

York Unpaid Carers Consultation Report

“Until you take on the role of carer you can not possibly fully comprehend the magnitude of caring and its impact on your life”

Contents

Background	2
What we did	2
Summary of key findings	3
Next steps	5
Survey responses	6
Our shared vision.....	7
Priorities and commitments.....	10
Equality monitoring information.....	32
Feedback from face-to-face conversations	33
A big thanks.....	36
Alternative formats.....	37

Background

City of York Council is working with carers and partner organisations in York to develop a new Carers Strategy.

A carer can be defined as, “anyone who cares, unpaid, for a friend or family member due to illness, disability, a mental health problem or an addiction”¹

The strategy will provide an overall direction for how we support unpaid carers, of all ages, who live in or care for someone living in York. It will set out our shared vision and describe the key priority areas and commitments we will focus on to achieve the vision.

To deliver the strategy, we will develop and implement an action plan in partnership with carers and people who can influence change. We will review our progress on an ongoing basis to make sure we are taking the right action to improve the lives of carers, and the people they support. We will continue to be guided by what carers tell us is and isn't working.

We identified the vision, priorities and commitments based on local carer feedback, local and national data, and strategy working group discussions. We undertook a consultation to check these reflect what is important for different carers and to find out if we had missed anything. We also wanted to hear what it is like to be a carer in York, and what needs to change, to inform the action plan.

What we did

The consultation included a survey and face-to-face conversations with carers.

Survey

We invited people to take part in a survey between 9 January and 16 March 2025.

To take part, people were given the option of completing an online, electronic or paper questionnaire, with help to access a computer or complete the survey over the phone if needed.

We provided an Easy Read version of the questionnaire and offered it in alternative formats or languages on request.

¹ www.carers.org/about-caring/about-caring

With the help of our colleagues and partners, we promoted the survey via:

- York Carers Centre – newsletter sent to approximately 4,800 carers, social media posts aimed at young adult carers (16-25), carer hubs, support groups and stalls.
- Speaking to carers at Carers Action Group, Carers Strategy Group, dementia support and Parent Carer Forum meetings.
- City of York Council’s website, internal and external newsletters, social media pages and a press release.
- Asking a wide range of stakeholders (including voluntary and community organisations and networks, care providers, health, social care and education contacts) to give their views and share the survey.
- Posters displayed in York Hospital, various community settings and four Explore libraries (with paper copies made available).

Face-to-face conversations

York Carers Centre spoke with young and young adult carers about the strategy, their experiences, and their views on improving support.

We also spoke with carers (and people they care for) at a support group for people living with or caring for someone with dementia.

This report summarises the outcome of the survey and conversations.

Summary of key findings

The survey responses show strong overall support for the direction being set for the strategy through the proposed vision, priorities and commitments.

Out of the six priorities we asked about, these came out as the four most important to people:

1. Improve support for carers (84%)
2. Improve the health and wellbeing of carers (77%)
3. Improve joint working across health, education and social care (68%)
4. Improve how we identify and recognise carers (52%)

Responses also highlight concerns over how we will achieve the strategy’s aims. Some feel the proposed improvements are needed but are practically difficult to implement.

The main concerns are limited funding and resources, and the level of support currently available. Added to this are views that unless services and support improve for people being cared for, too little will change for carers.

People's caring commitments and a lack of time or energy may also be barriers, with carers feeling unable to step away from their roles, focus on their own needs, or seek support.

There were calls for the strategy's commitments to be more realistic, specific and measurable, and for more clarity around how the strategy will be delivered.

Feedback highlights that many carers are struggling and indicates that many face disadvantage or inequality because of caring. Based on the responses, the most significant impact is on carers' health and wellbeing. Caring is also affecting carers' finances, opportunities, independence, ability to work and study, and various other aspects of their lives.

Many carers told us they are not getting the support they need, for various reasons, but largely due to a lack of available or appropriate support. There is a strong need for financial support and support for breaks and respite (when someone else provides care to give carers a temporary break).

Accessing support for themselves or people they care for can be difficult and confusing. The burden is increased when services do not work in a joined-up way. Joint working is viewed as essential for reducing carer stress (made worse by constantly having to repeat information) and improving efficiency and outcomes.

Responses highlight issues with identifying, recognising, listening to and valuing carers across health, education and social care. Identifying and recognising carers (including helping carers to self-identify) is seen as critical to carers getting the support they need.

Comments emphasise that carers play a vital and heavily relied on role, reducing pressure and making huge cost savings for health and social care. Yet despite this, carers often feel undervalued, overlooked and unsupported.

Common themes of what needs to improve

- **Being able to get the right support at the right time** – support needs to be more available, easier and quicker to access, with a range of appropriate options to meet the individual and changing needs of different carers.
- **Help for carers to understand what support is available** to them, their rights and entitlements, and how to get support.
- **Financial support** such as better benefits for carers and help to understand and access entitlements.

- **Carer breaks and respite** need to be more available and easier to access and arrange. This includes more affordable and appropriate respite care and offering a range of options to meet individual needs. Plus, more support (including financial) for carers to organise and take breaks.
- **Joint working** within and between services, including improved communication and information sharing, less complicated processes and systems, and less reliance on carers.
- **How we value and listen to carers**, acknowledging their contribution and knowledge of what they and the people they care for need. Staff and services need to improve how they work together with carers, involve carers in decision-making and act on what carers tell them.
- **Identification and recognition** of carers across health, social care and education, acknowledging and considering carers' roles, needs and situations, and ensuring appropriate support is available following identification.

Next steps

As a partnership, we will use this valuable feedback to refine the strategy's vision, priorities and commitments. When producing the action plan, we will consider people's experiences of current support, what people have told us needs to change, and their suggestions for how to make things better.

People want more detail on how the strategy will be delivered, including specific and measurable objectives and outcomes, and we are working on this. We understand how important this is to help carers understand the changes or benefits they can expect to see. It will also enable us to monitor our progress and be accountable and take action if we are not successful.

We will continue to involve local carers in finalising the strategy, producing the action plan and monitoring progress. We know it is especially difficult for carers to participate in this kind of activity and we hugely appreciate everyone who has contributed to this work.

We acknowledge that we need to do more to make it easier for carers to get involved. We also need to consider how we reach carers we are not hearing from, to understand what they need.

We will share the feedback with our colleagues and partners, including York Carers Centre and other organisations supporting carers.

Survey responses

222 people responded to the survey. There were no mandatory questions and not all respondents answered every question.

