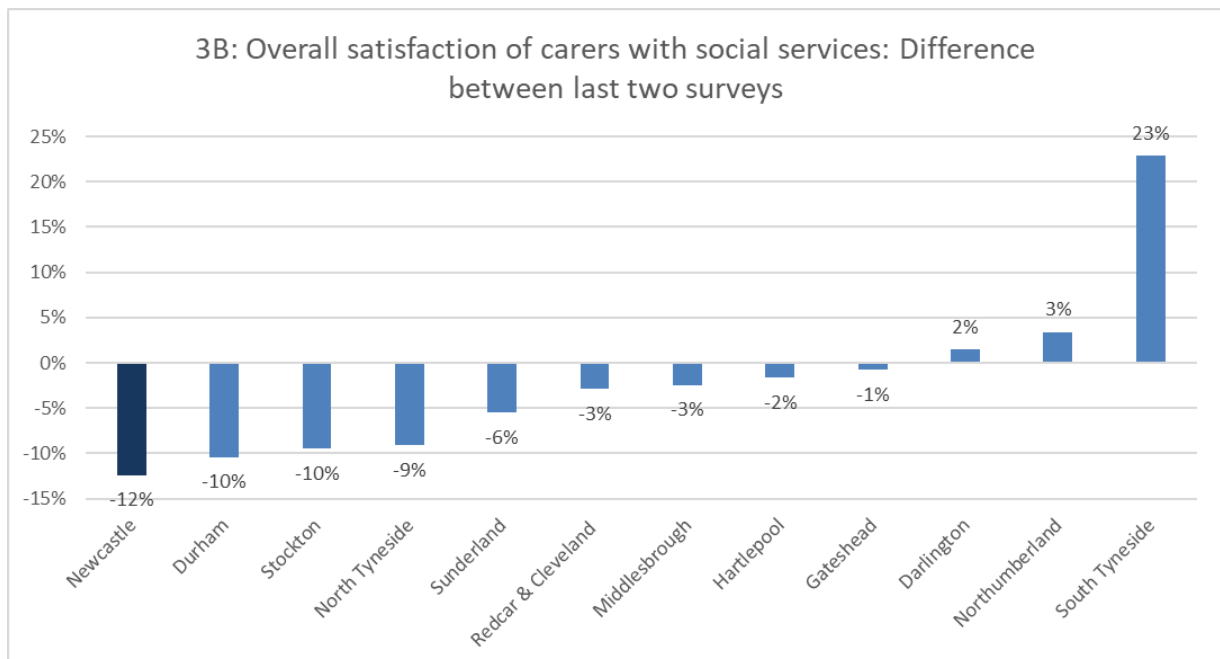
9 out of 12 authorities experienced a decline in this measure, Newcastle had the biggest decline.