Most responses came from carers or former carers (198 people or 89% of responses). The other responses came from:

- 4 people being cared for by unpaid carers
- 4 family members or friends of unpaid carers
- 14 people who work or volunteer (directly or indirectly) with unpaid carers

195 people confirmed the type of carer that best describes them, as shown in the table below.

Percentages have been rounded to the nearest whole number.

Which of the following best describe the type of carer you are?	% of people that responded (highest to lowest)	Number of people
Adult carer - an adult caring for another adult	59%	115
Parent / Family carer - a guardian providing care for a child	29%	56
Working carer	22%	43
Carer who is caring for more than one person	19%	38
Young adult carer - aged 18-25 caring for another adult or child	9%	17
Former carer - no longer in caring role	5%	9
Young carer - aged 5-17 caring for a family member	3%	6
Interdependent carer - a carer who is also being cared for	2%	3
Kinship carer - caring for a child whose parents are unable to	1%	1

Our shared vision

Our shared vision describes what we want the strategy to achieve for carers in York. We asked people questions about the vision below and invited comments.

In York, we work together to identify carers early and connect them to flexible, consistent support. Our support:

- recognises the diverse and unique needs of carers
- prioritises carers' health and wellbeing
- enables carers to be independent and keep their own identity
- helps carers find a balance between caring and achieving their goals
- makes carers feel valued, heard, and included

Is this vision clear and easy to understand?

91% (172 people) felt the vision was clear and easy to understand. Most people found it to be concise and written in clear and simple language.

Several people felt it was too wordy, repetitive or vague, or that it was lacking in meaning, or only meaningful if carers could get help when they need it.

If we achieve this vision, do you believe it will improve the lives of carers in York?

72% (136 people) felt that if we achieved the vision, it would improve the lives of carers in York.

Most people were supportive of the aims and scope of the vision. Multiple comments confirm that the vision includes the support carers need and recognises and values carers.

Key comments from carers in favour of the vision:

“It ticks the points that are important to carers.”

“Gives a good overview of the vast needs of carers.”

“Carers need respite from caring and support to achieve their goals - this is clearly articulated by the vision.”

“It is carer centred and helps carers value themselves.”

Some people expressed that the vision does not reflect the current reality for carers in York. They spoke of not being supported, receiving minimal support, or not being listened to or valued. A few people mentioned positive experiences of receiving support.

“I'm not sure how the Council's support makes carers feel valued, heard and included. Would this be something new because at the moment I don't think there's any support from the Council for me as a carer?”

“The “support” has not changed my life very much: invites to take part in things that mean I need to find MORE time in my day. Impossible. I am disabled with zero benefits, am an unpaid carer, already have 50-80 hrs a week of obligations. PAY ME, don't suck up more of my time.”

“In order to care for someone else, we must take care of ourselves first. York Carers help me to do this.”

Some people expressed doubt or disbelief that the vision can be achieved or make a difference to the lives of carers. They referred to:

- Limited funding, resources and financial support, and the time and commitment needed.
- The level of improvement needed across health and social care for the cared for and carers.
- A lack of available support or information when it is needed.
- Carers' commitments or obligations; a lack of opportunity to step away from caring roles.

“The vision is great but unachievable without vast improvements to the health and social welfare sector - carers (often juggling their own family life, work or education) cannot simply make time for themselves without someone else to take their place and demand currently vastly outstrips supply.”

“Will someone pay for me to get a massage? Take care of my child for me? Help with daily chores? I doubt it. Then it won't improve my life.”

“I just don't believe you will achieve it - words are easy, actually getting the right support at the right time is virtually impossible.”

There were calls for more detail on how we will deliver the vision. People stressed the need for clear actions and ‘SMART’ objectives and outcomes (the changes or benefits we hope to see). SMART objectives are specific, measurable, achievable, realistic and timebound.

“As long as the 'idea' is backed up by taking actual actions so that carers are able to have proper support on a regular basis not just when a situation reaches crisis point.”

Other things to consider for the vision

We asked people to tell us about other things we should consider for the vision. 76 people responded and some key themes emerged:

- **Being able to access the right support at the right time:** Carers need quicker, easier and earlier access to information and support. Support needs to recognise, and be more flexible to respond to, individual needs and circumstances.
- **Breaks and respite:** Carers need better access, or more support to access, breaks and respite care.
- **Financial support:** Carers need more financial support and advice about what financial entitlements are available.
- **Linking the needs of the carer and the cared for:** Issues for carers are often due to a lack of appropriate care and support for the person being cared for; improvements in provision would make the biggest difference to some carers.
- **Identifying and recognising carers:** Carers need to be recognised, listened to and valued. We need to help carers to recognise themselves as carers and find ways to reach carers (some may be hidden or overlooked).

“My own health has suffered from 24/7 care. Overweight, depression, high blood pressure and cholesterol problems from difficulty in care role. Need more time out but private care costs are very high.”

“Most people feel that they are on their own. I have engaged with school, doctors, police, social services and the job centre about my daughter and no one has ever mentioned that there is support as a carer.”

“The biggest part of my stress is the financial burden, I can’t work so struggle. Universal credit is classed as earnings for council tax so we now have to pay council tax too, it’s ridiculous, carers are broken!”

Priorities and commitments

We asked people whether they thought it was important to focus on the identified priorities and commitments. Nearly everyone responded positively, with 85% being the lowest level of agreement.

Of the six priorities, improving support for carers, and improving the health and wellbeing of carers came out on top with agreement from 99% of respondents.

The table below shows the percentage of people who agreed with focusing on each priority.

Do you think it is important to focus on this priority?	Yes	No	Don't know or no opinion	Number of responses
Improve support for carers	99%	0%	1%	167
Improve the health and wellbeing of carers	99%	1%	1%	151
Improve joint working across health, education and social care	97%	0%	3%	137
Improve how we identify and recognise carers	94%	3%	3%	155
Reduce carer inequality	90%	1%	9%	139
Maximise the voice of carers	89%	2%	9%	144

We invited people to explain their answers. Nearly all of the comments validate the need to focus on the proposed priorities and commitments.

We have included detailed summaries of what people told us on the following pages. The priorities are not numbered in order of importance.

Priority 1: Improve support for carers

The table below shows the percentage of people who agreed with the proposed commitments linked to this priority.