3B: Overall satisfaction of carers with social services 2021-22



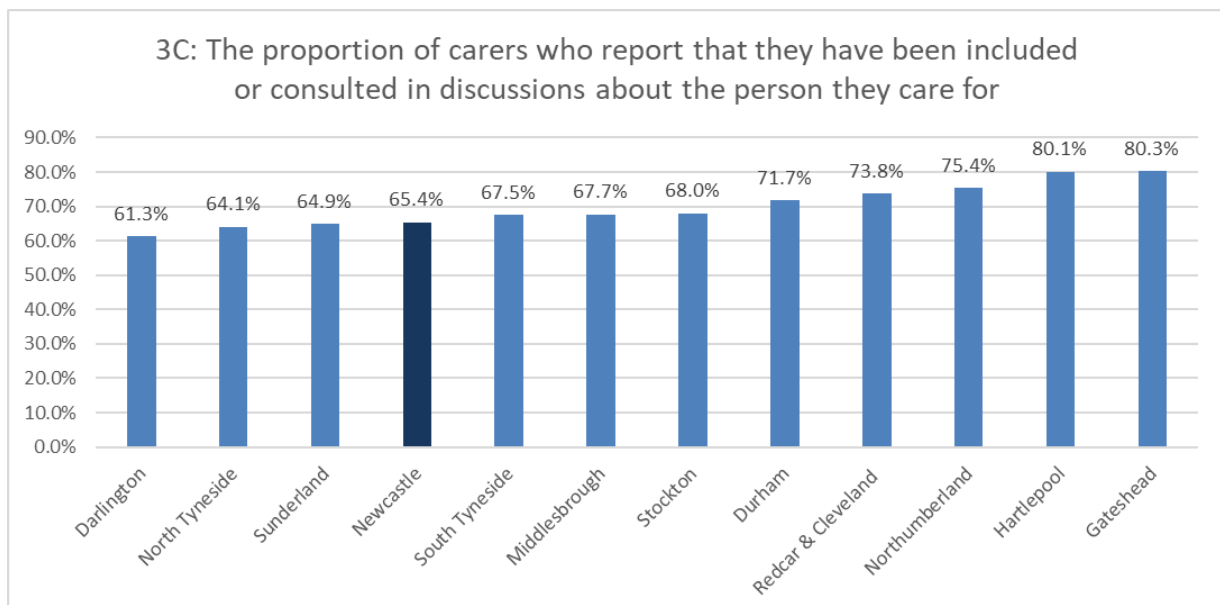
Newcastle: 31.5%

Rank position: 12th
 Regional average: 42.5%
 Regional spread: 31.5% – 52.1%

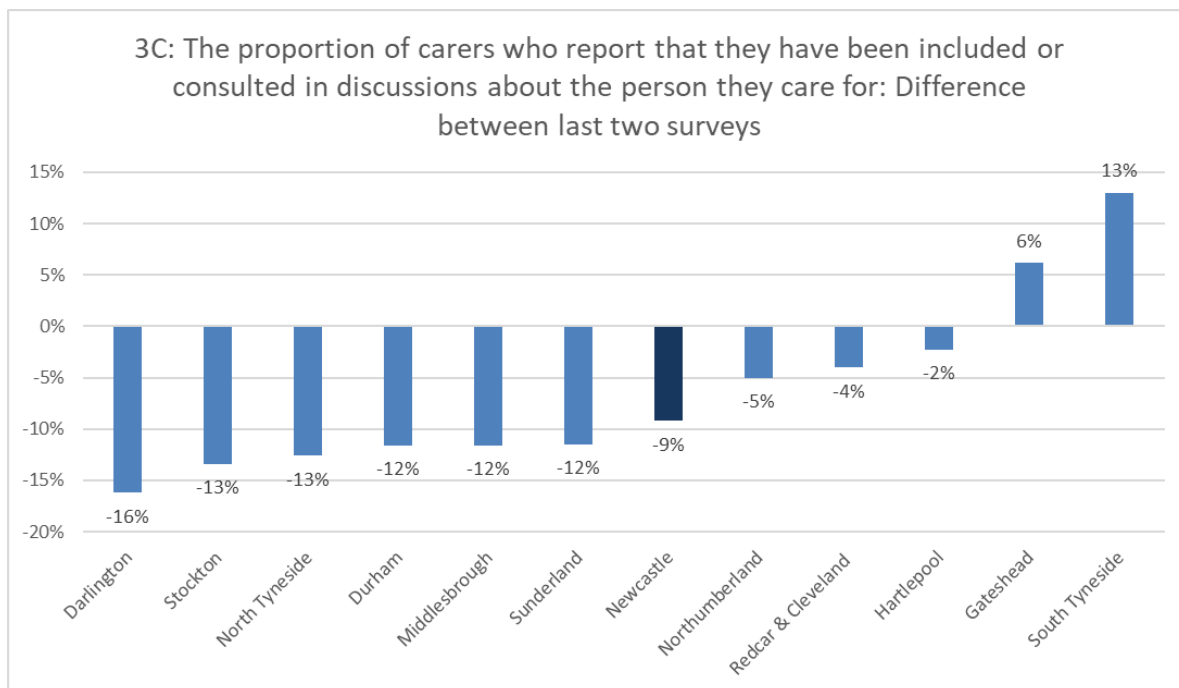


9 out of 12 authorities experienced a decline in this measure, Newcastle had the biggest decline.

3C: The proportion of carers who report that they have been included or consulted in discussions about the person they care for 2021-22