Do you think it is important to focus on this commitment?	Yes	No	Don't know or no opinion	Number of responses
Enable carers to make informed choices about available support at different stages in their caring role	94%	2%	4%	167
Ensure a range of support options are available in York, at the right time, including assessments and carer breaks	95%	1%	5%	166
Improve access to information and advice	90%	3%	7%	162

What people told us (key themes)

- **A lack of support or options:** The most common theme is people experiencing a lack of support or finding it difficult to access. Support (including information and advice) needs to be more available, timely and accessible and more reliable and flexible. Comments highlight that carers need a range of options to meet individual and changing needs. There is a strong need for more support to take breaks – see combined feedback under [What people told us about breaks and respite](#).
- **Understanding options and getting support:** Another common theme is carers not knowing or understanding what support they are entitled to, what is available or how to get it. Carers need to be kept informed and have more help to understand support options, processes and services. Some carers said:
 - Information can be hard to find, confusing or unclear.
 - The process of getting support or navigating different services and systems can be difficult, confusing and time consuming. A couple of carers mentioned challenges with filling in forms, with one person saying the “benefit application can be tortuous and intimidating”.

- Feeling overwhelmed or not having the time or energy can stop them from being able to look into options or get support.
- **How to improve access to support and information:** Suggestions included support outside of working hours and in emergency situations; options for people who struggle with IT; having a person to talk to; and receiving text messages with updates. A few carers felt having information or advice in one place would be useful. Examples included a roadmap, a detailed guide or a 'one-stop shop'.
- **Health and wellbeing:** Caring is affecting many carers' health and wellbeing. See combined feedback under [Priority 3: Improve the health and wellbeing of carers](#).
- **Reliance on carers:** Carers play a vital role, reducing pressure on an already stretched health and social care system, making huge cost savings.
- **Care Act assessments and reviews:**

Care Act assessments are carried out to decide if an individual has care and support needs, or if a carer has support needs. If a person has eligible needs, a care and support plan or a support plan (for carers) is produced.

Some carers spoke about difficulties or delays in getting a carer's assessment, a review of their support plans, or getting social care support or assessments for people they care for. Comments emphasise the importance of timely assessments, regular reviews, and having support in place following these.

A couple of people reported that assessments or support for carers is not available unless the cared for person has a social worker. One person felt that carers should have a right to an assessment in the area where the person who needs care resides.

Comments suggest that carers generally find assessments and reviews helpful and without these they may not get the support they need.

However, the right support needs to be available for this to make a difference. One person reported that their carer's assessment did not change anything for them due to the limited range of support offered.

Concerns raised about this priority and other things to consider:

- Be mindful of language that could "pile on the emotional pressure" and make carers feel they must carry on caring because they are relied on. Carers also need support to stop caring if it is better for the carer or the person being cared for.

- Improvement in this area may not be helpful depending on a carer's circumstances, the type of support being offered, or if they are able to take up the offer of support, a break, or information and advice.
- Not having enough funding or resources to provide the support.
- One person said of the commitment to enabling carers to make informed choices, "If the support is not available, and it often isn't, it seems a wasted exercise".
- Some carers feel there is already enough information available, they can access the information they need, or they feel support, advice or a break is more important to focus on.

Key comments

“There is a lot of information and advice, sometimes we are overwhelmed with it all, but there's often not good timely access to the right information or advice at the right time in the right way.”

“Understanding our options, what is available and when is absolutely vital to us providing the right level of help and feeling supported ourselves.”

“At present there can be a long gap (months) between requesting help or advice, and actually receiving it.”

“Carer stress is on the rise, access to the right support is getting harder, the cost of living is increasing, it is hard to work and care, employers are not flexible enough to support carers - basically, it is a constant struggle to survive and we need more help, support and understanding.”

“We don't need more information and advice we want a break.”

“It's so hard keeping someone alive and being so isolated. I struggle too but feel like no one cares. Constantly get referred elsewhere coz too complex.”

“Carers need practical support - I work full time, being given web sites of hundreds of independent carers to go through, most of whom didn't reply was time consuming and fruitless.”

“There is very little support out there. If you are a carer for your child it is virtually impossible to get a carers assessment.”

“Without a carers assessment I wouldn't have got the advice needed to help my son to claim benefits, as the system is so complex.”

Priority 2: Improve how we identify and recognise carers

The table below shows the percentage of people who agreed with the proposed commitments linked to this priority.

Do you think it is important to focus on this commitment?	Yes	No	Don't know or no opinion	Number of responses
Support carers in all communities in York to recognise themselves as carers	85%	3%	12%	156
Raise awareness of young and young adult carers in education so educators and young people recognise they are carers	94%	1%	5%	156
Improve how we identify carers in health, care, employment, education, and wider community settings	92%	1%	6%	157

What people told us (key themes)

- **Carers not recognising themselves as carers:** Carers may not realise, or take a long time to realise, what they are doing is caring. For some, caring is done out of love, or a sense of duty and they may see caring as a normal or expected part of family relationships or life. Parent carers (or other people) may not see their caring role as different from normal parental responsibilities. Young and young adult carers may be less likely to recognise themselves or be recognised by others as carers.
- **Carers not being identified and supported in education:** More needs to be done to identify and recognise young and young adult carers in education, understand their challenges and support them. There were reports of poor recognition and support, including schools not considering difficulties at home, or only being concerned or offering support if it affects results or behaviour.

“Carers are rarely recognised in education. They are just considered as normal students who should get on with school work. Teachers should have to have a lesson on carers and learn how to properly support them instead of letting them struggle.” (Young adult carer)

- **Carers not being identified and supported by health and social care:** Some people said that carers are not being recognised or identified by health and social care. This has resulted in carers missing out on support or not feeling valued. There were reports of staff being aware of people's caring roles and not considering their needs or providing support.
- **Benefits of identification and recognition:** This can help carers get support early or when they need it, know their rights, and access benefits and entitlements. It can reduce the impact of caring on various aspects of carers' lives and futures such as health and wellbeing, work and study. It can also make carers feel more valued and that their personal circumstances are considered. Being offered support or flexibility at work would help some carers who are struggling to work and care.

Concerns raised about this priority and other things to consider:

- There is a lack of support available once people recognise themselves or are identified as carers. Identifying carers without offering or providing support is unhelpful.
- Carers may not want to be identified or defined as carers for reasons such as concerns over being labelled, stigmatised or discriminated against, protecting privacy and it being a personal choice.
- Carers already being aware that they are carers and of their rights.
- People wrongly identifying as carers and making inappropriate claims to entitlements or being referred inappropriately by professionals.
- One person raised that it is difficult if the carer lives in a different area from the person being cared for and felt councils should work together more to improve support for carers in this situation.

Key comments

“Many parents, myself included, struggle or have struggled, to see themselves as carers. They think they have failed in some way and it's just part of being a parent.”

“Most people know they are carers. It is getting help for those roles that is difficult.”

“All carers should be identified. This would make balancing life so much easier.”

“It's important how we help carers identify as carers, as being a carer isn't something you want to sign up to, the label is more than just a tiny word - the meaning can be life changing and there can be resistance to that, I was resistant to it. It's important how awareness is raised and how professionals encourage carers to identify and seek support from local services. Sensitivity, empathy, compassion, patience and understanding is key.”

“Yes but it doesn't happen until a crisis happens and then they come to attention of social services. Also no good identifying them then ignoring them for years.”

“I have been a carer... for nearly 15 years. The council know this but the only time I received any support was when we had a named social worker. Since then support has all but evaporated.”

“For carers that are in school or university they may find it hard getting work in on time as they are a carer but people may not know so it gives us that extra stress so we need to be identified.”

“Especially important for educators to be alert to their responsibilities. There have been numerous carers strategies in the past...but too little has changed.”

“Because it is impossible to work when you're having meetings with school, needing to leave to pick your child up, taking them to appointments, trying to help them through self harm and overdoses and then be threatened to have your benefits cut.”

Priority 3: Improve the health and wellbeing of carers

The table below shows the percentage of people who agreed with the proposed commitments linked to this priority.

Do you think it is important to focus on this commitment?	Yes	No	Don't know or no opinion	Number of responses
Support carers to have a good quality of life outside / alongside caring	93%	1%	5%	149
Improve opportunities for carer breaks	89%	0%	11%	148
Reduce health inequalities and improve access to healthcare including mental health support	92%	1%	7%	145
Reduce isolation and loneliness	94%	0%	5%	145

What people told us (key themes)

- **The impact of caring on health and wellbeing:**
 - Many carers have had issues with their physical and mental health and wellbeing because of caring, such as exhaustion, stress, burnout, loneliness and isolation. Two people who work in roles supporting carers said they regularly hear from carers who are suicidal.
 - Financial problems due to caring can lead to stress and other issues. More financial support is needed, and this is critical to supporting health and wellbeing.
 - Caring can affect people's relationships and restrict carers from being able to have contact with others.
 - Caring and its impact on health and wellbeing can prevent people from working or being able to perform well at work.
- **Breaks and respite:** See [What people told us about breaks and respite](#).
- **A lack of available support:** Some carers shared that they have not been supported or there is not enough support available, there are delays and long waiting lists (particularly for mental health support) and getting health appointments can be difficult. Support is sometimes only available at crisis point.

- **Arranging and attending health appointments:** This can be a struggle for carers who do not have time or need to fit appointments around caring commitments, have no alternative care options or are not able to leave the person they care for. There is not enough flexibility offered.

A couple of people suggested priority access for carers and one person raised that, “parents with limited capacity (due to a condition or caring role) may not be able to consistently bang on the doors to access the healthcare their children need”.

- **Focus on the person being cared for:** Carers often ‘sacrifice’ or do not have the time or energy to consider their own needs or seek support, which can impact the carer, people who are cared for, and families.
- **Being able to continue caring:** Supporting carers’ health and wellbeing would help carers to continue caring and be more able to give effective care, benefitting the cared for, the health and social care system and society. People emphasised how much the health and social care system depends on unpaid carers, and how significant the impact and cost would be if they were no longer able to care or ended up unwell themselves.
- **Support to meet different needs:** Comments suggest there is a need for a range of timely and flexible options to support health and wellbeing, with consideration for carers’ individual needs and situations.

Concerns raised about this priority and other things to consider:

- May be difficult or impossible to achieve.
- Improvements to health and wellbeing and access to healthcare are required for everyone, not just carers, and services are already stretched. One person said, “all services are under pressure and the more groups we prioritise the longer the queue becomes overall.”
- Not everyone would want this kind of support, or it is for the carer to decide.
- More clarity is needed about what we mean when we refer to improving opportunities for carer breaks and supporting carers to have a good quality of life outside or alongside caring. We need to be more specific and make the commitments measurable.

Key comments

“It is very easy to lose your connections and sense of worth when you are heavily focused on someone else's needs.”

“I was given a list of mental health websites but they are almost impossible to access. It would be so helpful if I could sit, on a one to one basis, with someone who could listen to my concerns. The waiting list for this kind of help is, I believe, 2 years.”

“I need health services to have greater flexibility with appointments to reflect my caring role.”

“Because we carers can end up sacrificing ourselves for the people we care for. The person being cared for can be fine, well looked-after, but the carer can be broken, incredibly stressed, get health problems and mental health problems, not able to function well in everyday life.”

“Carers are a hidden army caring for loved ones, if we don't support carers, their health will deteriorate and the NHS will be flat on its back not just on its knees with the pressure.”

“My health, physical and mental is often affected by caring. I'm then not able to provide the right standard of care. This creates more problems.”

“If I am unwell or not coping there's no one to look after my dad or my daughter.”

“If right provisions were in place for people they care for without having to go to war to get it life wouldn't be this living hell it currently is.”

“I feel burnt out, undervalued and just a resource to save councils money. A lot of the things on offer through care newsletter fall on weekdays and if you are a carer that works, you are unable to attend.”

“At present nobody cares about myself as a carer. I am isolated and rarely see anybody outside the home I am unable to participate in activities due to lack of funding to enable me to have a break from my caring role.”

Priority 4: Maximise the voice of carers

The table below shows the percentage of people who agreed with the proposed commitments linked to this priority.

Do you think it is important to focus on this commitment?	Yes	No	Don't know or no opinion	Number of responses
Listen to carers and involve them in decisions that affect them or the cared for person, valuing their expertise	97%	0%	3%	144
Involve carers in the planning and development of services	93%	1%	6%	142
Reach seldom heard groups to understand their challenges. By this we mean carers who are less likely to be heard by services and are underrepresented.	91%	0%	9%	144

What people told us (key themes)

- **Lived experience:** Carers have firsthand experience and knowledge of caring and therefore have the best understanding of their caring roles and needs. They also have in-depth, expert knowledge of the needs of the person being cared for. This lived experience means they can give insight into what does and doesn't work, what is missing and how to improve things.
- **Being included in decision-making:** Carers should have a say in decisions that affect them and the support that is available to them, and decisions about the cared for person's care (which can also affect the carer). Understanding what individual carers need and taking the views of carers into account can make services and support more effective.
- **Being involved or listened to:** Some carers shared experiences of not being acknowledged or listened to by health and social care professionals, and not being involved in decisions. Being listened to contributes to carers feeling valued, recognised and respected. A few carers talked of positive experiences: participating in a group run by York Carers Centre, being listened to by the frailty team in Acomb, and participating in co-design workshops for new mental health hubs.