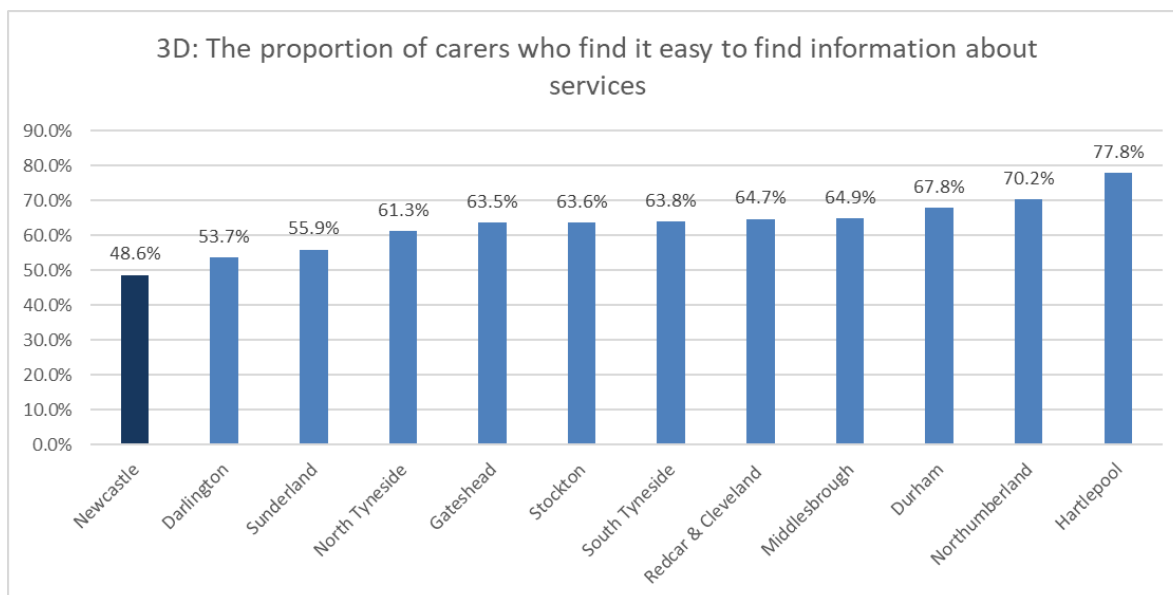


Newcastle: 65.4%
 Rank position: 9th
 Regional average: 70.0%
 Regional spread: 61.3% - 80.3%

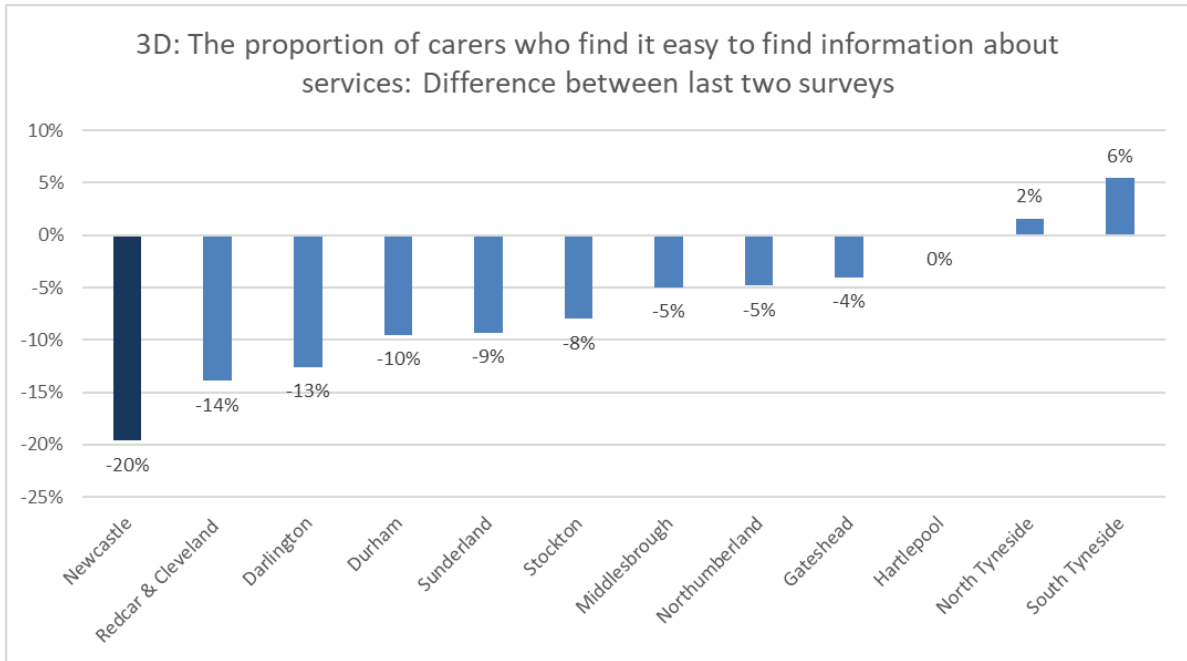


10 out of 12 authorities experienced a decline in this measure.

3D: The proportion of carers who find it easy to find information about services 2021-22