- **Making sure more carers are heard:** It is important for carers to be heard to know what different carers need and to make sure they are not overlooked. Some carers may be less likely to be heard. People specifically referred to: young and older carers, parent carers, LGBTQ carers, kinship carers and carers of adults with care and support needs. And barriers such as culture and language, not being able to access groups, services or IT, or not having the confidence to speak up.

Concerns raised about this priority and other things to consider:

- Involvement may not be worthwhile or meaningful or may not result in any positive change; listening needs to result in action.
- Every carer is different so cannot be represented as groups.
- Carers have limited time and may not have the opportunity, confidence, energy or desire, to share their views. Therefore, it is important to consider how we reach people and how to make it easy for people to get involved.
- One person said, “Without concrete definitions of 'listen to', 'involve' and 'value', and examples, it's not clear what this means to me in real life as an unpaid carer.”
- It may be more helpful to focus on more practical support.

Key comments

“When I have expressed how much I am struggling with my carers responsibilities and balancing my needs against my parents needs I have rarely had any response. Health professionals are focused on the person receiving care NOT the person giving care.”

“Decisions are made about my adult sons with no involvement with me but I am still expected to support them. Social workers hold meetings, make decisions and then tell me what has been decided and what I need to do.”

“But only if worthwhile carers taking part. Been involved in too many tick boxing exercises over the years, don't have time & energy for that.”

“I have recently been recognised for my lived experience. I was invited to participate in the co-design workshops for the new mental health hubs. This experience was wonderful. I really felt valued as a carer, with my own mental health journey, being positively acknowledged too.”

“We have some brilliant ideas that could make a real positive impact for ourselves and the persons we care for. To be part of the planning and development is critical in getting the correct support in place.”

“Vital as often even the professionals who do help such as OT’s, doctors etc can only give you text book answers and support which often aren’t practical in real life application and carers who do the work daily can better inform them and a collaboration of professional expertise and hands on knowledge will result in better care.”

“It is always a good idea to actively listen to the people on the front line of caring rather than people who 'think they know what carers want or need' but have no direct experience of how difficult it can be to get advice or assistance or just manage on a day to day basis.”

“The carer often knows the person the best, and can give a valuable insight. They are also the person who will have to pick up the pieces when they are not listened to and medical professionals etc get it wrong.”

“At the moment it depends very much on personal qualities of involved professionals and assertiveness and confidence of carers. It shouldn’t be like this. Carers have unique knowledge about their cared for person. This knowledge should be valued and recognised.”

Priority 5: Reduce carer inequality

The table below shows the percentage of people who agreed with the proposed commitments linked to this priority.

Do you think it is important to focus on this commitment?	Yes	No	Don't know or no opinion	Number of responses
Address financial hardship from caring and the impact of the cost-of-living crisis	94%	0%	6%	140
Support carers to access and remain in employment and education	90%	3%	7%	139
Support carers to access healthcare services	93%	1%	6%	138

What people told us (key themes)

- **Carer inequality and disadvantage:** Comments indicate that many carers face disadvantage or inequality because of caring, mainly in relation to the impact it has on their finances and health and their ability to work or study. Some carers may be at a disadvantage compared to other carers, particularly in relation to being recognised as a carer or being able to access support. Carers mentioned factors such as: where they live, the type of carer they are, their needs or the needs or condition of the person they care for.
- **Health and wellbeing and accessing health services:** See [Priority 3: Improve the health and wellbeing of carers](#)
- **The impact of caring on employment:** Carers have had to give up work, work fewer hours, have missed out on work opportunities or are limited in the work they can do because of their caring responsibilities. Caring can affect people's ability to get higher paid jobs, progress, and perform well at work. One person said, "I've been turned down from jobs because of my caring role."
- **A lack of support in education and employment:** Some carers report being given no support from educators or employers to help them work or study. One person said they had been bullied at work due to being a carer.
- **The impact of not being able to work or study:** This can lead to poorer outcomes for carers. This can affect many aspects of their lives, such as: finances, prospects and choices, health and wellbeing, social connections, identity and independence, and their ability to have a break from caring.
- **Financial hardship:** Many carers are struggling financially and have less money because of caring, causing stress and worry. Contributing factors are not being able to work or work enough hours, the cost of care and support for the cared for (travel, medication, household items etc) and insufficient financial support. Some things carers are struggling to afford are bills, food, fuel, leisure activities and study.

Carers need more financial support including help to know what is available and what they are entitled to. Carer's Allowance is too low or too restrictive to meet people's needs. This has stopped some carers from being able to give up work to care, or increasing working hours because they risk losing the allowance.

Concerns raised about this priority and other things to consider:

- It may be difficult to achieve or make a significant difference in this area or it is only possible if improvements are made to health and social care.

- Need to define carer inequality and include SMART outcomes.
- Not everyone wants to work or study and there should not be any pressure to do so. Provisions to allow carers to continue caring or care full time should be available.
- Addressing financial hardship may not be achievable due to a lack of government or local authority funding.
- Work to reduce inequalities could result in more means testing and forms to complete and this can be “a barrier rather than a help”.
- This may not help or be an issue for some carers.
- Carers may not want employers to be aware of their carer status.

Key comments

“My health is affected by my caring demands. My sleep is poor at times, my blood pressure drops when I am stressed and tired leaving me more tired and dizzy. I am not living in poverty but would be working more hours if I was less involved in caring. I need to work hard to ensure my life doesn't shrink down to simply meeting other people's needs.”

“Since becoming a carer, I have experienced significant challenges (financially, socially, in employment and education) - things I never previously experienced.”

“Financial help for kinship carers is a postcode lottery. Support for kinship carers in other areas is superb but there is nothing in York. I cannot access classes or evening clubs as I have no respite or support.”

“We are the forgotten ones who have no access to carers services...because we live in the wrong postcode and to access have to travel for an hour instead of 15 mins.”

“Being a carer in education is hard as you have 2 full time jobs, additional recognition and communication between educators and caring services is important to address this issue.”

“Having recently completed further education, it was extremely challenging to do this whilst caring. I was not supported by my college either.”

“I reached burnout and used the Integrated Mental Health Community Team for 1 week of support. Care is a very lonely and stressful time, but also very rewarding.”

“Too many carers are forced to give up work due to their caring role, then face a DWP system that fails to value the contribution they are making through caring.”

“I want to work as it helps give me a sense of identity other than a carer. I need to have a purpose and if I don't work, I fear I'll become nobody.”

“Some may choose to work but an increased carer's allowance should mean employment is an option not a necessity.”

Priority 6: Improve joint working across health, education and social care

The table below shows the percentage of people who agreed with the proposed commitments linked to this priority.

Do you think it is important to focus on this commitment?	Yes	No	Don't know or no opinion	Number of responses
Ensure that people working in health, education and social care recognise carers and work together to support their changing needs	91%	1%	8%	135
Better communication within and between services to avoid unnecessary burden on carers	97%	0%	3%	134

What people told us (key themes)

- **A lack of joined-up working:** Many carers have experienced health, education and social care services not working together or communicating with each other effectively, or at all, increasing the burden on them.
- **Information sharing:** Carers reported having to continually repeat information to different services or professionals, describing this as frustrating, tiring, stressful and distressing.

Some carers feel that information should be shared (with consent) between and within services. A couple of people raised that carers should also have access to the information.

- **Navigating and accessing support:** It can be a struggle for carers to understand and navigate health and social care systems and services.

Some carers are having to contact multiple professionals and be the link between services rather than services communicating with each other directly. Carers or those they care for may also “fall through the cracks”, being passed to different services without getting support.

A few carers emphasised the need for flexibility or consideration of individual or changing needs.

- **Valuing, recognising and involving carers:** Recognition and understanding of carer roles needs to be improved, along with how services work together with carers, involve them in decisions and value their contribution.
- **Fighting for support:** Some carers report having to “fight” or “battle” to get the support they or the person they care for needs. One person described having to fight for support to help their child stay in education and two carers reported that EHCPs (Education, Health and Care Plans) are too focused on education.
- **Benefits of joint working and better communication:**
 - Better outcomes for carers and the people they care for, improved carer wellbeing and reduced burden on carers.
 - Reduces the need for carers to repeat information and the duplication of work, saving time, resources and money.
 - Helps carers know what support is available and makes it easier and quicker to access resources and support (for themselves or the person being cared for). It also helps to ensure there are no gaps or overlaps in support.

Concerns raised about this priority and other things to consider:

- Confidentiality and the need for informed consent to share information.
- Achieving this in practice may be time consuming, difficult or unlikely, requiring resources, training, and services having the same priorities.
- Using the word ‘ensure’ makes the target very difficult to achieve.

Key comments

“I have worked in these areas for more than 40 years, it [joint working] has always been important, but why is it so rarely achieved?”

“Often there is poor communication with community services when a patient is discharged from hospital. A carer can feel solely responsible and out of their depth.”

“The systems that professionals work with seem to be a bigger barrier to effective integration than the knowledge and approach of the professionals themselves.”

“Horrendous having to keep bearing your soul to countless strangers.”

“Stop relying on carers to be the go-between between services - they have enough to do. Carers often have to piece things together themselves to work out who they need to speak to to resolve a problem. They shouldn't have to work so hard.”

“Sometimes it feels like you have to fight for the support you need, and that the support available is hidden or requires hoop jumping to access which you don't have the mental energy to do when you're already burnt out with care and would be better if they just spoke to each other and joined all the dots for you.”

“Essential for anything to work properly. As a carer fed up of the disjointed working of various services. Invariably chasing up and constantly repeating myself. My energy is taken up needlessly at times. Even when I have time not caring for my daughter can be on phone trying to find out about various appointments, meetings, etc... frustrating.”

“Vital but I can see it would be time consuming. I am reminded of a time when my husband had been in hospital and needed to see a GP and the GP had immediate computer access to all the 'paperwork' written up by the hospital, excellent care given, no mixed messages, no Chinese whispers!”

“I think most cases they do recognise the work that Carers do but unfortunately haven't got the resources to support them.”

What people told us about breaks and respite

Many carers are not getting breaks from caring or are not getting regular or sufficient breaks. Comments suggest that having breaks would help carers:

- improve their health and wellbeing and prevent or reduce exhaustion, stress, burnout, loneliness and isolation.
- be able to have some time, or do something, for themselves, be independent or have an identity outside of being a carer.
- improve relationships or social contact.
- be able to continue caring or give effective care.

Barriers to taking breaks:

A variety of factors are preventing carers from being able to have breaks from caring, including:

- Opportunities for breaks and respite are currently poor, non-existent or difficult to access or arrange, particularly due to a lack of care and support options for the cared for (including specialist support), and the high cost of care provision.
- Not having enough money, financial support or funding to pay the cost of activities, respite or replacement care, holidays etc.
- Caring commitments, obligations, or the person being cared for not agreeing to someone else providing the care, which can make it difficult or “impossible” for carers to have breaks.
- Concerns over the quality of respite care; carers and the cared for need to have confidence in care providers.
- Needing support to be able to take breaks, a lack of suitable options, or the time and effort involved in organising a break. One person described accessing short breaks and short breaks funding as, “a terrible unfit solution” which “is more effort than the benefit the short break gives”.

What would help carers to take breaks:

- Financial support to take breaks, or more affordable or free respite care.
- Offering regular, flexible and meaningful breaks and a range of break options to suit individual needs.
- Better choice, availability and quality of care and support for the cared for person, plus support for carers to find suitable care options.

- Consideration of how carers can take the breaks that are offered, and information and practical support to take breaks.

Key comments

“This needs to be hugely improved and expanded. It’s essentially inaccessible in the York area.”

“It is generally acknowledged by carers in York that you cannot receive carers breaks unless you have a social worker.”

“I got 3 days away in October and it made a huge difference physically and psychologically.”

“You could immediately improve my opportunity for a break by taking the person I care for into properly funded residential care.”

“Support groups are always offered – personally I don’t want that. I want a helpful team to support me to find caring support so that I can have a break. I have not had a break for 5 years. I support someone with mental health difficulties who needs companion care and this has to be a longer term relationship. I have struggled to find this.”

“It would have probably been a lot less stressful if the burden could have been decreased around exam times.”

“Carers I speak to feel strongly about offering ‘carers breaks’ as a solution to the pain they feel. To them it feels like a lazy option to offer support in this way without thinking through how a carer would actually take the break offered...it feels like someone is adding even more responsibility as they have been offered a solution they can’t take so therefore shouldn’t complain.”

“I have experienced more than one case where a carer needed a break to undergo an operation (with several weeks’ notice) and was put on a list for respite break with no definite place which vastly added to the carers stress. The place was not found in time and the carers operation had to be deferred.”