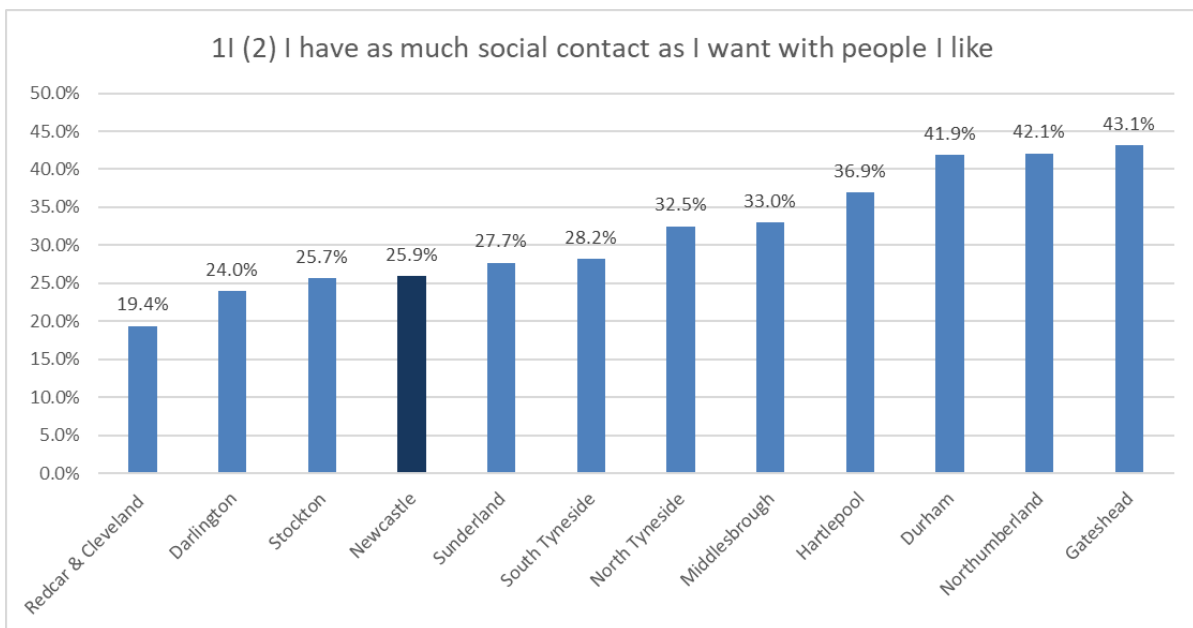


Newcastle: 48.6%
 Rank position: 12th
 Regional average: 63.0%
 Regional spread: 48.6% - 77.8%

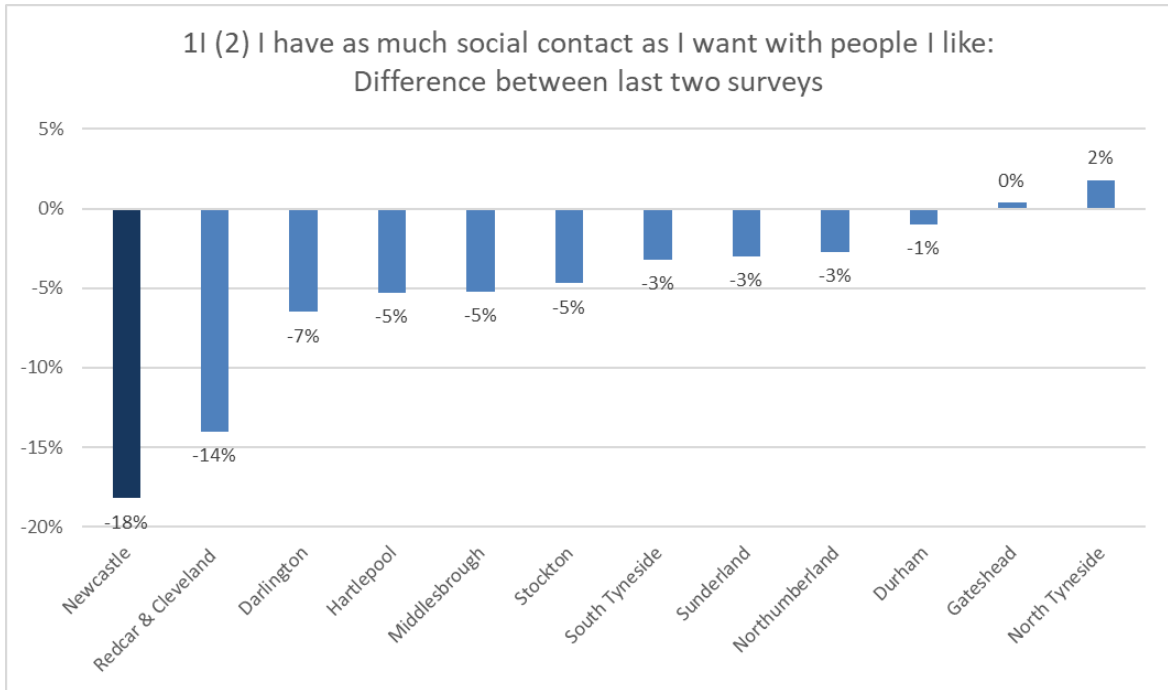


9 out of 12 authorities experienced a decline in this measure, Newcastle had the biggest decline.

11(2): I have as much social contact as I want with people I like 2021-22



Newcastle: 25.9%
 Rank position: 9th
 Regional average: 31.7%
 Regional spread: 19.4% - 43.1%



10 out of 12 authorities experienced a decline in this measure, Newcastle had the biggest decline.