“Work, exercise, spending time with others and being in nature are all important for wellbeing, but lack of affordable resources mean that for many carers their break is going to the supermarket!”

Out of the priorities we have described which four are the most important to you?

131 people answered this question. The top four priorities are:

1. Improve support for carers (84%)
2. Improve the health and wellbeing of carers (77%)
3. Improve joint working across health, education and social care (68%)
4. Improve how we identify and recognise carers (52%)

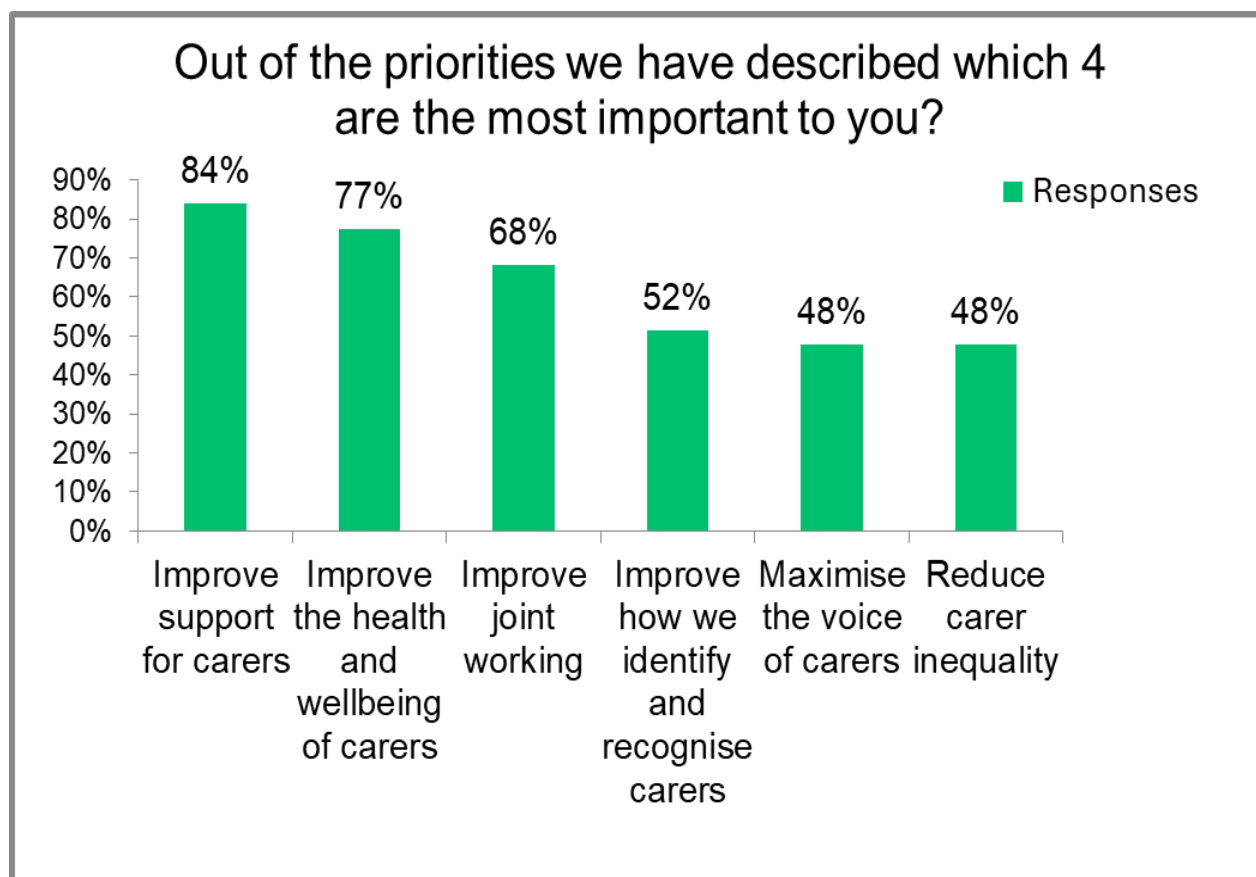


Figure 1: Priorities in order of most important as selected by respondents.

Is there anything else you feel is important for the strategy to focus on?

37 people responded to this question.

The most common theme is **improving health and social care provision**. This includes ensuring funding and resources are available and that those being cared for have the services and support they need, including timely diagnosis.

“If the person being cared for had enough support, the carers would not be in such need of help. Therefore fix the cause and not the symptoms.”

Other themes included:

- **Improving financial benefits** for carers, such as increasing Carer's Allowance, not making carers pay council tax and offering discounted or free transport, parking, activities, counselling etc. One person suggested, "involving national government agencies in the conversation to try and increase financial support".
- **Recognising different carer roles and individual situations**, including recognition that not all carers want to care. Examples given were kinship carers, those who care for people who are not family members, and disabled carers.

"Recognise that DISABLED CARERS exist and actually have a much harder time of everything."

- **Poor experiences of support.** Examples included: not being told about direct payments; not getting a social care review for over 12 years and grant money being delayed. One person spoke of unhelpful signposting and a lack of practical support, and said, "everyone means well but ultimately you have to find Your own way".

Responses included various other specific issues and suggestions such as: help to make difficult decisions, support to manage in a crisis, checking in on carers who rarely engage, and balancing confidentiality with involving carers.

One person called for professionals to build effective relationships with carers. Another called for York as a whole to be encouraged to, "develop a culture where caring is seen as skilled and valuable – not something to be hidden away."

Two people felt that by addressing some of the other priorities, it would reduce inequality.

"I think if you identify carers and improve their support and lessen the burden they are expected to carry, outcomes in education, employment etc. will then become more equal as they are able to do more outside of their caring role."

Other general comments about the strategy included making sure the commitments are followed through on and making the strategy "a live process and not a static document with no relevance". One carer pointed out that, "Small practical things make more of a difference than big sweeping positive statements".

It's not all bad!

Some carers shared positive experiences, particularly about the support provided by York Carers Centre. Here are some of the things they said:

“I accessed counselling through York Carers and it helped enormously.”

“I now have 3 singing groups each week and Moving Minds at Clement Hall, so socialising has been a big improvement.”

“Some people find it really difficult to leave the person they're caring for due to reasons such as guilt, but services like The York Carers centre, are amazing for getting people out. The way they can arrange activities that suit to everyone and then encourage them to attend is something to be looked up to, other services should be taking notes on how it should be done.”

“I have found the frailty team in Acomb very good at listening to what my thoughts are about my parents on the whole.”

“My GP often asks after my health when I attend with my wife.”

“I know York Carers are there if I need them.”

“I feel recognised and supported as a carer. I am encouraged to attend wellbeing sessions and other events.”

“A G.P. lead Social Prescribing support made a big difference to moving forward and mixing with others.”

“CYC [City of York Council] by supporting York Carers, Dementia Forward, Be Independent and their own in house services do give much help.”

Equality monitoring information

Of those who answered the equality monitoring questions:

- Most were aged 40 or over; the biggest proportion of respondents were aged 40 to 55 (39%)
- 86% were female
- 90% were White – English / Welsh / Scottish / Northern Irish / British
- 21% considered themselves to be disabled.

Feedback from face-to-face conversations

Young Carers

York Carers Centre worked with small groups of young people at their activity sessions and youth clubs. They spoke to a total of 24 young carers (14 secondary age and 10 primary age) who care for siblings or parents. Four of the young carers care for two or three people.

Key points:

- Some support is being offered in schools, but more can be done to raise awareness of carers and offer more support to assist carers. This includes health and wellbeing support and staff being more flexible and understanding.
- Most confirmed they get (or sometimes get) a break from their caring roles.
- Some feel they are not able, or only sometimes able, to prioritise their own health and wellbeing.
- There are long delays in young carers being identified – four or more years in some cases.
- Ideas of extra support that would help young carers in schools included:
 - Time out of lessons, fewer lessons, longer breaks or being able to leave early if needed.
 - More young carer activities and being informed of drop-in sessions.
 - Teachers listening before telling students off and not getting angry if they are late for school.
 - Being able to have a phone out in class in case of emergencies.
 - Extra time for homework, or a club at lunchtime to do homework.
 - Being able to wear whatever shoes they want (they are expensive and do not last).
 - Assemblies or PSHE (Personal, Social, Health, and Economic education) lesson about carers.
- The support York Carers Centre offers allows young carers to have a break from caring or school, meet other carers, make friends and take part in activities. Some would like more activities, youth clubs and cookies.

Young Adult Carers

York Carers Centre discussed the strategy's priorities with young adult carers attending a social group. They spoke with 11 young adult carers aged 16-25. This is what the carers said:

Improving support for Carers

- Before offering support, it is good for the support worker to come to your house to observe the situation and your caring role as that will make the support more helpful and comprehensive.
- Information on support for carers should be more easily accessible and available.
- A carer's assessment is a good way of finding out what support is available.
- Things change so you need different things at different times.
- Word of mouth is important – "I didn't find out that I was a carer until I left York."

Improving health and wellbeing for carers

"It's difficult to create a balance between your wellbeing and your caring role because when you are looking after yourself, it feels like you are not giving enough care to the person you are caring for, and when you're spending a lot of time caring for someone you feel like you neglect your own wellbeing, it's like a rotating circle."

"A lot of carers often have to work part-time or not work at all due to their caring role, so they don't have the money to fund leisure activities."

- Access to sufficient funding could enable carers to take part in activities they are interested in.
- Some young carers have to "fit in" at schools as their peers do not really understand the struggle they face, such as why they cannot go out or travel. It can make it hard to make friends or social connections. More awareness on caring roles in school would help other people understand the complexity of being a carer.

Reducing carer inequality

- Training and education in school about caring roles would increase self-awareness and young carers can self-identify that they are carers, rather

than relying on someone else to tell them. They can seek support when they understand they are carers.

- Carer's Allowance should be paid to people in full-time education to reduce inequality. This would allow young carers to prioritise their caring role as well as their education.
- When you want to move on with your life and move out it is almost impossible because you still have someone to care for and no financial support.

“I didn't know I was a carer until someone in school told me later.”

Carers supporting people with dementia

City of York Council and York Carers Centre attended a dementia support group attended by around 10 carers (and people they care for). Carers shared some of the challenges they have faced as carers, and what they feel needs to change:

- There is a lack of information to help carers understand entitlements, benefits and available support. Information needs to be clear, explained and not hidden. Some carers said that if they did not attend the support group, they would not get to know about things.
- There needs to be clearer information about paying for care; people can lose a lot of money (e.g. paying through joint accounts) and then have to go through the process of trying to recover it.
- The stress of being a carer has caused health issues.
- Allowances for carers are too low.
- Poor experiences of dealing with GPs. Examples included not being recognised as a carer and GPs prescribing without getting to understand the problem. One person described an experience where a GP ignored a letter intended to help them discuss their carer role at an appointment. Another spoke of having to wait a year to get a reduction in council tax (backdated), due to a delay caused by their GP.
- Long delays in dementia diagnoses for people they are caring for, resulting in delays in getting allowances and council tax reductions. A pack explaining entitlements at diagnosis would be useful.
- Complicated and lengthy forms to claim entitlements, and issues with claims (allowances, council tax, blue badge). One person described having to, “go through hoops to get things”.

- Sitting services would be helpful. However, it is difficult when the person being cared for does not recognise they need help, will not accept support, or does not want to attend activities.
- The high cost of care homes is causing stress around finances. More affordable options are needed in York.
- Issues with parking at York Hospital - carers can get free parking but it is very difficult to find a space. Depending on the time of day, you may need to arrive an hour early to park.
- Carers talked positively about support from Dementia Forward, York Carers Centre, Older Citizens Advocacy York and Beetle Bank Farm.

A big thanks to everyone who took the time to share their views and to the carers who helped us develop the survey, along with other partners. And thanks to everyone who helped us get feedback from carers, particularly York Carers Centre, who made sure the voices of young and young adult carers, and many other carers were included.

If you have questions about this report or the Carers Strategy, please email: allageconsultation@york.gov.uk

Alternative formats

To request reasonable adjustments or to provide this document in an alternative language or format such as large print, braille, audio, Easy Read or BSL, you can:



Email us at: cycaccessteam@york.gov.uk



Call us: **01904 551550** and customer services will pass your request onto the Access Team.



Use our BSL Video Relay Service:
www.york.gov.uk/BSLInterpretingService
Select 'Switchboard' from the menu.



We can also translate into the following languages:



我們也用您們的語言提供這個信息 (Cantonese)

এই তথ্য আপনার নিজের ভাষায় দেয়া যেতে পারে। (Bengali)

Ta informacja może być dostarczona w twoim własnym języku. (Polish)

Bu bilgiyi kendi dilinizde almanız mümkündür. (Turkish)

یہ معلومات آپ کی اپنی زبان (بولی) میں بھی میا کی جاسکتی ہیں۔ (Urdu)